ENCYCLOPEDIA OF
DISABILITY

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Australian Rehabilitation Assistive Technology Association (ARATA)
Disability Rights Education and Defense Fund
Disabled Peoples' International
Easter Seals
European Disability Forum
Handicap International
International Disability Organizations
League of the Physically Handicapped
Leonard Cheshire
Liliane Foundation
National Center for Medical Rehabilitation Research (United States)
National Institute on Disability and Rehabilitation Research (NIDRR) (United States)
People First
Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)
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Union of the Physically Impaired against Segregation (UPIAS)
United Nations
United Way of America
World Bank
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INTRODUCTION

Gary L. Albrecht, General Editor

It has become a commonplace to claim that disability is on the rise in the modern world. Such recognition arrives as we and our families age and modern medicine ensures the viability of children who, only a few decades ago, would not have lived into adulthood. Those who sound this alarm would seek to spoil our attachments to more progressive historical models in which disability, apparently, does not take part. As a marker of our contemporary "decline," one might cite the predictable "nicks and dents" of aging now compounded by the obesity epidemic with concomitant rises in diabetes, osteoporosis, and heart disease. Asthma is often identified as one of the leading disabling conditions resulting from urban growth and environmental pollution. Furthermore, it would be truthful to observe that the upsurge in wars and civil strife around the world has produced millions of men and women who have been permanently injured by land mines, machetes, bullets, bombs, and beatings. Similarly, in developing countries, one might also argue that populations continue to experience the ravages of presumably eradicated diseases such as tuberculosis as well as newer epidemics such as HIV/AIDS. Finally, given the stresses of contemporary life in industrial and developing countries alike, depression has become the number two cause of disability in the world.

Yet this catalogue of contemporary disability sources does not touch on the true significance of disability, particularly with respect to the degree to which people with disabilities exemplify the dynamic variability, vulnerability, and mutability that exist across individuals, populations, cultures, and histories. Perhaps the most surprising observation of all is that disabled people persist in record numbers despite continuing prophecies from medicine, genetics, and rehabilitation about the ultimate eradication of congenital and acquired impairments. In this post-eugenics era, disabilities remain with us but the lived experience of disability has undergone radical changes. Consequently, at its most basic level, the *Encyclopedia of Disability* serves as a reminder that regardless of who we are, where or when we live, disability is with us.

Based on this perspective, the *Encyclopedia of Disability* was conceived as an effort to bring current knowledge of and experience with disability across a wide variety of places, conditions, and cultures to both the general reader and the specialist. An encyclopedia is an introduction to a topic that leads a reader through subjects of interest to greater depth and breadth of understanding and provides the reader with a road map to other sources of information. In this work, the entries, bibliographies, websites, search strategies, cross-references, chronology, visual images, and primary source (original) material will conduct the curious reader along a path to a clear understanding of the definitions, fundamental concepts, basic history, diversity, cultural contexts, experiences, health care issues, environmental constraints, helpful accommodations, social movements, laws and policies, and theories and practices in the disability arena. Furthermore, the encyclopedia seeks to demonstrate that our largely negative view of disability must be challenged by the significant contributions to all cultures made by disabled people and committed allies—in art, in politics, in cultural production, in private and public life. May this encyclopedia improve the reader's understanding and appreciation of the world of disability.

The *Encyclopedia of Disability* was conceived in a broad context. While there has been much research on disability, the research presented in these volumes has usually been approached from an interdisciplinary perspective whenever possible and broken into manageable topics for investigation. For example, the descriptions of public health show how it aims to improve the quality of life by minimizing the effects of diseases, living conditions, work, and the physical and social environments on mortality and disability. The discussion of medicine focuses on diagnosis of disabling conditions, prevention, and treatment. A number of entries describe the multitude of therapies that are designed to operate individually and in concert to return disabled people to as full and complete a life as possible. The overview of rehabilitation engineering concentrates on assistive technologies aimed at accommodating the environment to the individual and the individual to the environment. Disability studies refuses the equation of disability with inferiority and instead aims its analytical lens at the social obstacles that produce disability as a devalued experience. To do so, disability studies examines the definition, meaning, and representation of disability in various social and cultural contexts by incorporating the voices of disabled people and disability communities into the discussion. The history of medicine's contribution is in placing medical conditions and disability into a historical and cultural context to unveil the shifting determinants of disease and difference. Contributors from the fields of sociology, psychology, and anthropology apply analyses that help us better understand disability as a product of interactions between bodies, environments, and belief systems. Economists draw our attention to the monetary and social costs of disability and the benefits of supporting disabled people and helping them reintegrate into society. Lawyers, government officials, and policy makers consider how the modern state can best respond to the reality of variation across populations. Philosophers and ethicists ponder the value of human life, physician-assisted suicide, and human rights to test contemporary culture's commitment to all citizens despite ability levels. The encyclopedia also demonstrates that disabled people and their families are concerned with how they can exercise full citizenship in a society, have a high quality of life, and contribute as active members in a world that often rebuffs such efforts.

The idea for the *Encyclopedia of Disability* was hatched during 1999–2000 in conversations with Rolf Janke of Sage. The intent was to provide a resource that would be available in all of the major libraries of the world to scholars, disabled people, disability advocates and allies, and the general public. To be useful to a wide audience, the encyclopedia needed to have breadth and depth and be written for a general audience. The project was also an opportunity to encourage creative people in different but related fields, all interested in disability, to talk with each other. Another desideratum was to make the encyclopedia as international as possible since disability is an issue that knows no national or cultural boundaries.

After signing the contract for the encyclopedia on September 10, 2001, an international editorial board of 74 editors from the Americas, Europe, Australasia, India, Japan, and China, who were all experts in their own subfields of disability, was constituted. After much discussion, the members of the editorial board and the publisher agreed that the encyclopedia would span five volumes: four consisting of alphabetically listed entries and a fifth composed of primary source materials representing the field of disability broadly defined across history and cultures. Volume V is organized into chronological categories that allow the breadth and depth of cultural thinking about disability to become evident for the first time.

The task of identifying the entries to appear in the encyclopedia was the next exercise in creativity. The major journals, books, government documents, and Web-based disability discussion groups in the world were searched for themes and topics. These were organized into lists and circulated. The editors iteratively added terms and suggested authors. The authors, in turn, often proffered other terms and authors. Great effort was taken to have a considerable number of authors from outside North America to provide balance to the work. Another source of global representation was to include internationally focused entries on most of the key concepts in the encyclopedia and to provide cross-cultural examples wherever possible. Yet, even in the wake of these commitments to achieve an international representation of disability, the encyclopedia cannot claim to be exhaustive to any degree. Because of the global, historical, and conceptual reach of the *Encyclopedia of Disability,* it is virtually impossible to cover every topic, person, and event. This is a mere introduction in many ways to myriad differences that characterize the world of disability. The editors decided to organize the entries hierarchically from large crosscutting concepts such as disability models to smaller entries such as those on individual people. At this point, the editorial board was divided into areas of expertise such as health and medicine, mental illness, cultural studies, rehabilitation, disability studies, rehabilitation engineering and assistive technology, law and social policy, and history, and teams were formed to oversee and deepen these areas and headwords.

A list of suggested authors for all of the terms was then formed and authors were invited to participate. With few exceptions, the editors and authors who were invited to participate in the project eagerly did so; all were experts in their own areas. Each entry is based on the personal expertise of the author, and further readings and websites are listed at the end of most entries. The draft of each entry was reviewed by the editor in charge of that group, by the general editor, and in the case of the more important or contentious entries, by other reviewers as well. Revisions were made based on these comments. At a later stage, entries were cross-referenced with other entries in Volumes I through IV to guide the reader in an exploration of a topic.

The covers of the five volumes were selected to represent disability in various historical periods and cultural settings. The jacket art provides an index to the cultural, historical, and representational diversity of disability imagery. The cover of Volume I, *Tree of Hope—Stand Firm!* (1946), portrays one of Frida Kahlo's many self-portraits as a disabled Mexican woman of color. In the painting, her identity is split. One image proudly holds her back brace while the other image portrays her impairment as if exposed as a medical specimen. The cover of Volume II, by Hieronymus Bosch, *Extraction of the Stone of Madness (The Cure of Folly)* (ca. 1475), depicts a fifteenth-century representation of treatment for mental illness in medieval Europe. The portrait assembles all of the constituent professions of the time—barber, friar, nun—as they treat a patient who looks out anxiously toward the audience as a tulip is extracted from his head. The cover of Volume III depicts the Chinese physician Hua T'o as he seeks to heal necrosis on the arm of the warrior Guan Yu in the fourteenth century. The work, created by the famous Japanese printmaker Utagawa Kuniyoshi in 1853, emphasizes the disparity that exists between social rituals of gaming that continue even as one receives serious medical attention. The cover of Volume IV, showing the early-fifteenth-century Nigerian King Oba being supported by his two personal assistants, captures the king's effort to explain sudden paralysis in his legs. Rather than confessing his incapacity, Oba argues to his subjects that he has become one with the revered mudfish of his day that walks on land and swims in water. At a time when physical, sensory, or cognitive disability in a king could mean expulsion or execution, the bronze demonstrates the necessity of quick thinking that often must accompany disabled persons' ability to fend off violent social tendencies. Finally, the cover of Volume V, *Beacon (Bless the Bastard)* (1991) by contemporary U.S. visual artist Tim Lowly, represents a mother deflecting the discomfort of a society unprepared to accept her disabled daughter in a common public context. In contrast, the multiply disabled daughter appears to revel in the sun while possibly imagining alternative futures for herself yet to be thought by the adults around her.

Taken collectively, the jacket images provide viewers entry into the diversity of cultural responses to, and portrayals of, disability at key moments in history. They become a patchwork of moments in the growing mosaic of our understanding of disability as a historical, cultural, and global phenomenon. In addition, there are more than 100 images related to disability in Volume V. These images illustrate the powerful representation and symbolism of disability in diverse societies.

The use of language and concepts is an issue in an international encyclopedia. Disability is often referred to by different terms and concepts. Rather than forcing each contributor to use the same language, the editors decided to let the authors use the terms and concepts of their culture but to explain them when necessary. This preserves the multicultural flavor of the enterprise. Likewise, when authors were writing about contentious issues, they were encouraged to present the various positions and their rationales. In terms of language, for example, the reader will see "persons with disabilities" and "disabled persons." "Persons with disabilities" is preferred by those who favor "people first" language capturing the importance of the individual in society, and disability as being something *not* inherent in the person. "Disabled persons" is a term used in the United Kingdom and Australia emphasizing minority group identity politics where community and group identity are forces that can be employed to fight oppression experienced in the physical and social environment. Other authors consider disability to be best understood in terms of human differences that should be accepted as such rather than as being seen as regrettable deficits. This position stands against the background where specific disabilities have taken on positive and negative meanings in various cultures. For example, in some societies, blindness has been associated with the characteristics of wisdom and prescience, which are valued, whereas AIDS and leprosy (Hansen's disease) are often stigmatized.

The Reader's Guide classifies entries into twenty-five thematic categories. In addition, the materials in Volume V are listed in the Reader's Guide to enable readers to integrate the content of entries with the primary source documents in Volume V. To put the concept of disability in a historical and cultural context, a chronology maps disability across time, culture, and geography and is repeated at the end of each volume.

"Searching for and Evaluating Websites," by Anne Armstrong, a University of Illinois reference librarian, describes how to use the references at the end of the entries, how to access and use websites related to disability, and how to assess whether websites and their content are credible. This valuable research tool appears at the end of each volume. In addition, throughout the encyclopedia there are listings of print and electronic references to government documents and data that are rich resources to investigate how disability is measured and treated on an international level. There are government documents that can be accessed over the Internet by just entering the keywords "disability" and the name of the country. The International Monetary Fund, World Bank, United Nations, and World Health Organization also are fine sources of data and policy initiatives related to disability, much of which can be accessed over the Internet.

May readers discover that the *Encyclopedia of Disability* provides a fascinating entry into the world of disability where minds are expanded, prejudices shattered, and spirits raised. The range of interrelated resources is designed to stimulate curiosity and encourage readers to move back and forth through the five volumes to pursue their interests. Internet references and search strategies assist the user in entering a larger world of online disability resources that are continually being updated and expanded. The encyclopedia is composed as a multidisciplinary, cross-cultural, and historically grounded resource tool that should lead the reader across fields, theories, debates, and practices. The experience of exploring the encyclopedia should answer the questions: What is disability, and why is it important in my life?

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The *Encyclopedia of Disability* is the result of an enormous worldwide, multidisciplinary effort that took six years to conceive and execute, involving 74 editors and more than 500 authors from over twenty countries. The work is the result of lively interactions at conferences, seminars, and editorial board meetings conducted over a cup of tea or a glass of wine, through email, and on conference calls. In many cases, the colleagues, students, and staff of the editors and authors in various parts of the world became support systems and sounding boards for component pieces of the project. Because of the size and complexity of the encyclopedia, it is impossible to recognize everyone who directly or indirectly contributed. Nevertheless, we express our deep gratitude to all of these researchers, colleagues, disabled people, advocates, students, government officials, and policy makers who made this incredible project happen and who stimulated others through their knowledge and resourcefulness.

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In sum, an enthusiastic team of researchers, disabled people, activists, and policy makers representing global social networks in multiple fields made this work possible. We dedicate the *Encyclopedia of Disability* to those people around the world whose lives have been or will be touched by disability. Finally, we thank our families and colleagues who provided their steadfast encouragement and heartfelt support during this difficult but rewarding project.

ABOUT THE ENCYCLOPEDIA COVERS: VISUALIZING VARIATION

Sharon L. Snyder

The five covers for the *Encyclopedia of Disability* represent a selection of artistic impressions across a range of cultures, time periods, and multiple disabilities. They also render some of the unique orbits for the complex relationships that disability experiences provoke. Each is purposively nontragic and discourages pathos or too easy sentiment. Instead, the covers emphasize the creative and self-inventive side of disability experience. All make disability a window onto diverse landscapes for the body different.

Taken collectively, they may even suggest an odd refuge in disability—the degree to which incapacities can be viewed as protecting us, and motivating creative agency, even as they may render us most vulnerable. Perhaps someone such as Frida Kahlo, who lived so intensely in her body, could identify the lure of incapacity to this extent. She wrote in her diaries:

> We take refuge in, we take flight into irrationality, magic, abnormality, in fear of the extraordinary beauty of truth of matter and dialectics, of whatever is healthy and strong—we like being sick to protect ourselves. Someone—something—always protects us from the truth—Our own ignorance and fear. (*The Diary* 1995:248–249)

Thought about in such a way, disability no longer means a condition, an incapacity, or lack that belongs to a body, but rather a product of the interactions between self, society, body, and the variety of interactions (from political economies to personal commitments) that they engender. Disabled bodies, then, are artifacts—found or experienced while saturated with the meaning of our own investments, concerns, hopes, and insignificance in the world.

That the relations precipitated by human differences so often become detrimental to people with disabilities, turning even families or institutions devoted to their care into warehouses or danger zones, does not lessen their significance. Analysis of disability from a social perspective reveals the extent to which cultures prove creative at inventing endless varieties of human diminishment. In response, one finds counter-creativity demanded of disabled people. Their own livelihood, and sometimes their very lives, can rely on an ability to subvert supernatural views held about their conditions, contest medical fascination with their corporeality as "specimens," or spend years finding the means to escape confinement from back wards, closets, and institutions. The art depicted on the covers of this five-volume set, then, present us with this multisided nature of disability experience. Each portrays individuals both marked as undeniably different and actively transforming of the social terms of their reception.

The bronze sculpture of the Nigerian King Oba (cover of Volume IV) speaks directly to this idea of disability as urgently necessary renegotiation of the terms by which the nondisabled may see us. The king stands between the dual supports of his personal assistants with his mudfish legs on full display to the viewer. Rather than a story of personal diminishment by paralysis, the king explains his condition, contrariwise, as a deepening of his power. Mudfish represented a revered species in Nigerian culture at the time of this event. A king who awakens to discover himself immobile—particularly when the appearance of physical or cognitive disability in a ruler results, by law, in exile or execution from his subjects—can avert certain catastrophe only by such inventive quick thinking. Instead of concealing his paralysis, the king parades his body transformation before more lethal rumors can begin to circulate.

The Oba's explanation for his sudden mobility impairment draws directly upon insider understanding: Difference of form does not equate with absence of kingly capacity. Legs bow out and gradually modify into the heads and forelegs of the mudfish as the product of a powerful formulation of the meaning of body changes. The king tells his subjects that he can now pass between earthly and spiritual realms just as the mudfish navigate land and sea as half-reptile and half-fish. Circling the human figures, a series of four amphibian heads stare out as totemic sentries. The artist admires the flexibility of such an in-between space occupied by the Oba in his claimed role as a mediator now between human assistants and animal protectors.

Both Oba and artist participate in the recognition that variation exists across species and hence offers to us a rich array of explanations for the value of bodily configurations that might otherwise be cast out as undesirable. The sculpture posits continuity to natures, creatures, cohabitants, in a portrayal of paralysis: mudfish legs, human assistants with partially truncated torsos, pineapples, elephant trunk, snake, and swamp tangle. All life forms mesh in a symbiotic system of mutual belonging despite intense differences of capacity. Diversity teems across the bronze figure's vertical and horizontal axes. A celebration of varying capacities from human to animal culminates in the exhibition of Oba's bowing legs in order that variations across bodies in nature can provide context for a human body with paralyzed legs without a lessening of value.

The nineteenth-century Japanese triptych *Hua T'o Treating an Instance of Necrosis on the Arm of the Warrior Guan Yu* (cover of Volume III, 1853) by the famous printmaker Utagawa Kuniyoshi, depicts a historical event from fourteenth-century China. To the far left of the work we witness a surgeon, dwarfed in the presence of the massive body of Guan Yu, plying his trade in spite of the recreational distractions taking place around him. The physician, Hua T'o, meaning "miracle working doctor" (or "divine physician" based on the Japanese word *shenyi*), concentrates on a lesion eating away at the general's right arm. His localized treatment effort contrasts with the social frivolity portrayed in the rest of the painting. Medicine pursues its healing art as the world continues on indifferent to the work of bodily salvage. In this reading, we could situate ourselves as admirers of precise medical application as the "patient" stubbornly pursues other desires with a reckless lack of concern: Medicine works against time and gross inattention to attend to human vulnerability. We are situated as admirers of medical technique; the physician's perseverance is sustained in spite of activities that might prove distracting to the treatment effort.

Likewise, a viewer of the painting may also contemplate the work as a commentary on war. Bodies are wantonly exposed to violence and disability, disease, and death. Human wreckage is exposed as the primary product of militarized clashes between individuals, tribes, and nations. The painting depicts Guan Yu calmly receiving treatment following a battle wound caused by a poison arrow. The warrior ignores the cleaning of the wound down to the bone as an example of the power of the first administration of anesthetic. He has adopted an attitude that places his body as fully secondary to more immediate concerns, whether the task at hand is a battle or gamesmanship. In the unfinished disability play *The Deformed Transformed* (1822), the renowned Romantic poet Lord Byron, argued that masculine able-bodiedness seemed to require that men put their healthy bodies at risk of violation, as if they could not feel their lives as "real" enough without exposing themselves to the potential of disability. The thrill of physical threats pursued and then evaded. The painting of Hua T'o suggests a similar reading in that the development of necrosis suggests a near-gangrenous wound progressing to the point of a serious medical condition. A poor result might yield the loss of a limb or disuse of his arm because the general has refused to attend to the initial laceration in a timely manner. This patient inattention to the poisoning produces an even graver medical predicament. From this vantage point, a viewer might choose to indict the warrior's indifference to his own health concerns or grow further weary of war's destruction.

Alternatively, one may also glimpse a cultivated demeanor in Guan Yu's laissez-faire attitude toward medical attention. We might draw an interesting parallel to the experience of medicalization by disabled persons—particularly in the case of individuals who have spent significant time "under the knife." While medicine demands the full attention of the patient to participate in its own healing mission, those exposed to continuous medical care often refuse this singular attention paid to their bodies. Undergoing medical care requires a multitasking mission, or the rest of one's life comes to a full stop. In this view, we might think of medicine as the disruptive event against which the rest of one's life must be experienced. A certain capacity develops among disabled people to handle their other "business" as the medical industry rages around them. In fact, there's a form of patient *cool* where one refuses to allow a medical event to eclipse the myriad other demands on one's life—such an attitude can be found on display in the Kuniyoshi print as the game of Go continues in the face of surgery. In fact, the medical activity is reduced to a mere third of the triptych while the game occupies the remainder of the artist's interest. The social interaction requires as much seriousness as the presence of necrosis itself.

Likewise, Tim Lowly's *Beacon (Bless the Bastard)* (cover of Volume V, 1991) emphasizes independent coexistence among bodies occupying shared space. Rocks, river, grass, and other earthly elements populate the scene with an adult care provider and a disabled child positioned a few feet away. The two female figures, out of doors and beyond the traditional confines of domesticity, do not show shame or efforts to hide from the world's discomfort with disability. The caregiver looks off in the distance responding to some unknown force with a stem wielded over her shoulder in the gesture of a blessing. Behind and below the caregiver, a child (the artist's daughter Temma) lies on a bright blue pallet that cushions her from the ground—the same ground on which her mother's bare feet are firmly planted. The disabled girl's body, illuminated in the landscape and sprawled beneath the sky, wears a one-piece playsuit with socks and shoes, carefully swaddled despite the apparent warmth of the day. The relationship between the two figures, emphasized by the colors in the child's garment and repeated in the mother's striped dress, openly proclaims their identification. This is Temma's consciously placed residence in the world; she might be lying there contemplating a future yet to be articulated by the adults around her. The daughter's figure, aimed like a magnetic compass arrow toward the bridge in the upper left canvas, serves as a beacon to the artist, and, in this landscape, literally could be cast in a red outfit as if a signal translated from one location to another. The way a painter selects and places a subject onto a canvas in a highly self-conscious act parallels how Temma's caregiver has consciously situated her in this setting. In other works, Temma lies near a muddy puddle, a pond, on a day bed, across a desert floor, near a wooded river stream; her figure a geographic nomad yet without apparent mobility. These portraits capture Temma's vantage point as contemplative of universes unrevealed in ordinary landscapes—and strangely altered by the insertion of a disabled body. The historical absence of disabled people in routine places makes every appearance potentially transgress audience expectations. Conversely, every insertion undermines the belief that there are some places disabled persons should not go.

Just below the bridge, a small group clusters around a makeshift stone altar and, in a rather ritualistic manner, evokes a history of atonement practices. These ritualistic acts often occur in response to a mystery disability seems to evoke. Why me? Or what did I do to deserve this fate? Or what does this difference mean for the community? Are we culpable in some way? Piled stones reference all the hard things humans negotiate, arrange, and work with, just as the allegorical landscape offers hugely divergent elements, from spongy riverbed to wooden platform, to inhabit. Each formation seems to be selected for its yielding principles. Fjords—irregular land and water masses—remind us of the nonstandard geometries of embodiment and mirror the daughter's figure akimbo on land. Bodies of water and of land encroach on and define each other—clearly etched by nonregimented and unpredictable shorelines. The work on the makeshift altar occurs while the determined "blessing" of the mother above also redoubles as a fending off of outside forces and even our gaze, as viewers prying into a private scene. As if we must first fathom the precision of the mother's expression and gesture in the foreground before gaining access to the proceedings beyond her, she stands as a cautious gatekeeper before the rest of the painting.

The subtitle, *Bless the Bastard,* refers not to the child but to the concept of flinging back insults with a shield of mercy. The artist explains the idea as a matter of how one might bless those who curse one with additional punch. The mother's determined motions, her turning outward and her gesture toward the past, and her daughter's resident outside location, present them as participants in a fully parallel existence. The story of disability unveils that even the most ordinary outing requires a variety of self-conscious placements and protective gestures.

Finally, a white building perched near the skyline in the upper-right-hand corner recalls, as well, the Olson house on the upper horizon of Andrew Wyeth's famous painting *Christina's World.* As in the Lowly work, the house in Wyeth's painting also makes a young disabled woman's predicament into an allegory. The disabled figure in each work lies in the foreground staring off into the distance—relatively immobile or alternatively mobile in body but imaginatively engaged in future prospects unknown to, and unimagined by, viewers. In *Beacon,* the far-off residence appears like a temple amid a landscape that is filled with objects that catch a viewer's eye. Each item serves as a potential enhancement or barrier to navigation across it. Certainly, both disability paintings place a demand on the viewer to acknowledge these scenes as complete worlds. In them an ordinary morning scene, the forthrightly mundane world, is lent a hue of studied complexity toward a disability's self-conscious placement therein. *Beacon* offers Temma's figure as a guidepost rather than repulsion. The disability-wise gestures of the figures themselves are understood to occur in the face of a modern hyperrational clarity that would dispense with disability experience as some all-too-obvious tragedy. The paintings provide a lesson in how to live in the world with severe disability. Both ask us to reexamine this premise by requiring that we look closely enough to discern the disability coordinates of lives that might at first glance appear wasted.

Whereas Lowly and Wyeth represent intimate works about disability by nondisabled artists, Frida Kahlo's work supplies an example of artistic traditions spawned by disabled artists themselves (cover of Volume I). Responses to the disability context of Kahlo's work and life have ranged from incredulity to simple disability disavowal: "Frida Kahlo—she's a national treasure. How could she be a disabled woman?" Contrariwise, the complex disability perspectives that inform her subject matter and the terms of her artistic exploration can become so central that disability interests may overwhelm all else in her work. Certainly, few artists since the Middle Ages made the topic of personal suffering such a wellspring for creative figuration. For disability critics, one must note the inventiveness that informs Kahlo's access to artistic practices, from painting on canvasses suspended over her bed to laptop easels to the elaborate journal she kept detailing her pain, confinement, and multiple surgeries (including the amputation of her right leg in 1955). Such investments in the ability of art to provide her with immense joy "in spite of my long illness" led her to have her four-poster bed dismantled and reconstructed in the national museum of Mexico City. The unusual accommodation occurred on an evening prior to the one exhibition during her lifetime in her home country for the purpose of being able to view the exhibit herself in comfort.

Kahlo's life, whether conceived as utterly conditioned by disability or as having disability merely incidental to it, has served as the topic of children's books and films. Controversies rage over the terms and origins of her multiple impairments. Some have identified her disability as resulting from a bus accident when she was 16 years old in 1926; others with the effects of polio contracted at the age of 6; and still others, such as Philip Sandblom author of *Creativity and Disease* (1997), propose that she was born with the congenital condition of spina bifida, which she spent her life concealing. We may be discussing some combination of all of these events in one body as well. These discussions are as interesting for the fears and concerns interpreters express about the meanings of congenital (as opposed to acquired) disabilities for stories of artistic achievement. Acquired disability makes one a hapless victim of circumstances while congenital disability signifies a status as metaphysical pawn.

Nevertheless, the latter attribution of spina bifida as an initial source of her disabilities becomes most provocative given her preoccupation with the spinal column in her work. Her paintings commonly depict Mexico as an ionic column with wings. In addition, she also uses duality or twinning such as in her work, *The Two Fridas* (1939), where we see her heart beating and a circulatory system that feeds the nearby identical body image with which she clasps hands. The work depicted here, painted in 1946 amid a flurry of surgeries and hospital stays, *Arbol de la Esperanza Mantente Firme* (*Tree of Hope—Stand Firm!*), associates an ironic meaning to the figure holding a back brace in one half and wounds along the supine figure's spine in the other. The sense of strength that Kahlo must have felt in herself—particularly through her political commitments to Communist revolution—resound as both a plea (make me strong in the face of pain) and a command to others (stand firm in your political convictions). These words, *"arbol de la esperanza mantente firme,"* which one of her biographers, Hayden Herrera, identified as the lyrics to a song she knew, would also appear a year later in a diary entry celebrating the 30th anniversary of the Bolshevik revolution. For Kahlo, debilitating physical anguish could be offset to some degree with a merger of disability and political images in that both coexist without eclipsing the other: The most disabled also embody the fiercest commitments for social justice. The two often become a self-referencing system in the body of her works.

Compositionally, the contrasted backgrounds of night and day suggest a confluence of binary associations between light and dark, health and illness, passive hospital patient and active revolutionary. Yet the painting throws such easy oppositions into question in that all coexist, and enlightenment may come from either source. The more medical image appears in the day where one might expect to find her more "public"—that is, less vulnerable—self. Thus, the work is an emblem of Kahlo's artistic *oeuvre* in that these versions of the self do not simply balance the subject but rather serve as wellsprings for creative vision in their own right. The pink brace grasped securely in the hands of the formally dressed figure who waves a small flag contrasts with the night and small moon on the right side of the canvas. The body of the fully draped figure situated at a perfect right angle to the reposed figure on the wheeled operating table function as two supports along the canvas's vertical and horizontal planes. The figure on the left displays open seeping wounds across a back that is exposed between pulled-apart sheets as if to unveil her body in a surgical cut-away.

Likewise, spinal lesions echo across both halves of the painting. They duplicate cracks and ridges that split dry earth across which the stretcher seems precariously perched. This yawning crevasse is exactly the same size as the wheeled bed. A surreal glittery ball stands for the sun, and her flowery headdress hovers suspended in this cosmic stratosphere. The velvet dress suggests a more formal version of the Aztec clothing that she wore throughout her adult life. It's also a chosen legacy rescued from a colonized past. Hence the more surreal aspect of this painting: The body left behind, ruptured, and lying across night and day is juxtaposed to the upright, dressed red figure who gazes at the viewer while holding the brace in full display. It also appears that the seated figure wears a similar corset-like apparatus beneath the dress because the bulbous endings appear around her chest and match the same design of the brace in her hands. In a *Time* magazine article of April 27, 1953, Kahlo insisted that "I never painted dreams. I painted my own reality" (p. 90). The painting may most of all render homage to her prosthetic back brace and her investments in it. Today, one can find the same pink back brace with personal decorations in a visit to her home, now a national museum. In either case, both portraits echo with Kahlo's disability markers that worked to flaunt, as opposed to mask them, from the viewer.

Kahlo's work has been often attributed to the influence of northern Dutch painters such as Pieter Brueghel the Elder, and particularly, Hieronymus Bosch (Jeroen Van Aken: 1450–1516). While Brueghel painted mimetic images of everyday northern peasant life, Bosch's impact on Kahlo is often identified through his portrayals of bizarre imaginings such as the events captured in his work *Extraction of the Stone of Madness (The Cure of Folly)* (ca. 1475) (cover of Volume II). Whereas Kahlo followed Vincent van Gogh in portraying her physicians in respectful portraits as a sign of appreciation, Bosch participates in a less reverent approach. In this painting, Bosch satirizes the medieval medical practice of removing stones from the head as a treatment for madness, traumatic brain injury, and insanity. In addition, the other two onlookers—a friar and a nun—represent alternative religious domains where madness was commonly addressed with alms and prayer. Thus, Bosch assembles the surgery's audience carefully in his effort to draw the three figures into the net of this parody—as if every charlatan, barber, and pious practitioner of his day comes together in this unholy gathering to witness someone else's suffering. Their own moral stature in the community depends on catering to those residing among the "less fortunate."

The subject of the surgery—a patient drawn in the guise of various "fools" of the day—undergoes a risky intervention. Hopes for release from such conditions as insanity resulted in a willingness to expose oneself to disastrous—and often life-threatening—efforts to alleviate symptoms. Similar practices for the treatment of mental illness were widespread in Bosch's day. Evidence also suggests that in spite of critiques such as this one, the practice continued into the Renaissance where similar procedures are documented as late as the sixteenth century. Like Kahlo, Bosch rarely ventured far from home, and his works include details of familiar scenes within a tightly circumscribed area. Yet, as in this work, Bosch's paintings place the rituals of life in question by unveiling the violence that often resides just beneath the surface. Consequently, *Extraction of the Stone of Madness* suggests that "deviant" behavior may be found on both sides of the treatment divide.

Bosch's painting, inspired by various folk tales and critiques of the physicians' guilds of his time, appears fairytale-like in its allegorical assemblage of medical and religious personnel. In each figure, the primary treatment tools come on display—from the barber's scalpel to the friar's chalice-like vessel to the nun who balances a book on her head. The physician applies his effort directly to the body, the male priest talks and gestures toward the patient during the ordeal as if performing an exorcism of demons, and the nun looks on in contemplation as if patiently awaiting inspiration from the text above. Each intervention strategy seems poised to encourage equal levels of suspicion. Rather than a stone, the surgery results in the extraction of a flower from the man's head. This is a curious object in that the flower appears much more at home in the naturalistic setting while the human practitioners seem out of place. The town situated off in the distance further emphasizes their displacement. As one commentator puts it:

> Moreover, this work of art bears the inscription 'Master, take away the stone, my name is Lubbert Das." It is worth pointing out that Lubbert Das was a comical character that originates in the Dutch literature of that time. The stone is represented as a flower (tulip) on the head of the patient near the surgeon's knife, because of the similarity between the words tulip (*tulp*) and madness in Dutch. (Babiloni et al. 2003:1)

This direct parallel between organic life and insanity may suggest Bosch's effort to equate both objects with the forces of nature that ultimately evade human control.

While madness may be commonly represented as severe distraction from the applications of daily living, only the patient's gaze breaks the painting's plane as he looks out uncertainly toward the artist capturing the event and/or the hapless viewer consuming the event. His look of personal concern contrasts with the concentrated efforts of the others as they attend directly to the site of conflict—namely, his brain as resident location for the "disorder"—and thus the "patient's" objectification turns out to be at least threefold on behalf of the barber, artist, and viewer. We participate as consumers of the discomforting scene. Bosch captures the worst kind of medical theater, one that not only subjects one to painful procedures of dubious merit but also is witnessed by others to further deepen the stigma.

The painting also comments on a long-standing belief in medicine that the body functions as symptomatic surface for otherwise ephemeral "cognitive" phenomena (i.e., madness in this case). Without a tangible bodily location, medicine would prove at a loss as to how to proceed in its material correctives. The concept of a "stone" of madness then takes an abstract matter of behavior perceived as deviant and objectifies it in physical terms. Thus, various bodily zones get targeted as the seat/source of intangible phenomena. In the eugenics period (1840–1940), "idiocy" was theorized as a lack of control of the will, and "docile" bodies were targeted through physical exercises, concentration rituals (e.g., standing in one place for minutes at a time), and hygienic grooming practices—a presentable body represents a compliant citizen. In each instance, exerting force on the physical body provided a route through which to impose control over minds.

In sum, these artistic works demonstrate that disability is both a product of specific local contexts *and* shared, even global, disability perspectives. Africa, Japan, the United States, Mexico, and the Netherlands all contribute to a multinational mosaic of disability representation; in doing so, disability transcends geography, culture, and history in its situation as a metaphorical and pragmatic device of social meaning making. The question "What do we do with our disabled people?" resonates in most cultures and across historical moments. In the midst of its invocation as perpetual crisis, disability can expose ruses to the control and mastery of human variation, give expression to individual assertions of difference and group identity, portray indifference or excruciating investment in the denial of deviance, resignify incapacity into unexpected ability, or provide opportunities of interdependency among human vulnerabilities in search of mutual support. On each cover of Volumes I through V, disability serves as the medium through which artists—and, consequently, the viewers of their art—may ponder cultural responses to the persistence of human heterogeneity. Difference prompts myriad social schemes of suppression in futile efforts to contain variation within a narrower range of expression. Artists of disability are not in any way immune to the homogenizing projects of cultures, but their work gives us perspective on how we might improve the future by contemplating the limitations of tolerance in our past.

Further Readings

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ABOUT THE GENERAL EDITOR

Gary L. Albrecht is Professor of Public Health and of Disability and Human Development at the University of Illinois at Chicago. His current work focuses on the quality of life of disabled people based on National Institutes of Health (NIH)–funded studies of disabled women experiencing the menopausal transition and a study of disability risk in the United Kingdom, France, and the United States. Complementary work on the experience of disability in the inner city has been funded by the National Institute on Disability and Rehabilitation Research (NIDRR). He is past Chair of the Medical Sociology Section of the American Sociological Association, a member of the Executive Committee of the Disability Forum of the American Public Health Association, an early member of the Society for Disability Studies, and an elected member of the Society for Research in Rehabilitation (UK). He has received the Award for the Promotion of Human Welfare and the Eliot Freidson Award for the book *The Disability Business: Rehabilitation in America.* He also has received a Switzer Distinguished Research Fellowship, Schmidt Fellowship, New York State Supreme Court Fellowship, Kellogg Fellowship, National Library of Medicine Fellowship, World Health Organization Fellowship, the Lee Founders Award from the Society for the Study of Social Problems, the Licht Award from the American Congress of Rehabilitation Medicine, and the University of Illinois at Chicago Award for Excellence in Teaching.

He has been elected Fellow of the American Association for the Advancement of Science (AAAS) and is a frequent Visiting Fellow at the University of Oxford and Scholar in Residence at the Maison des Sciences de l'Homme, Paris. He has led scientific delegations in rehabilitation medicine to the Soviet Union and the People's Republic of China and served on study sections, grant review panels, and strategic planning committees on disability in Australia, Canada, the European Community, France, Ireland, Poland, Sweden, South Africa, the United States, and the World Health Organization, Geneva. His most recent books are *The Handbook of Social Studies in Health and Medicine* (Sage, 2000, edited with Ray Fitzpatrick and Susan Scrimshaw) and the *Handbook of Disability Studies* (Sage, 2001, edited with Katherine D. Seelman and Michael Bury).

ABOUT THE ASSOCIATE EDITORS

Jerome Bickenbach is a full Professor in the Department of Philosophy and the Faculties of Law and Medicine at Queens University, Kingston, Ontario. He currently holds a Queen's Research Chair, and he was a previous holder of a Killam Fellowship, working on the law and policy of health systems performance assessment, including the legal and ethical aspects of summary measures of population health. His research is in disability studies, using qualitative and quantitative research techniques within the paradigm of participatory action research. Most recently, his research includes disability quality of life and the disability critique, disability epidemiology, universal design and inclusion, modeling disability statistics for population health surveys, the relationship between disability and health, and the ethics and policy implications of summary health measures.

As a lawyer, Dr. Bickenbach was a human rights litigator, specializing in antidiscrimination for persons with intellectual impairments and mental illness. Since 1995, he has been a consultant with the World Health Organization (WHO) working on the revision of the ICIDH, from alpha and the beta drafts, to the final draft leading to the ICF. He has participated in nearly all revision activities, and continues to consult with WHO on ICF dissemination and international disability social policy.

He is author of *Physical Disability and Social Policy* (1993) and coeditor of *Introduction to Disability* (1998), *Disability and Culture: Universalism and Diversity* (2000), *A Seat at the Table: Persons with Disabilities and Policy Making* (2001), *Quality of Life and Human Difference* (2004), and numerous articles and chapters in disability studies, focusing on the nature of disability and disability law and policy.

David T. Mitchell is Associate Professor of Disability Studies at the University of Illinois at Chicago. From 2000 to 2004, he served as Director of the first Ph.D. program in disability studies. He has also served as president of the Society for Disability Studies and as Chair and founding member of the Modern Language Association's Committee on Disability Issues. He has served on the Board of Directors for Chicago's Independent Living Center, Progress Center, and as an editor on numerous editorial boards including that of the journal *Disability & Society*. He earned his Ph.D. from the Program in American Culture at the University of Michigan, Ann Arbor.

Most recently, Dr. Mitchell has been concerned with the inclusion and advancement of students with disabilities in higher education. Disability studies takes as its charge the goal of making classrooms and the university more accessible. Similarly, fields of inquiry need to become more answerable for their embedded assumptions about disability. Part of this work involves querying the role that disabled persons play as objects for different kinds of knowledge acquisition about them. Consequently, he directed the first National Endowment for the Humanities Summer Institute in Disability Studies for Educators. In addition, he has traveled and lectured extensively on these and other disability studies topics, in the United States, Canada, Germany, Ireland, Russia, Britain, and Costa Rica. In 2004, he codirected a seminar project team that researched euthanasia murder files and original documentation from psychiatric institutions in National Socialist Germany. This commission remains committed to making the history of disability genocide more known, studied about, and understood.

He is coauthor of *Cultural Locations: Discourses of Disability* (2005), coeditor of *Eugenics in America: A History in Primary Sources* (2005), coauthor of *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), coeditor of *The Body in Physical Difference: Discourses of Disability* (1998), coeditor of a special issue of *Disability Studies Quarterly* on disability studies in the humanities, and coeditor of a special issue on disability issues in writing by the American author Herman Melville for the journal *Leviathan*.

Walton O. Schalick III is Assistant Professor of Pediatrics and of History at Washington University in St. Louis. He is a practicing pediatrician and physiatrist in the Division of Newborn Medicine at St. Louis Children's Hospital, where he works with children with disabilities and does clinical research, a portion of which involves practical ethics and children with chronic conditions. He is an award-winning teacher of medical students and residents, and, in the Faculty of Arts & Sciences, an award-winning teacher of undergraduate and graduate students in history, history of medicine, and disability studies.

He holds M.D. and Ph.D. (History of Medicine) degrees from the Johns Hopkins University. His Ph.D. included work in nineteenth-century European and modern American medicine, but focused on medieval European medicine. He completed two residencies, one in Pediatrics (Children's Hospital, Boston) and one in Physical Medicine & Rehabilitation (PM&R or physiatry) (Spaulding Rehabilitation Hospital) at Harvard University, and a Chief Residency in PM&R. Since that time, he has been on the faculty in both the School of Medicine and the Faculty of Arts & Sciences at Washington University in St. Louis.

Professor Schalick's historical work encompasses a study of children with physical disabilities from 1800 to 1950 in France, Germany, the United Kingdom, and the United States, funded in part through the Robert Wood Johnson Foundation's Generalist Faculty Award Scholars. His first book manuscript, *Marketing Medicine,* traces the origins of academic medicine and marketplace dynamics in medieval France. He has published widely on pediatrics, medieval history, and history of disabilities in both the clinical and the scholarly literature and is the recipient of numerous awards for history, including the Shryock Medal of the American Association for the History of Medicine.

Sharon L. Snyder is Assistant Professor in the Department of Disability and Human Development at the University of Illinois at Chicago. She is a founding member of the Modern Language Association's Committee on Disability Issues and of the Disability Studies Discussion Group. As a faculty member in the first Ph.D. program in disability studies in the United States, she has developed graduate courses including disability in film, the history of eugenics, representational history, globalization and political economies, and curriculum development for disability studies. In 2004, she directed the Legacies of Eugenics, a DAAD (German Academic Exchange Service) seminar for U.S. and Canadian faculty at the Einstein Forum, Potsdam, Germany. She has codirected a National Endowment for the Humanities Summer Institute and served as a faculty lecturer at the University of Costa Rica.

Dr. Snyder is coauthor of *Cultural Locations of Disability* (2005), coeditor of *Eugenics in America* (2005), coeditor of *Disability Studies: Enabling the Humanities* (2003), coauthor of *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), and coeditor of the first collection of essays on disability studies in the humanities, *The Body and Physical Difference: Discourses of Disability* (1997). As the series editor for Corporealities: Discourses of Disability, she has been instrumental in encouraging scholarly work in the new analytical field of disability studies. Her essays on disability theory, disability culture, and representational history have been published widely and translated for many international professional journals.

The founder of the independent production company Brace Yourselves Productions, she is also a documentary filmmaker whose work includes *Self-Preservation: the Art of Riva Lehrer, Disability Takes on the Arts, A World without Bodies*, and *Vital Signs: Crip Culture Talks Back*. Awards for her films include the Festival Grand Prize at Rehabilitation International's Film Festival, Achievement and Merit Awards at Superfest, and Best of the Festival at Moscow's Breaking Down Barriers.

ABOUT THE SENIOR ADVISORY BOARD

Scott Campbell Brown is an Education Research Analyst with the U.S. Department of Education, Office of Special Education and Rehabilitation Services, Office of Special Education Programs. His major focus is early childhood, with a long-term interest in promoting use of the World Health Organization's International Classification of Functioning, Disability and Health. He has served as a consultant to the United Nations on disability policy and to the International Labour Organization on disability statistics. His education includes a Ph.D. in demography from the University of Pennsylvania.

Dudley S. Childress is Senior Rehabilitation Research Scientist in the Jesse Brown VA Medical Center, Professor of Biomedical Engineering in the McCormick School of Engineering at Northwestern University, and Professor of Physical Medicine and Rehabilitation in the Feinberg School of Medicine in Chicago. He directs the Prosthetics Research Laboratory and the NIDRR Rehabilitation Engineering Research Center in Prosthetics and Orthotics, and is Executive Director for the Prosthetics & Orthotics Education Program.

He joined Northwestern's Department of Orthopaedic Surgery in 1966. In addition to limb prosthetics and orthotics, his experience includes almost 20 years of research and development (R&D) work in the general area of assistive technology for persons with disability, which include wheelchair controllers, communication aids, environmental controllers, computer systems, and other appropriate technology for activities of daily living. He holds an M.S. degree in electrical engineering from the University of Missouri (Columbia) and a Ph.D. degree in electrical engineering from Northwestern University.

He is currently engaged in scientific studies of human movement (particularly walking) and in the development of engineering systems that assist people with walking (e.g., artificial feet). He remains interested in control systems for artificial hand/arm replacements and with computer-aided engineering for fabrication of prosthetics and orthotics. He is a member of the Institute of Medicine of the National Academy of Sciences.

Joseph Flaherty is Dean of the School of Medicine and former Professor and Head of the Department of Psychiatry, as well as chief of the psychiatry service at the University of Illinois at Chicago, where he received his medical training and his psychiatric research training. He had additional research training in sociology at London University. Over the past 15 years, Dr. Flaherty has examined the effects of gender on the development of symptoms and illness as well as health-seeking behavior and treatments in alcoholism and depression. He also has been involved in psychometric testing of new instruments and their cross-cultural adaptation through research conducted in Peru, Panama, Israel, and the USSR. For more than 20 years, his research has been funded by branches of the National Institutes of Health, including the National Institute on Alcohol and Alcoholism and the National Institute of Mental Health, as well as the MacArthur Foundation, the Chicago Community Trust, and other governmental and private agencies. He is currently involved in a large-sample longitudinal study on the effects of occupational stressors on heavy drinking. He is also developing models of health care delivery for high-risk children in state care with the aim of early intervention and prevention.

Dr. Flaherty has published more than 180 professional papers, books, and chapters. He is an editorial member or reviewer for a variety of professional journals and consults with a number of agencies including the World Health Organization and the Falk Institute in Jerusalem.

Allen W. Heinemann directs the Center for Rehabilitation Outcomes Research, a rehabilitation-focused health services research unit at the Rehabilitation Institute of Chicago (RIC) where he has worked since 1985. He is also Associate Director of Research at RIC and Professor in the Department of Physical Medicine and Rehabilitation at the Feinberg School of Medicine, Northwestern University. He serves on the Coordinating Committee for Northwestern University's Institute for Health Services Research and Policy Studies. Research interests focus on health services research, psychosocial aspects of rehabilitation including substance abuse, and measurement issues in rehabilitation.

He is the recipient of funding by the National Institute on Disability and Rehabilitation Research (Switzer Fellowship, Field Initiated Projects, Innovation Award, DRRP on Health Services Research, RRTC components), the National Institute on Alcohol Abuse and Alcoholism, Centers for Disease Control, the Social Security Administration, the Substance Abuse and Mental Health Services Administration, the J. M. Foundation, the Paralyzed Veterans of America–Spinal Cord Research Foundation, and the American Occupational Therapy Foundation and Association. He is a Fellow of the American Psychological Association (Division 22) and a diplomate in Rehabilitation Psychology (ABPP). He serves as the president elect of the American Congress of Physical Medicine and Rehabilitation and the Rehabilitation Psychology division of the American Psychological Association. He serves as a study section member for the National Institutes of Health's Center for Scientific Review, on the editorial board of the *Archives of Physical Medicine and Rehabilitation, NeuroRehabilitation, International Journal of Rehabilitation and Health, Journal of Outcome Measurement, Journal of Head Trauma Rehabilitation, Rehabilitation Psychology,* and *Rehabilitation Counseling Bulletin.* He is the recipient of the Division 22 (Rehabilitation Psychology, of the American Psychological Association) Roger Barker Distinguished Career Award.

He is author of more than 100 articles in peer-reviewed publications and is editor of *Substance Abuse and Physical Disability*. He earned a doctoral degree in clinical psychology at the University of Kansas with a specialty focus in rehabilitation.

Tamar Heller is Professor and Chair of the Department of Disability and Human Development, University of Illinois at Chicago. She also directs the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, the Advanced Training for Disability and Rehabilitation Scholars program, and projects on support interventions for individuals with disabilities and their families. In addition, she is Director of the University Center of Excellence in Developmental Disabilities for the State of Illinois. Previously, Dr. Heller directed the Family Studies and Services Program, which included an interdisciplinary diagnostic clinic serving nearly 1,000 families per year from the inner city, a family support program, and studies on lifespan family support. Dr. Heller has served on the boards of the American Association on Mental Retardation, the European Course on Mental Retardation, and several leading national and international journals on disability issues.

Dr. Heller has written more than 100 publications and presented nearly 200 papers at major conferences on disability policies and interventions. She has coedited two books (*Health of Women with Disabilities* and *Older Adults with Developmental Disabilities: Optimizing Choice and Change*) and edited special issues of *Technology and Disability, American Journal on Mental Retardation, Journal of Policy and Practice in Intellectual Disabilities,* and *Family Relations.*

Christopher B. Keys is Professor and Chair of the Psychology Department at DePaul University and Professor Emeritus of Psychology and of Disability and Human Development at the University of Illinois at Chicago. Professor Keys's current research and interventions focus on the empowerment of people with disabilities and their families, the promotion of success in education and in life by youths and young adults with disabilities, and attitudes toward people with intellectual disabilities and disability rights. He is also conducting intervention research concerning the development of the program evaluation capacity of organizations that serve people of color with disabilities. He is particularly interested in the intersections of disability, ethnicity, and social class.

A Fellow of the American Psychological Association and the Society for Community Research and Action, Dr. Keys was one of the first to serve as president of the Society for Community Research and Action and Chair of the Council of Community Psychology Program Directors. His work has been recognized by awards, appointments, and honors from the American Psychological Association, the World Bank, the American Institutes of Architects, and the National Government of Australia. He has been invited to present his research in Asia, Australia, Europe, and Latin America.

With his colleagues, Dr. Keys has coauthored more than 100 journal articles, book chapters, and reports concerning people with disabilities, empowerment, disabilities, organization development, community research methods, and related topics. He has also coauthored more than 250 conference presentations and has been responsible for training more than 10,000 staff serving people with disabilities and working in other human services, education, and justice systems. Recently, he coedited *People with Disabilities: Empowerment and Community Action* and *Participatory Community Research: Theory and Method in Action.*

Trevor R. Parmenter holds a joint appointment of Foundation Professor of Developmental Disability in the Faculty of Medicine at the University of Sydney and Director of the Centre for Developmental Disability Studies (CDDS). He also holds the position of Adjunct Professor in the School of Education and Social Work at the University of Sydney. Prior to his appointment at CDDS in 1997, Professor Parmenter, Ph.D., FACE, FAAMR, FIASSID, held the position of Professorial Fellow in the School of Education, Macquarie University and Director of the Unit for Community Integration Studies. Previous to his appointment to Macquarie University in 1974, he held teaching and administrative positions with the New South Wales Department of Education (1953–1973).

Areas of research and publication include research into behavioral and emotional problems of people with disabilities; quality-of-life assessment; program evaluation; policy development; community living and employment for people with disabilities; assessment of cognitive processes; brain injury; family studies; transition from school to further study, work, and adult living; and aging and disability. He is a member of the editorial boards of eight international journals and a Fellow of the Australian College of Educators, the American Association on Mental Retardation, and the International Association for the Scientific Study of Intellectual Disabilities.

His international activities have included work in association with the World Health Organization and the International Labour Organization, presidency of the International Association for the Scientific Study of Intellectual Disabilities, and vice presidency of the International Sports Federation for Persons with Intellectual Disability. At the national level, he chairs the Advisory Committee on Australian and International Disability Data for the Australian Institute of Health and Welfare and is a member of the Institute's Burden of Disease Advisory Committee. He was a member of the Disability Council of New South Wales for several years.

Mairian Scott-Hill (who also published as Mairian Corker) earned a B.Sc. in biological sciences from the University of East Anglia as a mature student. She had previously been working in the hematology department at St. Thomas' Hospital in London after leaving school. Her employers recognized her outstanding intellectual abilities and sent her off on day-release classes to obtain an H.N.D. in science, after which she took her degree and then an M.Phil. on the subject of deafness. She then worked for the Deaf Children's Society, before returning to the field of education in a post at the City Lit institution. Subsequently, she was a senior research Fellow attached to several universities—including University of Central Lancashire, University of Leeds, and King's College London—although she never took up a full-time academic position. Mairian was a very original thinker, and a prolific writer. Her books include *Counselling—The Deaf Challenge* (1994), *Deaf Transitions* (1996), *Deaf and Disabled or Deafness Disabled* (1998), and two edited books, *Disability Discourse* (with Sally French, 1999) and *Disability and Postmodernity* (with Tom Shakespeare, 2002). Mairian's research interests centered in deaf studies and disability studies included linguistics, discourse, identity, childhood, law, and culture. She led the way in applying the insights of poststructuralism and postmodernism to British disability studies, and she was very active in online debates about disability theory, particularly in supporting new generations of scholars. Mairian died on January 22, 2004, and will be missed by the whole disability studies community.

Tom Shakespeare is currently Director of Outreach for the Policy, Ethics and Life Sciences Research Institute at the University of Newcastle, a project exploring bioethics and science engagement (www.peals.ncl.ac.uk). He earned his B.A. in Social and Political Science, M.Phil. in Social and Political Theory, and Ph.D. in Sociology from the University of

Cambridge. He did research and taught sociology at the Universities of Sunderland, Leeds, and Newcastle. He has been involved in the UK disability movement since 1986 and instrumental in founding Disability Action North East and the Northern Disability Arts Forum. He has experience as a performer and a writer, has given keynote speeches at academic and activist conferences throughout the world, and regularly contributes to UK print and broadcast media. He was awarded the UK Award for furtherance of the human rights of disabled people at the 2003 RADAR People of the Year Awards and delivered the Lister Prize Lecture at the 2003 British Association for the Advancement of Science Festival. His research interests in disability studies concern models of disability, disabled childhood, disability and genetics, disability and sexuality, disability and social care, and cultural representation of disability. He has many publications in the field of disability studies and bioethics and is coauthor of *The Sexual Politics of Disability* (1996), *Exploring Disability* (1999), and *Genetic Politics: From Eugenics to Genome* (2002).

A

AAATE

See Association for the Advancement of Assistive Technology in Europe

ABLEISM

Ableism describes prejudicial attitudes and discriminatory behaviors toward persons with a disability. Definitions of ableism hinge on one's understanding of normal ability and the rights and benefits afforded to persons deemed normal. Some persons believe it is ableism that prevents disabled people from participating in the social fabric of their communities, rather than impairments in physical, mental, or emotional ability. Ableism includes attitudes and behaviors emanating from individuals, communities, and institutions as well as from physical and social environments.

HISTORY

The term *ableism* evolved from the civil rights movements in the United States and Britain during the 1960s and 1970s, but prejudice and discrimination against persons with a disability has existed across the globe and throughout history. During the civil rights era, disability activists transformed religious and scientific understandings of disability into a political paradigm. In religious and scientific paradigms, disability is an individual characteristic. The disabled individual bears primary responsibility for enduring or remedying the disability through prayer in the religious paradigm or through medical intervention in the scientific paradigm. Although disabled persons are sometimes isolated from nondisabled persons, the dominant theme in both religious and scientific traditions is that nondisabled persons should behave compassionately toward disabled persons. From the civil rights perspective, often called a minority oppression model, society creates disability by creating physical and social environments hostile to persons different from the majority or "abled" culture. *Ableism* has become a term used to describe "the set of assumptions and practices that promote unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences" (Terry 1996:4–5).

MANIFESTATIONS OF ABLEISM

Discriminatory attitudes and practices that promote unequal treatment of disabled persons share many similarities with the discrimination against other minority groups. Discrimination may be direct or indirect, legally or culturally encoded, based on scientific norms or based on false assumptions. Stereotyped notions of the minority group, whether chosen by an individual or ascribed to an individual by others, may prevent members of the majority group from even perceiving individual characteristics. Common components of ableism include lowered expectations, normalization as beneficence, limitations in self-determination, labeling, and eugenics.

Lowered Expectations

Expectations refer to beliefs about probable future occurrences based on current observations. Expectations of parents, teachers, employers, and others often influence one's self-concept and one's achievement. Research demonstrates correlations between high expectation and high achievement among students in elementary through higher educational settings, as well as correlations between low expectation and low achievement. Moreover, research demonstrates that the younger the person, the stronger the influence of expectations held by others. The consequences of low expectation are particularly pernicious when those forming expectations erroneously evaluate ability and when they assume that low achievement in one performance domain automatically transfers to low achievement in other performance domains. For example, children with speaking impairments are often erroneously assumed to have more difficulty learning than those who are easily understood.

Two areas of lowered expectations receive special attention in the disability literature and in public policy: education and employment. Across continents, many nations prohibit certain forms of discrimination in educational and employment opportunity. In the United States, the Individuals with Disabilities Education Act (1975, 1997) requires schools to provide "free and appropriate education" for all students, and the Americans with Disabilities Act (ADA; 1990) provides employment protections for qualifying persons with disability. In Australia, the Disability Discrimination Act (1992) supports nondiscrimination in education and training and the Disability Services Act (1986) provides that a person with disability has a right to achieve his or her individual capacity for physical, social, emotional, and intellectual development. In the United Kingdom, the Disability Discrimination Act (1995) prohibits employer discrimination against disabled persons in recruitment, employment conditions, training, and promotion. One limitation of these and similar acts in other nations is that they cannot adequately protect persons from unspoken judgments of inadequacy that follow a person throughout childhood and adulthood.

Ableism manifested by lowered expectations in education may be remedied in several ways. Hehir (2002) wrote at length about policies to reduce ableism in schools. He asserted that children with learning disabilities should have access to the rest of the curriculum even if evidence suggests that reading and writing will always be weak. He proposes the elimination of policies in which schools are allowed to a priori exclude the performance of children with disabilities from overall school performance. Laws with this type of exclusion reinforce lower expectations, and consequently lower achievement, of children with disability.

Ableism causing lowered expectation in employment is also pervasive across cultures. Especially in capitalist economies, persons with disability are viewed as expensive labor or not suited for labor at all. The inordinate focus on the characteristics of the disability to the exclusion of that which a person can do exacerbates lower expectations and produces discrimination.

Normalization as Beneficence

Ableism is manifest whenever people assume that normal physical, mental, and emotional behavior is beneficial regardless of a person's actual physical, mental, and emotional attributes. Especially when strong research evidence supports alternate conclusions, the equating of normal with desirable may be harmful to disabled persons. For example, educators and parents may assume that deaf children will better negotiate the hearing world with oral language than with manual language (e.g., sign language). A large body of research, however, demonstrates that deaf children make greater educational achievements when manual, rather than verbal, language skills are emphasized. Language provides organization for the acquisition and utilization of knowledge. It is therefore logical that an emphasis of oral language over manual language would be detrimental to most deaf children. Normalization may be particularly noxious when persons without disability assume positions of power over persons with disability.

Limitations in Self-Determination

Self-determination describes the right and the responsibility of people to make decisions for themselves. Self-determination includes freedom to associate with whomever one chooses, authority to control money owned by or used to purchase services for oneself, autonomy to be the boss of one's own life, and assuming responsibility for the consequences of one's decisions. Self-determination is an internationally endorsed value. The United Nations General Assembly adopted the "Universal Declaration of Human Rights" in 1948. This document affirms that the "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world." A problem is that these inalienable rights have often been denied to disabled person. Ableism occurs whenever a group of persons endorses self-determination among most group members but restrict or inhibit disabled persons from making basic life choices. Even when legal codes establish the rights of disabled persons to exercise the same rights of self determination that are afforded to abled persons, disabled persons often are not able to exercise their rights to self-determination in education, employment, transportation, housing, medical decision making, and social interchange. These rights may remain inaccessible to disabled persons due to inaccessibility of physical and social spaces, limited financial resources, and disabling attitudes.

Labeling

Labeling a person as "disabled" requires a judgment, usually by a professional, that an individual's behaviors are somehow inadequate, based on that professional's understanding of community expectations about how a given activity should be accomplished. Professionals typically consider methods used by "abled" person of the same age, sex, and cultural and social environment to accomplish a task to be normal, and all other methods to be abnormal. A problem with this interpretation of disability is the duality of categorization. People are either "disabled" or "abled." "Abled" persons set the criteria for the categorization, and "abled" persons make the judgments that assign people to one of the two categories. The label "disabled" implies inadequacy as a person. The social meaning of a classification often more strongly influences the daily life of a labeled person than the characteristics that cause the person to meet the classification criteria. When a label carries positive social meaning, the labeled individual may experience expanded opportunities. When the label carries negative social meaning, opportunities often contract. The label "disabled" carries negative social meaning. In the United States, the authors of the ADA recognized the seriousness of the negative consequences of being thought of as "disabled." The ADA protects persons thought of as "disabled" equally to persons who otherwise meet the criteria for disability under the act. Few other countries have enacted laws to address disadvantage that results from simply being called "disabled."

Eugenics

Eugenics may be defined as development and improvement of the human race. Eugenic methods include preventing persons deemed deviant and defective from being born, preventing persons born deviant or defective from reproducing, and isolating persons deemed deviant and defective through institutionalization or murder. The systematic killing of disabled children by the Nazi regime in Germany during World War II illustrates an extreme form of ableist behavior. The identification of the human genome (entire genetic makeup of human beings) facilitates selective abortion based on ableism. Selective abortion is a contemporary form of eugenics. Societies that permit abortion for fetuses likely to be born disabled, but do not permit abortion for those likely to be born abled, invalidate the lives of disabled persons.

—Sandra J. Levi

See also Americans with Disabilities Act of 1990 (United States); Disability Discrimination Act of 1995 (United Kingdom); Eugenics; Individuals with Disabilities Education Act of 1990 (United States); Stigma; Stigma, International.

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ABU 'L-`ALA AL-MA`ARRI

(973–1057)

Arab poet and freethinker

The renowned Arab poet and philologist Abu 'l-`Ala lost most of his sight to smallpox in his fourth year and was blind as a youth. His memory developed well, and he retained huge amounts of Arabic literature. Abu 'l-`Ala took up the role of blind poet, having a tiny pension for himself and his sighted attendant. When that income failed, he moved to Baghdad and joined literary circles there, managing briefly to earn a precarious living from writing and public recitation of verses. While his talents were appreciated, they did not save him from some quarrels and humiliations. Within two years, he had returned to Ma`arrat and resumed his life there, in 1010. Extant correspondence shows him active in literary affairs and teaching. As his teeth began to drop out, he complained of his own mispronunciation, leading to his amanuensis writing mistakenly. Abu 'l-`Ala actively courted controversy with unorthodox religious views, even writing a book that could be considered as attempting to rival the Qur'an.

—Kumur B. Selim

See also Abu 'l Aswad ad-Duwali; `Ata ibn Abi Rabah; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

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ABU 'L ASWAD AD-DUWALI

(603-688)

Arab scholar

The scholar and innovative grammarian Abu 'l Aswad ad-Duwali lived in Basra, Iraq, and for a short period may have been city governor, under the caliphate of `Ali. In later life, Abu 'l Aswad suffered paralysis and could hardly walk, yet insisted on going to market in person, though he was wealthy. An acquaintance remarked that there was no reason to put himself to this trouble, so Abu 'l Aswad explained why he would continue to appear in public as long as he could: "I go in and out, and the eunuch says: 'He is coming,' and the boy says: 'He is coming,' whereas, were I to continue sitting in the house, the sheep might urine upon me without anyone preventing them" (*Ibn Khallikan's Biographical Dictionary*, 1842–1871). Another reason was that Abu 'l Aswad had lost all real influence after the murder of his patron `Ali, but in public he was still recognized as a man who had been of some consequence.

—Kumur B. Selim

See also Abu 'l-`Ala al-Ma`arri; `Ata ibn Abi Rabah; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

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ABUSE AND HATE CRIMES

Abuse and hate crimes are serious problems in the lives of many disabled people. Abuse can take many forms, including: physical, sexual, emotional, medical, and financial abuse, as well as maltreatment and neglect. Physical abuse can include hitting, slapping, and pushing; sexual abuse can involve unwanted touching, sexual contact, or rape; emotional abuse can including bullying, threatening, and intimidating a person; medical abuse can involve overmedicating a person or denying them appropriate medications; financial abuse involves wrongfully using someone else's finances; and neglect may range from failure to provide basic necessities to putting someone at risk through unsafe practices.

Many studies show that disabled people are far more likely than nondisabled people of the same age and gender to be the victims of abuse. However, the studies that have been carried out on disability abuse have often been conducted on small populations of people with specific impairments. For instance, Sullivan, Vernon, and Scanlan (1987) and Elder (1993) reported sexual abuse among Deaf youths at rates higher than 50 percent. Jacobson and Richardson (1987) found that 81 percent of psychiatric inpatients with multiple disabilities had been abused. Pava (1994) studied the vulnerability of vision-impaired people to sexual and physical assault, concluding that one in three of her sample had been targets of either attempted or actual assault. In an Australian study, Wilson and Brewer (1992) reported that people with an intellectual disability were 10 times more likely to experience violent crime victimization than other adults. McCabe, Cummins, and Reid (cited in Chenoweth 1999) found that 20.5 percent of people with an intellectual disability had been raped, compared to 5.7 percent of a control group of nondisabled people.

There is an abundance of literature suggesting that disabled children experience far higher rates of abuse than nondisabled children. Ammerman and Baladerian (1993) concluded that the rate of maltreatment of disabled children is 4 to 10 times higher than nondisabled children. Sullivan and Knutson (1998) examined nearly 40,000 hospital records and reported rates of maltreatment among children with disabilities that were 1.7 times higher than nondisabled children. A later review of school records by Sullivan and Knutson (2000) indicated maltreatment among 31 percent of disabled children compared to 11 percent of the overall school population. A number of studies suggest that abuse is often carried out by people who are known to the victim—family, friends, other disabled people, and even paid caregivers. However, many cases of abuse are not reported to authorities because of the victim's shame, fear of retaliation, fear of not being believed, or reliance on third parties to report the abuse.

Sobsey, Randall, and Parrila (1997) suggested that there may be different patterns of abuse for disabled boys than disabled girls. They reviewed the case files of 1,834 children and found that 62 percent of girls with disabilities and 38 percent of boys with disabilities experienced sexual abuse, 59 percent of girls with disabilities and 41 percent of boys with disabilities had been emotionally abused, and 56 percent of disabled boys were neglected, compared to 44 percent of disabled girls.

Dick Sobsey's (1994) major study, *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* suggested that disabled people are more likely than nondisabled people of the same age and gender to experience abuse and that this abuse is more likely to be prolonged and severe. Sobsey also suggested that a "culture of abuse" often existed in certain institutions. This argument is supported by Furey, Nielsen, and Strauch (1994), who reviewed cases of substantiated abuse and neglect of mentally retarded adults in Connecticut. They found that such abuse and neglect is far more likely to occur in group homes and institutional settings than in private residences. Chenoweth (1996) acknowledged that there may be a "culture of cover-up" in institutions and group homes. However, she emphasizes the importance of other social factors in creating environments where abuses take place, including the dehumanization of residents in institutions, a "paradox of care and abuse within the one system," and the enormous power differentials between people and the system.

The rates of abuse experienced by disabled women are particularly high. Nosek et al. (2001) also stated that 62 percent of physically disabled women in their study reported experiences of sexual abuse. The Disabled Women's Network of Canada surveyed 245 women with disabilities in 1989 and found that 40 percent had experienced abuse, and 12 percent had been raped (Riddington 1989). The most frequent perpetrators in these cases were spouses and former spouses. Less than half of these cases of abuse and rape were reported.

A number of studies suggest that the vast majority of perpetrators of abuse are male and are known to the victim (National Center for Injury Prevention and Control 1998). Perpetrators of abuse include caregivers, family members, other disabled people, health care providers, and acquaintances. The fact that many disabled people have a number of caregivers in their lives, whose work often involves rather intimate tasks, may be one of the factors that puts them at increased risk of abuse. Social and personal boundaries are often at risk of being blurred in the provision of personal assistance (Saxton et al. 2001).

Some of the responses that have been developed to prevent abuse include the following: training programs for both potential victims and caregivers to increase awareness of abuse issues; sex education programs that emphasize choice making, personal rights, and assertiveness training; and staff screening programs involving reference and police checks to weed out convicted sex offenders from caregiving positions (Sobsey and Mansell 1990). It is essential that child protection workers, law enforcement personnel, and educators (particularly in special education settings) be provided with sufficient training to appropriately respond to cases of disability abuse.

Unfortunately, many child protection workers lack knowledge about disability issues. This lack of confidence in dealing with disability issues has led to the situation where disabled children are overrepresented among victims of abuse but underrepresented among the caseloads of child protection workers (Orelove, Hollahan, and Myles 2000). As a result, disabled victims of abuse often experience significant difficulty in accessing appropriate services. Over 50 percent of the services studied by Sobsey and Doe (1991) did not provide any accommodations to meet the needs of their disabled clients. Many professionals also report a lack of training in dealing with abuse histories of male clients, which may compound these problems (Lab, Feigenbaum, and De Silva 2000).

DISABILITY HATE CRIMES

Disability hate crimes are criminal acts aimed at people because of their disability identity, or because of their connection with someone who is disabled. To prove that a crime is actually a hate crime, there must be evidence to demonstrate conclusively that the perpetrator discriminated in the selection of the victim. There are two victims in hate crimes: individuals and communities. Hate crimes not only represent an attack on the rights and freedoms of individuals, they indicate a lack of physical safety for anyone in the community that has been attacked. Because hate crimes have two victims (both individuals and communities), offenders are often given extra penalties for these crimes.

The unique aspect of hate crimes is that they involve "parallel crimes" (Jenness and Grattet 2001:130). That is, there are two crimes embedded in a single act: a crime such as vandalism, theft, arson, murder, or assault, and another crime, a bias crime. To prove that a bias crime has occurred, it is necessary to demonstrate that the offender discriminates in the selection of his or her victim. To prove a disability hate crime exists, discrimination on the basis of real or perceived disability must be a substantial reason for discriminating against this particular individual. Evidence of hate can include words or symbols associated with hate, demeaning jokes about a particular group, the destruction of that group's symbols, a history of crimes against a group, a history of hate crimes in the community, and the presence of hate group literature.

Hate crime legislation typically outlines specific identity categories that are protected from bias crimes. This has led some critics to suggest that there is a hierarchy of protected categories, with race, religion, and ethnicity being the least controversial categories and gender, sexual orientation, and disability being the most controversial (McPhail 2000). In *Hate Crimes: Criminal Law and Identity Politics,* James Jacobs and Kimberly Potter (1998) argued that protecting certain categories of identity generates political conflict, produces an overly negative picture of intergroup relations, and creates recurrent occasions for intergroup conflict. The proponents of hate crimes legislation counter these arguments by arguing that the legislation responds to, rather than creates, intergroup conflict—particularly the violent suppression of marginalized identities and the violent defense of hegemonic identities.

Hate crimes tend to be associated with high levels of violence. Compared to other forms of crime, hate crimes are far more likely to involve physical threat and harm to individuals, rather than property. Victims of a hate crime are three times more likely to require hospitalization than victims of a nonbias assault (Bodinger-DeUriate and Sancho 1992). In one study, half the victims of hate crimes were assaulted. This is a significantly higher rate than the national crime average, where only 7 percent of crimes involve assault (Levin and McDevitt 2002:17). The psychological consequences of hate crimes also seem to be more significant than those for nonbias crimes, in terms of depression, anger, anxiety, and posttraumatic stress (Herek, Gillis, and Cogan 1999; Herek et al., 1997).

Many hate crimes are committed by complete strangers—people who do not know the victim at all. Hate crimes are also often unprovoked (McPhail 2000). This aspect of the crime reinforces the sense that it is not something about the particular individual, but simply the person's shared identity with a collective group, that is the source of the victimization. In fact, this aspect of the crime is often seen as pivotal in establishing that the act was a hate crime rather than another form of crime.

Only a very small minority of disability hate crimes involve organized hate groups. However, it is important to acknowledge that some organized hate groups also overtly display their hostility to disabled people. Some neo-Nazi groups rely on eugenic ideas to debase disabled people and deny the right of disabled people to live. For instance, the white supremacist group Stormfront often discusses the need to "eliminate bad genes" and rid the world of disabled people.

Hate crimes often involve multiple perpetrators (whereas most assaults usually involve two mutual combatants), and often the victims are unarmed while the perpetrators are armed (Bodinger-DeUriate and Sancho 1992). Also, perpetrators of hate crimes often do not live in the area where they commit the crimes. They frequently spend time and money in traveling to unfamiliar areas in order to perpetrate the crime (Medoff 1999). And in most property crimes, something of value is stolen, but hate crimes that involve property are more likely to entail the destruction rather than the theft of that property (Medoff 1999).

Few countries retain national data on disability hate crimes. Often these crimes are not reported to police, or not recorded even if they are reported. Even when crimes against disabled people are neither random nor circumstantial, they are almost never acknowledged as "hate crimes." However, the FBI has published some data on disability hate crimes in America, suggesting that the most common forms of disability hate crimes are assault, intimidation, destruction of property, and vandalism. FBI data on American disability hate crimes from 1997 to 2001 indicate that the most common forms of disability bias crime are simple assault and intimidation, both of which comprise 29 percent of all disability bias crimes. The next most common form of disability bias crime is destruction, damage, or vandalism, which comprised 14 percent of all disability bias crimes.

For a range of bureaucratic reasons, those agencies responsible for reporting hate crimes may not have reported all crimes in their jurisdictions. This is a problem generally with hate crime statistics, and not just disability hate crimes. One of the serious misgivings that has to be voiced about these data is that less than 2,000 of the eligible 17,000 law enforcement agencies have ever filed a report of any sort of hate crime—whether by racial, religious, gender, sexuality, nationality, disability, or other bias (Center for Criminal Justice Policy Research and Justice Research and Statistics Association 2000).

The problems with these data stem from the fact that submitting hate crimes reports is voluntary, not all jurisdictions within states submit reports, and time frames for reporting are uneven—ranging from one month to one year (American Psychological Association 1998). Another problem is that there is a great deal of inconsistency in the location of hate crime units, the nature and amount of training received by responsible officers, procedures for screening and handling cases, and record-keeping systems (Martin 1996). Balboni and McDevitt (2001) suggested that lack of departmental infrastructure, lack of training and supervision, and communication breakdowns between line officers and those responsible for reporting the crimes may inhibit accurate reporting of hate crimes. Green et al. (2001:295) commented, "One cannot compare jurisdictions that use different reporting standards or have different levels of commitment to the monitoring of hate crime." Potok (2001) argued that the process is riddled with errors, failures to pass along information, misunderstanding of what constitutes a hate crime, and even falsification of data. Despite these misgivings, it must be acknowledged that many police departments are making significant efforts to implement hate crime policies and to monitor the incidence of hate crimes in their jurisdiction. Other factors may contribute to the failure to report hate crimes in such circumstances (Haider-Markel 2001).

—Mark Sherry

See also Child Abuse; Violence.

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National Criminal Justice Reference Service, http://www.ncjrs.org/hate_crimes/summary.html

▣ ACCESSIBILITY

Accessibility is a term with no precise definition. In the disability field, the concept of accessible environments is used to describe environments that are approachable, obtainable, or attainable. Often this means that the environment can be altered to enhance the individual's probability to participate in that environment in a way that is meaningful to the individual. Such environments are thus viewed as accessible. In this sense, issues of access and accessibility are usually not discussed in isolation, but rather in terms of specific environments to which access is desired. Examples of environments where accessibility is discussed are communication systems, education, employment, health care, housing, information technology, medical offices, polling places, public transportation, and websites. This list is by no means exhaustive. Any environment can be deemed as one to which accessibility is desirable.

Accessibility is a distinct characteristic from both participation and the environment. By its nature, *participation* refers either to an act of taking part or to a state of being related to a large whole. *Accessibility* is not an act or a state but a liberty to enter, to approach, to communicate with, to pass to and from, or to make use of a situation. The *environment* is either that large whole or parts thereof or that situation which is accessed. From these distinctions, it is clear then that the elements of accessibility are characteristics of an environment's availability but not characteristics of the environment itself.

By its nature, accessibility is interactive. An environment that is accessible to one person may not be accessible to another. As such, accessibility references issues to the interaction of persons and their environment. Hence, questions can be raised as to whether an environment has been formed or designed in such a way that a person can approach, obtain, or attain some aspect that is desired by that individual. Yet some enhancement of the individual's ability to obtain such access may be desirable. For instance, Braille can make linguistic communication that is usually obtained through sight attainable to persons who are blind, but those persons must know how to use the sense of touch to access Braille. Thus, written communication will not be accessible to persons who are blind if both of these conditions do not obtain—(a) written works must be available in Braille and (b) individuals who are blind must know how to read Braille. However, even the second part raises an issue of accessibility—the access of individuals who are blind to training in Braille. In this sense, accessibility is not a static phenomenon but can occur across different planes.

For more than 30 years in the United States, the concept of accessibility has been legally codified in Section 502 of the Rehabilitation Act of 1973, which created the Access Board. The work of this board interfaces not only with the Rehabilitation Act but also with the Architectural Barriers Act, the Americans with Disabilities Act, and Section 255 of the Telecommunications Act. The board grew out of the creation by Congress in September of 1965 of the

National Commission on Architectural Barriers to Rehabilitation of the Handicapped. As a result of the commission's June 1968 report, Congress enacted the Architectural Barriers Act (ABA) on August 12, 1968. The ABA requires access to facilities designed, built, altered, or leased with federal funds. However, there were no design standards to determine the accessibility of facilities.

To address this lack of standards, Congress established the Access Board, originally named the Architectural and Transportation Barriers Compliance Board in Section 502 of the Rehabilitation Act. The board's mandate was to ensure federal agency compliance with the ABA, and it was constituted of representatives from several different agencies. In the Rehabilitation Act Amendments of 1978, Congress authorized the board to establish minimum accessibility standards under the ABA, to ensure compliance with the requirements and to provide technical assistance. In 1984, the board issued the "Minimum Guidelines and Requirements for Accessible Design," which now served as the basis for enforceable design standards. The 1990 Americans with Disabilities Act (ADA) expanded the board's mandate to include developing the accessibility guidelines for facilities and transit vehicles. Facilities covered by these guidelines are restaurants and cafeterias; medical care facilities; mercantile establishments; libraries; hotels, motels, and transient lodging; and transportation facilities and vehicles. Under the Telecommunications Act of 1996, Congress authorized the board to develop guidelines for the accessibility of telecommunications products. The board issued its guidelines in 1998. The Rehabilitation Act Amendments of 1998 give the Access Board additional responsibility to developing accessibility standards for electronic and information technology. The Access Board has established ongoing committees to develop and update its accessibility guidelines and standards, which include those representing designers, industry, and people with disabilities.

Beyond the United States, the concept of accessibility has been a critical element in international disability policy for more than 20 years. Access and accessibility are concepts that are addressed several times throughout the World Programme of Action Concerning Disabled Persons, passed by the United Nations General Assembly in 1983. The World Programme references a concern with cultural, physical, or social barriers that prevent the access of individuals with disabilities to the various systems of society available to other citizens. The concept of accessibility is discussed in conjunction with the definition of equalization of opportunities as the process through which the general systems of society are made accessible to all people. Although addressed several times in the World Programme, accessibility is mainly discussed in terms of those societal elements that should be made accessible to all, such as community services.

Passed by the General Assembly in 1993, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities uses the term *available* instead of *accessible* in the context of defining equalization, perhaps because one of the rules, Rule 5, employs the term *accessibility* a little more narrowly. Accessibility is divided in two main areas: the physical environment and the communication environment. In terms of the physical environment, the Standard Rules offer the possibility of legislation, standards, and guidelines to ensure accessibility to housing, buildings, public transport services, and other means of transportation and outdoor environments. Those designing these environments, such as architects and construction engineers, would, hence, have the means to acquire information on measures to achieve accessibility. The rules urge such consideration at the beginning of the design process.

For information and communication, the importance of access to information about rights, services, programs, and diagnosis is considered of paramount importance. The issue of alternative formats for persons with vision and hearing and other communication issues is raised, along with media and computer accessibility. To ensure such accessibility, the role of persons with disabilities and their organizations is stressed. If the more broad term of *availability* is considered as the concept of accessibility, then the rules offer guidance for accessibility in all the designated target areas for equal participation—education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion.

Somewhat more complicated than issues related to accessibility of the physical or built environment is addressing the issue of accessibility to programs, such as access to education. Prior to passage of the Individuals with Disabilities Education Act (IDEA) in the United States, individuals with disabilities were not in school until the idea of access to school as a civil right emerged. Upon passage of the act, progress was made in gaining access to school, in a physical sense. Then, accessibility involved the concepts of mainstreaming and least restrictive environment. The emphasis in each of these approaches to access was the setting, in particular the classroom setting.

While setting remains important, attention is increasingly focusing on curriculum access. To that end, the U.S. Department of Education's Office of Special Education Programs has provided funding to the American Institutes for Research to house a national technical assistance (TA) center called the Access Center. The center strives to improve educational outcomes for elementary and middle school students with disabilities by building the capacity of TA systems, states, districts, and schools, to help students with disabilities learn from the general education curriculum. The center's goals are as follows:

1. Increase awareness of research-based programs, practices, and tools.
2. Strengthen the ability of educators to be informed consumers of programs, practices, and tools.
3. Assist educators to implement and evaluate programs, practices, and tools.

The Access Center has developed a framework for thinking about access to the general education curriculum. It views access as a multidimensional and dynamic process that involves a combination of instructional practices and supports. Under this approach, the general education curriculum is operationalized in terms of appropriate instructional and learning goals for individual students with disabilities, including appropriate scope and sequence. Appropriate research-based instructional methods and practices that have a track record of helping students with disabilities learn general education content and skills would then be employed alongside appropriate research-based materials and media, as well as supports and accommodations. Finally, appropriate tools and procedures would be used to assess and document whether students with disabilities are meeting high standards and achieving their instructional goals. The center has noted the importance of universal design in providing accessibility.

Whether the discussion focuses on access to programs or to the physical environment, the two approaches for achieving accessibility have been considered to comprise accommodation and universal design. Whereas accommodation involves changing existing environments to enhance accessibility, universal design occurs at the environmental design stage, where products and environments are created to the greatest extent possible to be accessible to persons of all ages and abilities. Often one or both of these approaches are implemented based on practical considerations. When institutions are well established and cannot be redesigned, accommodation solutions may be chosen. When institutions need to be designed or redesigned, principles of universal design may be employed to enhance accessibility.

Accessibility can be viewed as a multidimensional phenomenon. At this time, at least four models attempt to more fully explain the concept of accessibility. The first is the World Health Assembly's adoption in 2001 of the International Classification of Functioning, Disability, and Health (ICF). (The World Health Organization's [WHO] classification systems must be approved by the World Health Assembly, which consists of the member states that belong to the WHO.) The ICF incorporates for the first time in a health taxonomy the systematic consideration of environments whose accessibility can be evaluated. Broad categories include products and technology, as well as the natural environment and human-made changes to the environment. These encompass many of the areas previously discussed. Also considered, however, are elements of a more sociological nature, such as attitudes and support and relationships. Finally, services, systems, and policies are included. These environments can be characterized as barriers or facilitators. Though it does not employ the concept of accessibility in a systematic way, the ICF does note that accessibility can be dependable or variable, as well as of good or poor quality. Not only that, but environmental access may be limited due to the presence of a certain phenomenon, such as stairs, or the absence of a phenomenon, such as a ramp.

The multidimensionality of accessibility has led to attempts to systematically define access and describe its dimensions. Some of the earliest work in this area was conducted not in the disability field, but in the area of access to health care. In 1981, Pechansky and Thomas defined *access* as a concept representing the degree of "fit" between the clients and the system. Recognizing the multidimensionality of access, Pechansky and Thomas proposed that five dimensions be considered:

1. Availability—Type and extent of services, supports, and resources relative to personal needs
2. Accessibility—Location of the environment
3. Accommodation—The way services and resources are provided relative to persons' abilities to make use of them
4. Affordability—The cost vis-à-vis the resources of individuals
5. Acceptability—The match in attributes and attitudes between providers and clients

This health care model of accessibility has been applied by Simeonnson and colleagues (Simeonnson et al. 1999) to persons with disabilities. They argue that the notion of "fit" is compatible with person-environment interaction. In this manner, accessibility is not only the location of the environment, but it also may refer to interaction with the environmental barriers, such as stairs, referenced earlier.

In a similar vein, Whiteneck and colleagues (Whiteneck, Fougeyrollas, and Gerhart 1997) have proposed five general characteristics of environments that influence how poorly or how well an individual becomes an active, productive member of society. Three terms (accessibility, accommodation, and availability) are used in both models and appear to correspond with each other. Their five dimensions are the following:

1. Accessibility: Can you get to where you want to go?
2. Accommodation: Can you do what you want to do?
3. Resource availability: Are your special needs met?
4. Social support: Are you accepted by those around you?
5. Equality: Are you treated equally with others?

The five characteristics do not constitute a classification of the environment or a ranking of the environment but a classification of different kinds of interactions that the environment has with individuals, with the environment as a reference point. Despite the use of the term *accessibility* for one of the interactions, this taxonomy of interactions can be viewed as an attempt to understand the dimensions of how environments interact with individuals or how such environments are accessible to individuals. In this case, the unit of analysis is the environment, rather than the fit interaction of the Pechansky and Thomas model.

A fourth model derives from the Handicap dimension of the International Classification of Impairments, Disabilities, and Handicaps (World Health Organization 1980) and classifies the dimension of access across planes of interaction, such as who, what, where and when. This system is more like the Pechansky and Thomas approach in that the unit of analysis may be individuals or the environment. The seven dimensions in this model are the following:

1. Orientation: Who—do you have information you wish?
2. Independence: What—do you choose what you wish to do?
3. Mobility: Where—do you go where you wish?
4. Occupation of time: When—do you engage when you wish?
5. Social integration: With whom—are you accepted by others?
6. Economic self-sufficiency: With what—do you have the resources you need?
7. Transition: Change—are you prepared for change?

This model attempts to meet the criteria of universality attempted in the ICF, but would constitute a dimension currently not distinct in it, although some elements may be present.

The dimensions of accessibility as elaborated in the four models have been proposed as potential elements for human rights frameworks relating to disability. However, their theoretical nature and the complexity of performing analyses at the level of interaction may inhibit their use in the short run.

—Scott Campbell Brown

See also Americans with Disabilities Act of 1990 (United States); Communication; Handicap; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Models; Participation; Rehabilitation Act of 1973 (United States); United Nations Disability Convention; United Nations Standard Rules; World Health Organization.

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ACCESSIBILITY CODES AND STANDARDS

There are many standards and codes that apply to building design. Accessibility is only one issue that codes address. Accessibility standards and codes have been developed to provide architects and other designers with clear guidance about how to implement accessible design. Accessibility codes are regulations promulgated by governments to implement laws that mandate accessibility. The term *guidelines* is also associated with accessible design, for example, Americans with Disabilities Act Accessibility Guidelines or Fair Housing Accessibility Guidelines. In some cases, guidelines may be more general than standards and codes. For example, a guideline might read, "Provide a space for turning a wheelchair" as opposed to a standard that could read, "Provide a space with a five foot turning diameter."

Accessibility standards that are developed in the United States by the American National Standards Institute (ANSI) A117 Committee are consensus-based documents developed for use as criteria in the design of buildings and facilities. The ANSI A117 Committee is an independent professional organization that oversees the process of developing standards. In Europe, accessibility standards are developed by the International Standards Organization and various public agencies. The European Manual for an Accessible Built Environment was developed to promote standardization in access across Europe. Yet it uses the more general form of a guideline. But in other cases, such as the Americans with Disabilities Act (ADA) and the Fair Housing Act, the term *guidelines* is sometimes used in place of the term *standards*.

While standards and guidelines are often voluntary and nonbinding, regulations and codes are always legal mandates. Standards and guidelines usually focus on the technical criteria for providing accessibility, for example, how much space is needed and the configuration of the space. Regulations, on the other hand, usually have technical criteria but also include rules defining the scope of accessibility—what types of buildings and facilities are covered, how many accessible elements are required, and when exceptions can be made. Regulations can reference standards. On the other hand, regulations do not have to reference standards. In fact, some U.S. state laws require the detailed technical criteria to appear directly in their regulations.

The content, form, and intent of accessibility standards and codes vary significantly from one society to the next. This variation is caused by differences in cultural attitudes toward accessibility, building technologies available, the local built and natural environment, the legal system, and the process for developing standards. Since the regulatory process is political, different interest groups can influence regulations while under development or revision. Consumer advocacy groups work to ensure that the scoping and technical criteria will satisfy the needs of their constituencies, while representatives of the building industry strive to make sure that the codes will not negatively affect their businesses. Design professionals and building officials seek to ensure that the codes will be understandable and enforceable. This process may be more democratic in some societies than others.

In general, accessibility regulations improve the level of accessibility in a jurisdiction. In places where accessibility codes are first being introduced, goals may be modest, whereas in places with a long history of accessibility codes, the goals may be much broader and the criteria much more inclusive and restrictive. The differences in goals can apply within a jurisdiction due to differences across sectors of the building industry or across types of construction. Thus, in the United States, new efforts to mandate accessibility to detached single-family homes are focused primarily on homes built with public funding because there is much political opposition to regulating the design of privately built homes. As another example, the ADA Standards for Accessible Design apply only to new construction and those portions of buildings undergoing renovation. In existing buildings, only "readily achievable" modifications to remove barriers to use need to be provided. Readily achievable modifications are a far lower standard.

Accessibility standards may be organized together in one document or dispersed among several. Most accessibility standards are independent stand-alone documents that include criteria for general design issues and specific criteria for many built elements. In some countries, such as in Sweden, criteria for accessibility to different parts of buildings have been incorporated into standards for those elements. The advantage of having an independent inclusive document is that the human and economic resources needed to develop, monitor, interpret, and improve the standards are easier to assemble and organize. When accessibility standards are dispersed in many different documents, each developed by a different industry, expertise is diffused among many different committees. Moreover, the coordination of criteria can be an overwhelming task.

Accessibility standards are generally organized into several parts. The first part is an introductory section that explains the purpose of the document, describes how it should be applied, and provides definitions of technical terms used in the document. The second is often a technical section that covers the main issues of accessibility, for example, wheelchair sizes, clearances for wheelchair maneuvers, and reach limits. Other sections of the document follow with provisions for specific parts of buildings and facilities, for example, parking lots, entrances, interior circulation, and toilet rooms. These sections include technical criteria and usually include any exceptions to the rules.

In the United States, the legal implications of misinterpreting the detailed technical criteria are great, and as a result there is a tendency to provide extensive text and great detail, referred to as the "prescriptive" approach to standards writing. Some U.S. experts feel that the more flexible "performance" standards approach is desirable, leaving room for new and innovative ideas to emerge, and encouraging the development and use of new products. The European Union's guidelines are much more "performance oriented," specifying the objectives to be reached rather than the means. This performance approach is clearly appropriate in Europe where the guidelines have to be used in a very diverse set of legal and built contexts—an approach that works in Italy, for example, may be totally inappropriate in Denmark.

Accessibility codes may include the scope of application, the method by which the code will be implemented, a process for design review and appeal, referenced standards, exceptions, penalties for noncompliance, and other administrative issues. If the accessibility code is a part of a general building code, most of this material will be covered by general sections of that building code. In other cases, there may be a separate administrative process. Many of the states in the United States have a separate accessibility code committee that works independently of the general building code process.

Exceptions and variances are an important part of any standard and code. They define the specific situations where the rule may be waived or altered. There are many examples where the provision of full accessibility, as defined by a standard or code, may be infeasible. For example, historic buildings sometimes cannot be made fully accessible without destroying their cultural value. Building codes usually include provisions that allow some flexibility in renovation of such buildings. Other reasons for exceptions and variances include unusual topography, geological conditions, climate factors, very small size, uninhabited structures, and short-term or temporary structures. In general, blanket exceptions are not usually needed or allowed.

Accessibility standards and codes in the more industrially developed countries are often complex and highly technical. They often represent a significant change in the practice of building design, especially for certain types of buildings such as civic buildings where monumental stairs are traditional. Many countries have experienced difficulties actually implementing accessibility standards, even those with highly educated professional designers and extensive building regulatory apparatus. These countries are gradually adopting new approaches, often modeled on the experience of the United States, Canada, or Western European countries.

At an international level, there are certainly many factors that suggest that there should be differences in standards across countries and within regions of a country. The use of Imperial units of measurement in the United States is clearly an important difference that cannot be ignored. Another factor that encourages differences in standards is attitudes toward disability and rehabilitation practice. Northern European experts criticize U.S. standards for toilet stall sizes because, in the United States, space on either side of a toilet with fold-down bars is neither provided nor allowed. On one hand, the Northern Europeans believe that a toilet stall should be usable for a transfer from either side, whereas the U.S. experts believe that it is important to have the side grab bar mounted on a wall to provide additional stability and support, thus eliminating the possibility of transfer from that side. U.S. code groups have also not been willing to accept the fold-down grab bar that is needed for this type of design as an alternative to the fixed wall mounted bar, believing that many people with severe disabilities will have difficulty moving the bar.

In spite of the need for national or regional differences in standards and codes, consistency of standards around the world would be very useful, especially as international travel and tourism become increasingly popular. To participate in our global culture, people with disabilities need to be able to find facilities that they can use wherever they may travel. Moreover, international standards could be adopted by international agencies and multinational corporations for application to their facilities around the world. International standards would make it easier for less developed countries to make progress in accessibility more rapidly. However, it is important to consider the implications of such a development. There is a tendency to adopt the standards and codes of countries where accessibility laws are more advanced as models.

But this may not be the most appropriate approach for places in the world where accessibility to the built environment is a new idea. The adoption of an unrealistic standard or code could easily lead to widespread lack of compliance and therefore no progress at all. Countries that do not have an educational and regulatory infrastructure developed to ensure that standards and codes will be implemented should consider a different approach, one that is more realistic, easy to communicate, and easy to enforce. Thus, at this point in time, international standards should probably include a minimal set of "must have" requirements. They could have more extensive optional requirements. But they should be performance oriented and designed for flexible application to different local conditions.

—Edward Steinfeld and John P. S. Salmen

See also Fair Housing Act Amendments of 1988 (United States); Home Modification; Housing: Law and Policy.

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ACCESSIBLE INTERNET

Accessible Internet is the manner of creating websites that are as usable as possible by web surfers with disabilities. To access a website, individuals with disabilities rely on assistive devices, such as screen reader software, which translates information on a computer screen into automated audible output, and refreshable Braille displays. However, there has been continuous concern surrounding the issue that the information that disabled persons receive from a website may not be equivalent to the information that individuals without disabilities get. With rapid advances in Internet technology, assistive technology has had considerable difficulty in keeping up with web browsers with special features: electronic forms, HTML tables, style sheets, multimedia presentations, applets and plug-ins, scripting language, and more. Therefore, the designer of the website needs to provide the information carried by the special features in the formats/methods that assistive devices can easily use. For example, a screen reader cannot describe a picture, but it can convey the text information to the user who has visual impairments. Thus, the provision of special feature information by web designers is imperative for the most efficient use of assistive technology within Internet technology.

Section 508 of federal law has established design standards for federal websites to be compatible with existing and future assistive devices. However, these standards do not apply to private sector websites, which might not be prepared for products of assistive technology. The proposal of Section 508 was first initiated in 1996, when the U.S. Department of Justice asserted that the Americans with Disabilities Act (ADA) would apply to the coverage of websites. Two years later, former President Bill Clinton signed into law the Rehabilitation Act Amendments of 1998, which included the legislation component of Section 508. According to Section 508, federal websites must be made accessible to individuals with disabilities (federal employees and the general public), unless an "undue burden" is imposed on the department or agency. In addition, the Architectural and Transportation Barriers Compliance Board (Access Board) was required to establish and publish technical standards, among others, for federal websites to ascertain compliance with Section 508. In December of 2000, the Access Board published final rules, and the enforcement provisions of Section 508 took effect in June 2001. Many state governments are following the federal example. Nearly every state now has some sort of web accessibility policy, and more than 20 states have accessibility laws modeled on Section 508.

The Access Board's standards are based on access guidelines developed by the Web Accessibility Initiative of the World Wide Web Consortium. Issues such as the usability of multimedia presentations, image maps, style sheets, scripting languages, applets and plug-ins, and electronic forms are addressed within these standards. The provisions do allow the use of such advanced web technology or enhancement technology but require that equivalent information be provided in a format compatible with assistive technology.

A website required to be accessible by Section 508 would be in complete compliance if it met the standards of paragraphs (a) through (p) of the final rules' Section 1194.22. Most of these provisions ensure access for people with vision impairments, although some provisions address the needs of individuals with both visual and hearing impairments. Paragraph (a) requires that a text equivalent for every non-text element, such as photographs, images, and audio presentations, be provided. For example, when audio presentations are exhibited on a web page, text, in the form of captioning, must accompany the audio, to allow people who are deaf or hearing impaired to comprehend the content. Furthermore, when an arrow image is used to indicate a navigational action such as "move to the next screen" the image must be accompanied by actual text that states the purpose of the image. Similar to audio presentations, when an image is used to represent page content, the image must have a text description accompanying it that explains the meaning of the image.

Paragraph (c) does not prohibit the use of color to enhance identification of important features, but it does prohibit its use as the single method for indicating important information on a web page.

Moreover, paragraph (d) does not prohibit the use of style sheets that allows website designers to create consistent appearing web pages that can be easily updated. Instead, it requires that these web pages employing style sheets can be read accurately by browsers that do not support style sheets, as well as browsers that have disabled the support for style sheets.

Paragraphs (e) and (f) address image maps that provide different "links" to other web pages, depending on where a user clicks on the map. Client-side image maps, as opposed to server-side maps, can display links related to the map in a text format that can be read with the use of assistive technology. By contrast, a server-side map cannot. Therefore, when only a server-side map is available, a web page designer must add the equivalent text link.

Paragraphs (g) and (h) permit the use of tables but require that the tables be coded according to the rules for developing tables of the markup language used. If row and column headers are not identified for data tables, some assistive technology cannot accurately read the content. HTML table codes must be used to associate data cells and header cells for data tables that have two or more logical levels of row or column headers.

Paragraph (i) addresses the use of frames, a common technique used by web designers to create different "portions" or "frames" of their screen that serve different functions. This provision requires that frames be titled with text to identify and assist in navigating the frames by labeling them as "navigation bar" or "main content."

Paragraph (l) handles the use of special programming instructions called "scripts." When pages use scripting languages to display content, or to create interface elements, the provision requires web page authors to ensure that all the information placed on a screen by a script shall be available in text format for assistive technology.

Paragraph (n) requires that people with disabilities have access to interactive electronic forms. When electronic forms are designed to be completed online, the form must allow people using assistive technology to access the information, field elements, and functionality required for completion and submission of the form, including all directions, feedback, alerts, and cues.

Some provisions apply to individuals with hearing impairments or to overall individuals. Paragraph (b) provides that real-time captioning of an audio be provided. However, providing captioning does not preclude posting a transcript of the speech for people to search or download, although the real-time captioning is usually preferred over the delay in providing a transcript. In addition, paragraph (j) sets limits on the blinker or flicker rate of screen elements (a frequency greater than 2 Hz and lower than 55 Hz). Furthermore, paragraph (m) requires that web pages that provide content, such as Real Audio or PDF files, also provide a link to a plug-in that will meet the software provisions. Moreover, paragraph (o) mandates that a method be used to facilitate the easy tracking of page content that provides users of assistive technology the option to skip repetitive navigation links. Finally, paragraph (p) dictates that when a timed response is required, the user be alerted and given sufficient time to indicate more time is necessary in order to respond.

Congress established the Compliance Office to monitor federal law relating to employment of and access to public services and accommodations by disabled persons. One compliance case illustrates a growing demand for accessible websites for people with disabilities. In October 2002, the Atlanta-area people with disabilities complained about numerous problems they experienced with accessibility in the Metropolitan Atlanta Rapid Transit Authority (MARTA) website, including difficulties in obtaining schedule and route information in an accessible format. This information was available on the MARTA website, but people who used screen readers to access the site could not get complete access to schedule and route information. It was ruled that although MARTA provided information to people with visual impairments over the telephone, this service was not equivalent to that provided over the Internet to nondisabled passengers.

Web pages accessible to individuals with disabilities offer practical advantages that go beyond simple access. On March 13, 1998, President Clinton issued an executive order ensuring that the federal government assume the role of a model employer of adults with disabilities. The order addressed the concern that people with disabilities are markedly less likely to be employed, even though they received comparable levels of education to people without disabilities. For example, less than half of the people with significant disabilities who have a college education are employed. In the same year, Congress passed the 1998 Government Paperwork Elimination Act, which required that federal agencies make electronic versions of their forms available online when practicable, and allow individuals and businesses to use electronic signatures to file these forms. Electronic forms are a popular method used by many agencies to gather information or to permit a person to apply for services, benefits, or employment. Because Section 508 requires all electronic forms to be made available to individuals with disabilities, accessible web pages may have enhanced employment opportunities for disabled persons. Furthermore, accessible Internet may also have enhanced the productivity of federal employees with disabilities.

Advantages offered by accessible web pages are not limited to federal employees or federal job seekers with disabilities. Because accessible format often means better structured code that follows the standards of the World Wide Web Consortium, the compliant code can give better search engine rankings by separating the content of pages from the code required to style or present the pages. The ratio of information to overall code on the page increases, which becomes more attractive to search engines. The code also makes atypical web browser devices, such as Internet-able cell phones or PDAs (personal digital assistants), to assist in more effectively using the site. Again, this is due to the separation of content. In addition, the site is more effective as a communications tool. Accessible Internet makes its site more available to dial-up Internet users, since accessible standardized code is often smaller in size. Being accessible can also help increase customer base. Currently, there are 30 million Americans ages 21–64 with disabilities, comprising almost 20 percent of the U.S. population. The disabled are the country's largest minority group and collectively possess a disposable annual income of more than $175 billion. Although the Section 508 requirement does not apply to private sector websites, they will soon follow suit to address the growing trend of use of Internet and the diversity of Internet users.

Section 508 does not require that assistive technologies be provided universally. The standards of Section 508 focus only on compatibility with existing and future assistive devices. Provision of assistive technologies is still governed by the reasonable accommodation requirements contained in Sections 501 and 504 of the Rehabilitation Act. However, Section 508 does not require that assistive devices be purchased, although it does require that covered electronic and information technology be capable of having such devices added at some later time as necessary. Therefore, Section 508—accessible web page design—is insufficient to ensure accessible Internet. Access to a computer is a prerequisite for the use of the Internet. But unlike persons without disabilities, they need alternative computer access tools for physical reasons. Examples of input methods include alternate keyboards, interface devices, joysticks, keyboard modifications, keyboard additions, optical pointing devices, pointing and typing aids, switches with scanning, scanners, and optical character recognition, trackballs, touch screens, voice recognition, and arm and wrist supports. Examples of output assistive devices include Braille embossers and translators, refreshable Braille displays, monitor additions, screen enlargement programs, and talking and large-print word processors in addition to screen readers and speech synthesizers mentioned earlier.

A recent study suggests that Internet use among persons with disabilities has beneficial impacts on health-related quality of life. It has been found that, after controlling for sociodemographic factors (e.g., race and education), a higher level of Internet use, among persons with spinal cord injuries, was associated with a higher quality of life, such as a higher self-perceived health status, a better health status compared to 1 year ago, less severe depression, a higher social integration score, a higher occupation score, more frequent contacts with friends, more business contacts, and higher levels of satisfaction with life. The study also found that there were significant differences in Internet access among specific subgroups, indicating more barriers among persons with less education and among African Americans and Hispanics.

In conclusion, accessible web page design enables people with disabilities to use the Internet—and assists in the better overall utilization of the Internet for everyone. However, accessible Internet cannot be completed without the availability of assistive technology. The finding of disparity in Internet use among specific groups may indicate the need for assistive devices. Moreover, accessible Internet is important because it can be related to better quality of life among persons with disabilities, in addition to practical matters such as better employment opportunities. Research commissioned by Microsoft and conducted by Forrester Research of Cambridge, Massachusetts, suggest that 60 percent of U.S. adults ages 18–64 and 57 percent of working-age computer users could benefit from accessible technology for vision, hearing, dexterity, or other impairments.

—Kyusuk Chung

See also Assistive Technology; Communication: Law and Policy; Computer Software Accessibility; Computer Technology; Information Technology; Rehabilitation Act of 1973 (United States).

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ACCIDENTS

Accidents occur everywhere and have always been a common feature of the human experience. Every year, large numbers of people across the world are injured and permanently disabled in accidents. Others are temporarily disabled and have to spend months, sometimes years, in therapy to regain their previous function. Despite the best intentions, accidents can occur anywhere: in the home, during transportation, in the hospital, on the sports field, and at work.

Road accidents are one of the largest contributors, in both the first and developing worlds, to the numbers of disabled people. The number of cars on the road increased steadily over the twentieth century and continues to rise in the twenty-first century. Despite ever improving safety features, large numbers of people are disabled in road accidents each year. Speeding is often the cause of accidents. This is not a recent phenomenon; before the Road Traffic Act of 1930, which abolished the speed limit, the courts and the police in Britain tried to cope with the hundreds of thousands of speeding cases each year as drivers exceeded the limit of 20 miles per hour. The Royal Society for the Prevention of Accidents was formed in 1916 as a response to the number of road accidents from the increasing numbers of cars on the road. A speed limit was reintroduced in Britain in 1934.

Besides vehicular speed, the nature of the vehicle can alter accidents. Motorcycles are particularly dangerous, and in the United Kingdom alone 28,000 motorcyclists per year are currently injured as a result of accidents. During World War II, 23,000 British servicemen were injured in motorcycle accidents. Other users of the road—bicyclists, horse riders, and pedestrians—are all regularly involved in accidents. In New York City in 1992, there were 3,250 bicycle-motor vehicle collisions, of which 17 were fatal. In the same year, there were 13,599 pedestrian-motor vehicle collisions, of which 294 were fatal, and 298 pedestrian-bicycle collisions, leading to 2 fatalities.

As well as the incidence of death, such accidents result in a wide range of injuries and often permanent disability. In an attempt to limit some of this damage, in some countries such as Australia, it is mandatory for children riding bicycles to wear protective helmets. Accidents involving buses are also responsible for large numbers of people becoming injured, although many countries are making seat belt use in buses mandatory to reduce the injury rate. Equally, safety features on cars including seat belts, side-impact reinforcement, and airbags have contributed to fewer injuries that result in permanent disability. Externally, cars have been fitted with bumpers that cause less damage to pedestrians who may be hit. Preventive measures such as campaigns on the dangers of drunk driving, enforcing speed limits and using cameras to catch traffic law violators, and educating children about road safety have raised awareness but seem to have little effect on the numbers of people disabled in car accidents. The World Health Organization has estimated that by 2020 road accidents will be one of the top three causes of death and disability.

Accidents on the sports field have long been the cause of disabilities. Since the rise of modern organized sports in the latter half of the nineteenth century, all sports, especially those involving contact, such as American football or U.K. rugby, have witnessed crippling injuries, disability, and death. One well-known person disabled in a sports accident was actor Christopher Reeve (1952–2004), star of the *Superman* films, who in 1995 fell off his horse in a jumping competition and was rendered tetraplegic. Sports such as horse riding are by their very nature dangerous and account for a high number of disabling injuries in any national statistics, as do traditionally dangerous outdoor sports such as mountain climbing, rappelling, and alpine sports. Since the 1970s, the number of sports that deliberately court danger, the so-called extreme sports, has grown rapidly and resulted in a concomitant number of injuries.

Sports accidents are not limited to adults; many children are injured in sports accidents, often causing disability. Contact sports are often more likely to be the sports in which people are injured, so rules have been changed and safety equipment introduced to reduce the incidence of accidents and severity of injuries on the sports field. However, such action does not eradicate injury. In ice hockey, for example, a 1994 survey found that 12 percent of players suffered accidents resulting in shoulder injury and 11 percent in knee injury, which can cause temporary disability and often result later in replacement surgery. In Ontario alone, 79 players had accidents that led to permanent disability or death, although with better safety regulations and improved on-site medical treatment, this number was reduced to 26 by 1992.

The home is a site for many accidents, and falls in particular are the cause of many disabling injuries. The success of home improvement programs on television has resulted in many people doing their own home maintenance, which has resulted in many accidents and permanent disability. In the United Kingdom, each year 3,900 people require hospital treatment as a result of accidents relating to home improvement activities, while 70 people are killed (50 alone from ladder-related accidents) and nearly 250,000 are hospitalized. Accidental fire caused by poor wiring or malfunction of electrical items in the home can cause disabling burns. For example, poorly wired or old electric blankets cause 5,000 house fires in the United Kingdom every year, which leads to 20 deaths and 200 disabling injuries.

Children can be disabled in the home by falls or from burns from boiling water, for example. In Britain, children celebrating Guy Fawkes Night on November 5 have become blind through accidents involving fireworks. In 2001, fireworks were responsible for 1,362 injuries, of which 469 required hospital treatment and 73 resulted in permanent injury.

Accidents involving procedures or medication can occur in hospitals, and these can cause permanent disability. These include brain damage caused by problems during birth, or in some cases people are given the wrong medication while in a hospital. It was estimated in 2002 that 2,610 American children died from infections caught while staying in hospital, while between 44,000 and 98,000 Americans died from preventable medical accidents.

Accidents involving ordnance left over from war or accidents involving noncombatants such as children occur every day. Since the end of the twentieth century, the focus of this problem has been land mine accidents. Land mines can be hidden in most types of ground, and they are designed to disable as opposed to kill. Unfortunately, they are difficult to clear and many civilians, particularly children, have been disabled by land mines. At present, it is estimated that there are 110 million active land mines buried across the globe. As a result of this huge number of active mines, more than 70 people are killed each day, and 300,000 children under the age of 16 are disabled each year. In less developed nations, where land mines are often located, problems of disability are exacerbated because there is little money for artificial limbs and aids to assist those who have lost limbs as a result of land mines.

Work is hazardous. In some occupations, the threat of accidents is very real, particularly in industries such as construction and mining where heavy equipment is used. Industrial accidents are associated with the modern age of factories, mines, and foundries. In the twentieth century, work was still dangerous and many people were still disabled as a result of accidents at work. Some disablement, such as “beat knee” or later “vibration white finger,” was caused by constant and repetitive work with machinery in the mining industry, or long-term exposure to dangerous materials such as asbestos. There was little in the way of safety equipment to prevent accidents, and long-term exposure to dangerous chemicals could cause severe disablement and death. Before factory owners were called on to make their workplaces safer, many workers were injured in accidents. When permanent disability was the result, often that worker was doomed to a life of poverty as there was often little in the way of compensation for their injury. In Britain, while the National Insurance Act of 1911 allowed workers to insure themselves against injury, the 1937 Workers Compensation Act was a more beneficial piece of legislation for those with permanent disabling conditions. In some cases, disabled people were seen as perfect for certain types of work. In World War II in factories in Britain, deaf people were employed in the very noisy occupation of shell filling because it was believed that no further damage could be done to their hearing. In less active occupations, the risk of falling, strains, or even stress can cause debilitating conditions that can mean that a person is unable to work and has to rely on state support.

Safer work environments and better compensation for workers were an aspect of the twentieth century. Despite that, there is still a potential for accidents whether it be in the home, as a result of a fall, or in some countries at war with each other, from the lurking and ever present threat of land mines. Accidents also continue to happen because of the natural fallibility of both technology and humans.

—*Julie Anderson*

See also Burns; Spinal Cord Injury; Sports and Disability; Traumatic Brain Injury.

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ACCOUNTABILITY

Persons with disabilities, as well as the general public, are increasingly demanding greater accountability from politicians, government bureaucracies, teachers, public school systems, physicians, and health care organizations. The term *accountability* is widely used by the public in diverse and changing contexts, which conveys different meanings of the term at various times and places. Although there are numerous definitions of accountability, in general, it is commonly understood to mean the giving of an explanation for the discharge of responsibilities entrusted to individuals or organizations. In short, accountability is a reckoning, or a justification of conduct.

To have accountability, three mechanisms are required: the identification of the specific responsibilities given to an individual or organization, the provision of information about the actions that were or were not taken, and the availability of appropriate sanctions. Accountability provides a set of constraints on actions or omissions because someone or some organization is held responsible. Accountability also implies an implicit or explicit set of criteria against which comparisons are made, and then penalties or rewards are applied.

Individuals and organizations frequently deal with multiple, overlapping, and sometimes conflicting accountability systems. Some of the more common types of accountability systems include political, legal, bureaucratic, economic, moral and ethical, and professional accountability.

Political accountability refers to the democratic process by which national, state, and locally elected officials periodically submit their past actions to an electorate. Democratic control is based on ballot counts and the overall preferences of the voters. If a political official is viewed as having increased the public's well-being through appropriate actions and services, he or she will be elected to office again, if not, the person will be voted out of office.

Legal accountability systems are generally based on the relationships between an individual or organization and an outside controlling party. The outside party may be an individual or group in a position to impose legal sanctions or assert formal contractual obligations. Typically, these outsiders make the laws and other policy mandates, which the individual or organization is obligated to enforce or implement. Legal accountability relationships emphasize compliance and external oversight of performance. These systems typically use contracts, audits, inspector generals, oversight hearings, and court proceedings.

Bureaucratic accountability refers to large government and private sector organizations that require subordinates to both formally and informally answer to their superiors. The functioning of bureaucratic accountability systems requires an organized and legitimate relationship between superiors and subordinates in which the need to follow "orders" is unquestioned. Subordinates are under close supervision for meeting standards of performance, and they must follow explicit organizational directives, rules, regulations, and standard operating procedures. In these systems, the relationship is hierarchical and based on the ability of supervisors to reward and punish subordinates.

Economic accountability refers to the market relationship of consumers and providers. The marketplace operates on a supply-and-demand basis, with both consumers and providers expected to economize if buying and to maximize profits if selling. One type of economic accountability is corporate accountability. This type of accountability requires managers and board members of for-profit corporations to prudently and wisely use the human and capital resources of the firm to return a profit to the corporation's owners and stockholders.

Moral and ethical accountability systems are standards of good behavior that arise from conscience, religious beliefs and norms, and concerns for the general welfare of society. These systems reflect concerns with the concepts of how or by what means individuals and organizations choose a course of action and how they subsequently defend it.

Professional accountability refers to the relationships among peers with similar training and expertise. This type of accountability employs peer group pressure almost exclusively to discipline and reward its members, although licensing is the formal device for entry and expulsion from the profession. It relies on specific performance standards derived from professional norms and prevailing practices of peers. Because professionals have special knowledge and expertise, they are generally given much discretion, have a high degree of job autonomy, and are self-regulated.

Professions such as medicine, law, clergy, and university teaching are self-regulated for a number of reasons. Members of these professions tend to be carefully recruited and supervised. To be in good standing within the profession, members are required to follow and adhere to codes of ethics and practice standards (e.g., the American College of Physicians–American Society of Internal Medicine requires its members to advocate and assist medically disabled patients to obtain their appropriate disability status and to complete all disability evaluation forms factually, honestly, and promptly). To enforce their standards, these professions have their own review boards, which police individual members. Last, members of these professions have a fiduciary responsibility to place their clients' needs ahead of their own self-interest.

Professionals tend to have high prestige and power in society because of indeterminacy and uncertainty. Many of the tasks performed by professionals cannot be easily broken down or otherwise routinized (indeterminacy). Similarly, many professionals deal with areas of high uncertainty or risk for their clients.

Professional accountability in medicine is particularly difficult to determine. Accountability is problematic because of asymmetric information, difficulty in evaluating the outcomes of care provided to patients, and the ever-changing complex nature of health care medical errors that tend to frequently occur. Asymmetric information exists when one party to a transaction possesses more information than the other. Because of their years of training and experience, physicians have a much greater knowledge of health care and health than patients do. It is very difficult for patients to judge whether they received appropriate and efficacious care from their physicians. Some medical conditions are self-limited and patients will get well regardless of what physicians do or do not do. Conversely, other medical conditions are incurable and physicians can do nothing to stop them from progressing. Last, because of increasingly new and complex medical technologies, drugs, and treatments, and the sheer volume of care provided, medical errors commonly occur.

Attempts to hold physicians accountable for the care they provide are probably as old as the medical profession itself. For example, the 4,000-year-old Babylonian Code of Hammurabi, one of the world's oldest known collections of laws, contains several statutes that set fees for surgical operations and establish penalties for surgical errors. Specifically, a physician was held liable when a patient died as a result of an operation or lost an eye because of his surgical intervention. Penalties varied according to the social status of the patient. The penalty for death or loss of an eye in the instance of an upper-class person was having the physician's hand cut off, but only compensation was required from the physician in the cases of commoners or slaves. This is the earliest recorded instance in history of the legal consequences for medical malpractice.

The Hippocratic Oath, written more than 2,000 years ago, presents the first known ethical standards for physicians. In the oath, the Greek physician Hippocrates, the father of Western medicine, outlines the physician's duties and responsibilities. The oath is divided into two parts. The first part specifies the duties of the physician toward his teacher and his obligations to transmit medical knowledge; the second part gives a short summary of medical ethics. Some of the ethical duties of the physician include keeping patients from harm and injustice, not dispensing deadly drugs, not giving a woman an abortive remedy, not indulging in sexual contact with patients, and not divulging confidential patient information. To this day, many physicians graduating from medical schools throughout the world recite the oath or some modification of it.

An important figure in modern professional accountability in medicine was Ernest A. Codman. In the early 1900s, Codman, an eminent Boston surgeon, was one of the first to apply outcomes management concepts to medical care. Specifically, he developed a system of tracking the long-term outcomes of hospital patients to identify clinical success and failure (e.g., medical complications and preventable deaths) to improve the care of future patients. He also believed that this information should be made public so that patients could be guided in their choices of physicians and hospitals. Unfortunately, his ideas were not accepted by the medical community of the time. And his work was forgotten for decades.

Since the 1980s, there has been a large movement in the United States to measure and improve the quality of health care and increase the accountability of physicians, health care plans, and health care institutions. A number of factors were responsible for this movement. Large computer systems became widely available, which could cheaply and quickly analyze millions of individual patient insurance claim records. Government and business groups were increasingly concerned with the rising costs of health care, and they believed that improving the quality of care would help keep costs down. And many managed care organizations wanted to closely monitor the costs and quality of care provided by the physicians they employed, and to hold them directly accountable for it.

As a result of these efforts, a number of medical quality indicators have been developed including various measures of clinical outcomes, operational performance, and patient satisfaction with care. Today, the federal government, many state governments, and several private sector firms compile and publish printed reports, and post on the Internet medical quality indicators of individual physicians, hospitals, managed care organizations, and nursing homes.

—Ross M. Mullner

See also Consumer Satisfaction; Health Management Systems; Hippocrates.

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▣ ACTIVISM

Activism is a term used to characterize the activities of people with disabilities who are engaged in advocacy actions intended to advance their policy agenda at the local, state, or national levels. Activism refers to the active participation of people with disabilities in visible efforts to address the issues that concern them. Activism in the disability community can be distinguished from other forms of advocacy because it includes direct action and confrontational tactics. Conceptually, advocacy goals and strategic tactics can be placed along a continuum ranging from those that emphasize a high degree of confrontation and visibility to those that rely on them minimally. For example, acts of peaceful civil disobedience in which people with disabilities block traffic in a street or the entrance to an inaccessible store involve a high degree of confrontation and visibility. In the middle of the continuum would be less confrontational tactics, such as town meetings or rallies. Tactics such as signing petitions or building coalitions have a low degree of confrontation.

Activists in the disability community often refer to a sense of urgency for increasing the level of confrontation necessary to achieve their goals, as "time to escalate." Most disabled activists try to use tactics that generate media attention for their cause, which increases public sympathy for their predicament. However, using more confrontational actions also increases the likelihood of police repression and legal action against the group members. These are risks that advocates consider as they engage in the advocacy process.

The history and development of disability services and policies have been significantly marked by the critical role that a number of individual activists have played in promoting change. Of course, the actions of the leaders are almost always accompanied by the actions of many others who remain unknown but whose involvement is critical to the success in achieving a particular aim. The history of activism associated with the advancement of policies and services for individuals with disabilities in the United States can be categorized in two distinct periods.

The first period was led by professionals and other well-intended individuals who took upon themselves the task of starting institutions or services to help individuals with disabilities. Examples of leading activists of this time in history include Thomas Gallaudet, who opened the first American asylum for the education of the deaf in 1918 in Hartford, Connecticut; Francis Fauquier, who opened the first facility for mentally disabled individuals in Virginia in 1773; and Dorothea Dix, who advocated for the creation or expansion of asylum facilities for the mentally disabled from 1840 to 1870. With few exceptions (e.g., Helen Keller, Clifford Beers), individuals with disabilities themselves did not lead the efforts for reform during this period, being considered for the most part incapable of such a task.

The role of individuals with disabilities in charting their own destiny became the most important change during the second period of activism in the United States. Inspired in part by the civil rights movement during this period, individuals with disabilities themselves took the lead in organizing and leading the fight for reform. Examples include Ed Roberts, who was one of the founders of the independent living movement, and Judy Heumann, who founded Disabled in Action in 1970 to address barriers faced by people with disabilities. A vanguard of leaders with disabilities took direct action in several forms at historic moments thereby helping to create, energize, and sustain the disability rights movement. More recently, people with intellectual disabilities established a national organization called Self Advocates Becoming Empowered (SABE) to promote the closure of state-operated mental retardation institutions in the United States.

In this second period of activism, the broadness and complexity of social and policy changes gave rise to a variety of advocacy and social activist groups. During the 1970s, people with disabilities organized themselves to establish the first center for independent living in Berkeley, California. Federal funds for these community-based organizations were later expanded. This expansion was a direct result of disabled activists confronting the political unwillingness and perhaps even the ineptitude of the federal government that delayed, for several years, the enactment of the rules and regulations for the implementation of the Rehabilitation Act of 1973. On April 1, 1977, in various cities across the United States, disabled activists organized protests at the federal offices of the Department of Health and Human Services. The confrontational protest that occurred in San Francisco, California, stands out in history due to its length and the impact it had on social and political change. Wheelchair users, people who were deaf or blind, and people with developmental and other disabilities organized themselves to exercise their collective power and political might. The protesters held the regional offices hostage for 28 days, gaining national attention and resulting in an agreement with federal officials for the rapid establishment of the rules and regulations to implement Section 504 of the 1973 Rehabilitation Act.

Disability rights activists usually learn and practice direct action as part of single-issue, grassroots community organizing. For example, during the 1980s in the United States, many grassroots activists organized to gain access to accessible mainline public transportation through a group called ADAPT (American Disabled for Accessible Public Transit, now also called American Disabled for Attendant Programs Today). Their struggle for "lifts on buses" at both the national and local levels emphasized that disabled people had a civil right to access public transportation. By the end of the decade, these disabled activists had won a victory in the courts and access to mainline buses on the streets. They helped drastically change public opinion about civil rights for people with disabilities. They used the media effectively to portray the images of disabled individuals being arrested or being pushed to the ground by the police. They also chained themselves to buses and often engaged in civil disobedience. ADAPT developed a reputation across the country as the radical wing of the disabled movement that actually helped change the perception of people with disabilities as uninvolved and apathetic to their issues. These were people who were willing to die for their cause.

Activism is a cornerstone of democracy and, as such, epitomizes the role of the citizen as willing and entitled to act in benefit of the common good. Critical characteristics of a first-rate citizen are being informed in order to make sound decisions and being willing to join with others to act on relevant issues. In many ways, good citizenship is associated with social activism as a commitment for improving society for all its members. Typically, grassroots activism occurs within members of the educated middle class who have a sense of entitlement and are savvy about lobbying and advocating for their rights. Unfortunately, poor people with disabilities have been denied full citizenship rights for many years and have been segregated and marginalized from the decision-making forums of society.

A long history of oppression and discrimination against a particular group of people can lead to negative societal beliefs and low expectations about the group's capacity to transform the group's social reality. Individuals with disabilities have to overcome such a history, as well as self-defeating perceptions of their own inferiority and inadequacy, to become activists. It is precisely through active involvement in community change efforts that most people with disabilities develop their critical awareness and some radicalize themselves. In some cases, the fight for justice and equality becomes the reason to be, the reason to overcome barriers and discrimination. There is an obvious parallel with the perceived conditions that led to the civil rights movement in the United States.

Effective social change requires both critical reflection and understanding of the issues affecting a particular group, as well as careful planning of actions intended to generate the most impact with the least cost to the groups involved. Activism is focused on producing shock and getting attention to the issues. Good activists are always reviewing the impact of their actions and planning their next step accordingly. Typically, the activists' actions prepare the context for negotiations and compromises, and the actual agreements are usually reached in private meetings and with only a few representatives.

The members of the coalition or group leading the change effort have to be prepared to overcome unanticipated challenges, delays, attacks, setbacks, or diminishing resources. The strengths of the activists lie on their numbers, their resilience, and the fact that often their conditions are so desperate that they have nothing more to lose and a lot to gain by engaging in a particular struggle. In many developing countries, this kind of activism is leading to gradual improvements in services and policy changes to protect the rights of people with disabilities. Disabled organizers have learned effective strategies for social activism from community organizing, labor movements, civil rights movements, and other national efforts intended to promote social justice and political change. These models indicate that to achieve desired change, people with disabilities have to become actively and visibly involved in the struggle and that they should be ready to take some risks.

—Fabricio Balcazar and Rene Luna

See also ADAPT; Advocacy; Citizenship and Civil Rights; Consumer Control; Justin Dart; Empowerment and Emancipation; Independent Living; Ed Roberts.

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ACTIVITIES OF DAILY LIVING

Activities of daily living (ADLs) are most broadly described as those tasks that are commonly completed by most persons in a culture, often habitually or done repeatedly at regular intervals, and often serve as prerequisites for other activities (e.g., laundering clothes or taking them to the dry cleaners in order to have clean clothes to wear to work or for leisure activities). ADLs may be perceived as routine, but they may in fact be quite creative endeavors (e.g., choosing clothes to wear to create a certain "look," or cooking a meal in which ingredients are selected for complementary flavors and color). In particular, ADLs are important for the roles they serve in maintaining social life and connections with other persons.

ADLs are distinguished from productive activities such as paid employment, volunteerism, and education and also from leisure, recreational, and social activities. ADLs are sometimes divided into basic or personal activities of daily living (BADLs or PADLs) and instrumental activities of daily living (IADLs). The distinction may be somewhat vague and academic, although ADLs (or PADLs or BADLs) are more often activities that are related to taking care of one's own body while IADLs are more often activities that support others in addition to self and are often thought to be more "complex" in nature. Whether ADLs are distinct categories or simply two ends of a continuum remains open to debate, particularly among those involved in development of instruments that measure a person's performance on these activities.

ADLs (or BADLs or PADLS) include, but are not limited to, activities such as washing oneself, bathing and showering, bowel and bladder management, caring for one's own well-being and comfort, communication and communication device use, dressing, eating, feeding, functional mobility, personal devise care, personal hygiene and grooming, sexual activity, sleep/rest, and toilet hygiene. IADLs include activities such as caregiving, care of pets, child rearing, community mobility, financial management, health management, procuring and caring for necessities, procuring and maintaining a home, meal preparation and cleanup, and safety procedures.

It should be clear from the preceding lists that deciding whether an activity is an ADL or IADL can be quite arbitrary. For example, meal preparation could be regarded as part of self-maintenance, and communication and communication device use are just as often considered as ADLs as IADLs. In addition, while the concept of ADLs is distinct from productive, educational, and leisure activities, the categorization of particular activities is less clear. For example, some ADLs and IADLs may be performed for remuneration (such as grooming, home maintenance, child care) or for leisure (such as cooking, shopping). While activities may be broadly categorized as ADLs and IADLs, whether a particular activity is considered as such for a particular individual is much more dependent on the context and meaning of that activity for that individual.

Society often has expectations of how ADLs should be performed, and they are often used to describe what a person can or cannot do, what they need assistance with. These culturally accepted forms of performance are often based on how able-bodied persons might complete the task. This is of particular consequence because unacceptable performances of ADLs and IADLs are all too frequently invoked as indicators of disability. Particularly in Western cultures, inability to perform ADLs, particularly self-care activities, without assistance is a strong indication of disability.

The social disability model challenges this view. Social disability theory helps us to recognize that in the same way able-bodied persons may use a computer to order and have groceries delivered to their homes, or may choose to drive to work instead of taking public transportation to have more time and energy for work, a person with a disability may choose to have a personal assistant help with morning self-care activities to have more time and energy to be gainfully employed. Typically, however, the latter example is viewed as an indication of dependence while the former example is viewed as independence, even though all of these "time and energy saving" strategies require the assistance of other individuals.

Determining independence in ADLs is often narrowly defined as completing a task completely by oneself, which ignores the often highly social components to ADLs such as asking someone to stir a pot while more ingredients are added by another, having someone set the table while another finishes preparing the meal, receiving assistance with bringing groceries into one's home, or assistance with folding sheets after being laundered. Defining what "basic" components of ADLs should be completed alone, by an individual, in order to be considered independent are quite arbitrary and reflect goals and values of both the individual and the larger society. Often task completion is related not to independence but rather to notions of intimacy.

ADLs have also become linked to definitions of disability and dependence through the development of a wide, and ever-growing, range of assessments that rate a person's ability to perform ADLs independently or how much assistance they require to complete an ADL. In general, the items on assessment tools, which reflect only a small and rather impoverished number of ADLs, are commonly referred to as limited data sets. Often for reasons of time, cost, and efficiency, the number of items included is kept to a minimum and focus only on those activities that are not influenced by societal gender roles. For example, IADLs such as home maintenance and shopping are often thought to be more closely associated with women's roles. In addition, the ADLs selected for use within medical systems may be more a reflection of service delivery concerns rather than what is most important to the person and his or her family. Thus, the activities that have come to most commonly define ADL assessments (PADL or BADL) include eating, bathing, dressing, toileting, bowel and bladder control, functional mobility (transfers, walking, stair climbing), and sometimes grooming, and IADL assessments generally include telephone use, shopping, laundry, meal preparation, housework, and sometimes reading, driving, finances, and medication management.

ADL and IADL instruments are frequently designed to meet pragmatic goals, such as assessing the outcomes of treatment programs; to predict successful living in a home or community setting, need for assistance, or the need for nursing home care; and to evaluate the impact of impairments on daily life. Observational or self-reported scores of performance of ADLs are often used as a description of an individual's "functional status," or as a measure of "disability." ADLs are even used as a large component of, or even as a substitute for, quality of life, sometimes referred to as health-related quality of life. However, disability scholars have pointed out that "disability" is essentially a political term, connoting a status that arises from discriminatory actions of an able-bodied society that fails to take full account of the rights of all citizens and creates barriers to full inclusion.

A broader way of thinking about ADLs is as a person-task-environment transaction. A person-task-environment (PTE) transaction approach does not consider whether a person is dependent in ADL but under what conditions can a person successfully complete ADLs in a manner that he or she finds personally acceptable and satisfying. By viewing performance of ADLs as PTE transactions, the strengths and limitations of a particular individual, the specific components and requirements of the particular task, and the supports and barriers within the physical and social environment in which the person is performing the task are all considered of equivalent status in determining how successful and satisfying any particular ADL performance is. From this perspective, there are not prescribed or generally acceptable ways to perform or complete ADLs, but rather ways that are unique and personally acceptable. Instead of asking, "Can a person dress independently?" or "How much assistance does he or she need with cooking?" the question becomes, "Under what circumstances can or does this person get dressed or cook in a way that he or she finds most satisfying?" Thus, one person may choose to employ a personal care attendant to complete ADLs that are viewed as laborious in order to have enough time and energy to do the things that are most important, while another person chooses to adapt the environment, methods, or use assistive devises to complete the same tasks.

—Trudy R. Mallinson

See also Aids for Activities of Daily Living; Self-Sufficiency.

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ACUPUNCTURE

Acupuncture has been practiced in China for at least 2,500 years and is an essential component of traditional Chinese medicine (TCM). This practice involves the insertion of fine needles just beneath the skin's surface at specific points along clearly defined paths to treat a variety of different medical conditions. These paths, which are usually called channels or meridians, pass through every organ and are interconnected through a network of branches and collaterals. They all carry intrinsic life energy called *qi* (pronounced chee). Because of its emphasis on interconnectedness, acupuncture takes a holistic and nonlinear approach to treating health problems. In the past four decades, acupuncture has gained increasing acceptance in the United States and other Western nations and is now used increasingly by itself or as a complementary therapy in combination with Western medicine. Acupuncture is generally used to treat disability in two ways: to alleviate disabling symptoms (e.g., treating nausea in people undergoing chemotherapy) and to strengthen the body overall (e.g., creating an appropriate immune response in people living with HIV/AIDS or lupus).

TCM views the body as an integrated whole, with mind, body, and spirit as one indivisible entity. This medical system stresses finding and healing the underlying cause of ill health rather than treating individual symptoms. For example, while a Western doctor may prescribe the same medication for all of his or her patients complaining of chronic indigestion, an acupuncturist would first seek to discern the distinct energy imbalance in each patient and treat that accordingly. As a result, acupuncture treatment is unique and specific to each individual patient. Many believe that this holistic, patient-centered approach makes acupuncture particularly useful for treating the complex, chronic medical conditions associated with disability.

Fundamental to acupuncture and TCM is the concept of yin-yang. According to this theory, we find the opposing forces of yin and yang in all of nature. Yin energy is dark, damp, cool, earthy, and female, while yang energy is light, dry, warm, celestial, and male. Yin cannot exist without yang and vice versa. In addition to being interdependent, they are also the source of each other's genesis. Yin and yang are often described as "divisible but inseparable."

Qi arises from the interplay and interdependence of yin and yang. It travels along an interconnected series of 12 major meridians and eight related collaterals called vessels to nourish every part of the body. On the skin, at least 350 points exist that allow an acupuncturist direct access to these meridians.

When yin and yang are in balance in the human body, an individual will be in good health, adaptable to many stresses, and able to fight off most pathogens. When yin and yang are unbalanced as a result of environmental, physical, spiritual, mental, or emotional stress, *qi* can become unbalanced, weak, and/or blocked. As a result, ill health occurs. According to TCM, people with chronic illness and/or disability are particularly vulnerable because they often face a multiplicity of stressors. For example, the stresses caused by multiple sclerosis, HIV, and type II diabetes typically result in a yin deficiency along one or more vital meridians in most individuals.

When an individual goes to an acupuncturist, he or she will be diagnosed through a process called the four examinations: (1) observation of the patient's overall demeanor and appearance with specific emphasis placed on the condition of the tongue; (2) inquiry about health including questions about pain, sleep, dizziness, appetite, thirst, and elimination; (3) listening to the patient's voice and breathing and checking for abnormal or strong body odors; and (4) palpation of the patient's body with specific emphasis placed on the pulse. In acupuncture, 12 different types of wrist pulses are observed that correspond with each of the 12 meridians. Acupuncturists have 28 different descriptive terms to accurately describe each pulse.

From the four examinations, the acupuncturist determines which energy channels and corresponding organ systems have unbalanced, blocked, or deficient *qi* and then inserts acupuncture needles into appropriate points along the appropriate channels in the patient's body. Sometimes an acupuncturist may also pass a small electric current through the needle in a process called electroacupuncture. The acupuncturist may also use other elements of TCM including *moxibustion* (the burning of the herb moxa close to the skin), herbs, dietary suggestions, and massage.

Although archeological evidence suggests that acupuncture has existed for at least 4,000 years, its recorded history begins with *The Yellow Emperor's Internal Classic,* the first text to outline acupuncture practice, compiled around 300 BCE. Two other texts form the backbone of acupuncture's early development and dissemination. In about 282 CE, Huang-fu Mi described the major acupuncture points, many of which are still in use today in *The Systematic Classic of Acupuncture and Moxibustion.* Last, around 1000 CE, Wang Wei-Yi compiled all existing knowledge of acupuncture, accurately charted the energy meridians, and described them in *The Manual of Illustrated Points for Acupuncture or Moxibustion.* He also commissioned two bronze figures with acupuncture points clearly marked and named, making it possible for acupuncture to be widely taught, researched, and disseminated for the first time. As a result, the practice of acupuncture traveled to other Asian countries, including Korean and Japan. The term *acupuncture* (*acu* = with a needle + *puncture*) was actually coined by Dutch physician Willem Ten Rhyne when he visited Nagasaki, Japan, in 1684.

Although some Western awareness of acupuncture has existed for centuries, it did not capture the Western imagination until 1971 when *New York Times* journalist James Reston was stricken with acute appendicitis while in China, covering Henry Kissinger's work toward normalization of that country's relationship with the United States. Chinese doctors operated on Reston using acupuncture instead of Western methods of anesthesia. When he returned to the United States, he wrote of his experience, piquing the interest of the American public.

Western medicine has been cautious in acknowledging the effectiveness of acupuncture, because *qi* and energy meridians cannot be detected through its methods. Much research has been devoted to finding a way to prove the mechanisms of acupuncture through Western methods. Current theories suggest that acupuncture works by directly altering the body's biochemical, bioelectrical, and/or neurological systems. While acupuncturists do not dispute these findings, they interpret them differently: They perceive these measurable changes as a manifestation of the correct flow of *qi* rather than a beginning and end result.

With increasing acceptance has come broader acknowledgment from government organizations. The World Health Organization compiled a list in 1979 of more than 40 medical conditions that lent themselves to acupuncture treatment. In 1996, the U.S. Food and Drug Administration shifted the classification of acupuncture needles from experimental to standard medical devices and approved their use by licensed practitioners. In 1997, the National Institutes of Health used stringent guidelines to create a consensus statement based on a review of all existing literature on acupuncture and clinical trials. The statement deemed acupuncture an effective therapy for treating postoperative and chemotherapy-based nausea and alleviating postoperative dental pain. The statement also noted that acupuncture could be an effective complementary therapy to Western medicine for certain types of pain, addiction, stroke rehabilitation, and asthma.

Acupuncture is used for people living with disability to relieve disabling symptoms and to strengthen an individual's overall body and immune response. Acupuncture's common uses for symptom relief fall into at least five categories. First, it can relieve nausea in people undergoing drug treatments such as cancer or HIV/AIDS chemotherapy. Second, it is used to alleviate dizziness characteristic of people with Meniere's disease, anemia, and other chronic conditions. Third, acupuncture is used as treatment for peripheral neuropathy in people with HIV/AIDS and type II diabetes. Fourth, acupuncture is often employed to treat symptoms and cravings associated with nicotine, cocaine, or heroin withdrawal. Fifth, acupuncture is used to alleviate chronic pain for many disabling conditions including fibromyalgia, osteoarthritis, and carpal tunnel syndrome.

Use of acupuncture to strengthen the overall well-being of an individual tends to require a systematic long-term series of approaches and techniques. It is often used in three ways. First, it may be used in conjunction with Western medicine to treat the energy imbalances that TCM believes exist in certain mental illnesses such as major depression and bipolar disorder. Second, it may be used to strengthen specific organs that are severely taxed by specific pathogens, for example, treatment of the liver and related meridians for people with hepatitis C. Finally, it can be used to strengthen and/or balance the overall immune system for people facing HIV/AIDS and autoimmune diseases such as lupus or multiple sclerosis.

—Martha E. Lang

See also Complementary and Alternative Medicine; Disability in Contemporary China; Experience of Disability: China.

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ACUTE AND CHRONIC CONDITIONS

This entry discusses acute and chronic conditions in the context of ability and disability. The focus of the discussion is the nature of different conditions and how they affect function. Clinical or case examples illustrate acute and chronic conditions that affect people and how they interact with their environment. Other entries in this encyclopedia elucidate many issues that directly relate to specific conditions and their functional impact; therefore, the examples found herein are for illustration only.

A *condition* in the context of ability and disability can be described in terms of physical, cognitive, or behavioral changes that affect one’s ability to participate in functional activities. For example, osteoarthritis of the knee results in anatomic and physiological changes to the joint that render it less capable of bearing an axial load such as when bearing weight. The resultant loss of mobility renders the person less able to walk long distances or remain standing. The functional outcome of this limitation is less mobility independence. If this limitation is concurrent with other limitations (such as shortness of breath due to cardiovascular disease), then the person’s independence might be impaired such that he or she would be considered disabled using standard societal definitions.

Using this definition, an acute condition is one that has an immediate effect on the individual. The type, degree, and severity of the condition may then produce functional limitations. The time course for an acute condition is generally short in duration, with most authorities such as the Centers for Disease Control and Prevention in the United States considering an acute medical condition as one lasting three months or less. Such definitions are predicated, however, on the immediate and accurate identification of the condition. For example, an individual with buttock pain present for 11 months that multiple physicians have failed to identify and treat adequately is evaluated by a consulting expert and found to have specific pathology affecting the piriformis muscle in the buttock. Shortly after the initiation of a treatment program for the specific problem, the condition completely resolved, rendering her fully functional. The condition cannot therefore be considered chronic in nature, but rather the result of inadequate identification of the acute condition.

It is for this reason that purely time-based considerations relating to acute conditions must be considered in their context. Some conditions will present themselves immediately or, with rapid progression, affect the individual, then abate, leaving the person fully functional at the conclusion of the condition. Others will affect the individual at the outset, with residual impairments that extend beyond the period of illness or injury. Polio would serve as an example of an acute illness that produces limitations that persist beyond the period of the infection.

In the United States, disability resulting from an acute condition can be measured in terms using temporary partial disability, temporary total disability, permanent partial disability, or permanent total disability based on the degree and severity of the impairment and its affect on the person's employability during the period of acute illness or injury. European systems offer a similar approach to temporary incapacity, with most systems considering the transition from acute to chronic disability occurring on or around the first anniversary of the onset of the disabling condition. Differing systems exist for the determination of income replacement when substantive improvement cannot be expected beyond the 360-day period of temporary disability. Most programs will use some formula for the determination of benefits at the determination of maximum improvement but may differ widely from state to state (as in the United States) or from country to country (as in the European Union).

From a biopsychosocial perspective, a more appropriate definition of an acute condition is one that manifests itself rapidly with demonstrable changes in function and one that in most circumstances will improve with appropriate identification and treatment. Some conditions, such as pneumonia or meningitis, will manifest themselves rapidly and result in either death or recovery with appropriate treatment. Other conditions represent the more immediate manifestations of a chronic condition (see below). Defining disability in acute conditions revolves around the duration that the impairment results in functional limitation.

A chronic condition can therefore be considered one for which there may be neither rapid onset nor rapid resolution. Some chronic conditions, such as spinal cord injuries, manifest different limitations during their acute and chronic phases. With many other conditions, chronic manifestations can be present even during the acute phase of the condition. For example, suffering behaviors can be identified in some individuals who are experiencing acute low back pain. This likely relates to that person's pain threshold and any other psychosocial factors or life stressors that might exist concurrent to the acute episode. Similarly, an acute psychosis may demonstrate features that represent an underlying and more chronic psychiatric condition. The goal of treatment of the acute condition is to reduce or eliminate the potential conversion to a chronic condition with resultant functional impairments.

Other conditions progress gradually over months or years and only become manifest or clinically evident when functional ability begins to decline. Various neurodegenerative conditions manifest themselves slowly over time, with functional limitations dependent on where in the course of the condition that person might be. Some chronic conditions have an exacerbating-remitting course, with acute phases interspersed with more chronic manifestations. Malaria, once considered virtually eradicated but increasingly evident in developing countries, is a good example of a condition with an exacerbating-remitting course superimposed on chronic disease-related manifestations. Therefore, as with acute conditions, chronic conditions do not require a specific time interval before being manifest, nor are they necessarily predictable in how they impair the individual. Nor does a chronic condition necessarily impair function. There are many chronic conditions, such as psoriasis, for which there are no specific functional limitations. The goal of treatment and rehabilitation of chronic conditions is to minimize the impairments that are due to the condition and when necessary to establish compensatory strategies (through the use of assistive devices, prostheses, or alternate methods to subsume the same activity).

The physical and functional manifestations of acute and chronic conditions can help differentiate their respective impact on the individual. Acute mycoplasma pneumonia will result in fatigue, lethargy, and respiratory manifestations. These acute changes will result in an immediate loss of endurance and strength, and they may result in shortness of breath that limits the individual's function. Once treatment is initiated, the condition will generally improve such that the functional limitations abate. In contrast, chronic obstructive pulmonary disease (COPD) results in similar feelings of fatigue, lethargy, and shortness of breath. Treatment for this condition is directed toward minimizing the impact of the condition and resultant impairments but generally does not change the underlying condition. With chronic conditions, there is a higher likelihood that treatment is more commonly directed toward palliative measures or treatments directed toward minimizing the impact of the condition rather than its elimination.

Other conditions, such as spinal cord injury, will manifest different functional impacts at different phases of the condition. Acute spinal cord injury results in significant hypotension that limits a person's ability to go from lying to sitting. This substantially limits rehabilitative efforts, necessitating aggressive measures to maintain blood pressure. In chronic spinal cord injury, a condition termed *autonomic dysreflexia* can occur (depending on the type and level of the paralysis) that results in overactivity of the autonomic nervous system. This overactivity causes severe increases in blood pressure that can be life threatening if left untreated. Aggressive measures must be taken to ensure that blood pressure does not rise uncontrolled. This example illustrates how treatments can differ substantially during the acute and chronic phases of the same condition.

Behavioral as well as physical manifestations can also be differentiated between acute and chronic conditions. Acute pain is most often associated with tissue trauma. As the tissues become traumatized, inflammatory mediators are released, initiating transmission by peripheral pain fibers to the central nervous system. After modulation at the spinal cord, the signal is then transmitted to the brain where pain is sensed. A simple example of this would be spraining one's ankle. Acute pain is usually described as local or regional in nature (i.e., the hip does not hurt if the ankle has been injured) and can be identified by appropriate diagnostic testing. The pain response associated with the acute event results in protective reactions that reduce function to an even greater degree. In the circumstance of an ankle sprain, weight bearing is limited both due to the original injury and as a protective mechanism to reduce further injury. Once the acute condition has either resolved or been treated, the functional limitation resolves. Chronic pain by contrast results from multimodal changes that occur both at the site of injury and more centrally. Additional behavioral changes are commonly associated with chronic pain. Due to the neurochemical and behavioral changes manifest in chronic pain, the same protective mechanisms fail to apply to the injured area or the whole person, resulting in continuing and persistent limitations.

The resultant physical or cognitive limitations of acute and chronic conditions impair the individual's ability to interact with his or her environment. Using the framework of the International Classification of Functioning, Disability, and Health (ICF), acute and chronic conditions represent only one of three dimensions that result in disablement. Specifically, an acute or chronic condition impairs body functions and structures. The result of that condition is the restriction of personal activities (dimension 2) that limits the person's ability to participate (dimension 3) in his or her environment.

Traumatic brain injury (TBI) is an example of a condition that manifests acute and chronic features and for which the functional limitations result in a loss of ability to participate in the environment. The acute phase of the condition is often manifested with spastic paralysis and profound cognitive impairment (dependent on the severity of the TBI). As a result, there is an immediate loss of bodily functions that include mobility impairments as well as cognitive alterations that limit the injured person's ability to interact with the environment.

In the chronic phase, there is some improvement of bodily and cognitive function such that the limitations experienced in the acute phase are less profound, or where compensatory strategies have been found for lost bodily functions. For example, a person with TBI would manifest limitations at the level of the person that consisted of right upper and lower limb weakness, speech limitations, and slowed cognitive processing and memory. This would result in activity-specific limitations (previously considered as an "impairment") including dressing, grooming, and toileting. As a result of these person-level limitations, the individual with a TBI would be less able to participate in activities requiring his direct involvement, such as driving a motor vehicle. Other functions, such as using an adapted computer for access to educational resources or memory augmentation, would not be impaired and could partially ameliorate other person-level limitations. The societal context of the person and activity level impairments relate to the external implications of the limitations. Using the ICF as the framework, these society-imposed "limitations" relate to access to public spaces, social service resources, and vocational opportunities. Exposure to negative societal attitudes and pity among "able-bodied" persons represent additional external factors that impair the ability of the person with TBI to interact within a social context.

It is therefore evident that acute and chronic conditions represent powerful contributors to the occurrence of disability. Acute conditions impair an individual's ability to engage in functional tasks during the period of incapacity. Some acute conditions produce long-term residual impairments that affect the individual well beyond the acute episode of illness or injury. Chronic conditions may represent the continuum of a condition from the acute to the chronic state, or may gradually affect function as the condition progresses. Both acute and chronic conditions result in limitations that can be defined at the tissue or organ level. These physiological or cognitive limitations will result in either temporary or longer-lasting activity deficits that can be expressed in functional terms. The disability that results from acute and chronic conditions results from internal and external factors that contribute to that person's ability to participate fully in his or her environment.

—Anthony Margherita

See also Accidents; Health; Pain; Spinal Cord Injury; Traumatic Brain Injury.

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ADAPT

ADAPT, the American Disabled for Attendant Programs Today, also called American Disabled for Accessible Public Transit, is a grassroots network of disability rights activists within the United States. Unlike many advocacy organizations, there are no monetary dues or membership cards. Individuals "join" ADAPT by becoming active within the ADAPT community. While the overall structure of ADAPT is informal, activities function at both local and national levels. There are more than 40 active local groups within 25 states and the District of Columbia. Each local ADAPT group develops its own style and structure, with decisions typically made through group consensus at meetings. Local groups often take on particular local issues but are united in a shared vision at the national level. For over the past decade, ADAPT's mission has focused on expansion of community-based attendant services and supports.

The origins of ADAPT trace back to Atlantis Community, located in Denver, Colorado. Atlantis Community was founded in 1975 as the second independent living center, following the establishment of the first in 1972 by Ed Roberts and fellow disabled students at the University of California, Berkeley. Simultaneous struggles for community-based independent living services and social justice prompted Wade Blank to found Atlantis Community. Blank was working in a nursing facility known as Heritage House with young disabled residents. After being fired for his advocacy to integrate the youths back into the community, Blank "freed" nine young disabled individuals from Heritage House, initially providing personal assistance services himself at no cost. Access to public transportation became an essential issue for this group in order to live independently in the community. On July 5–6, 1978, Wade and 19 disabled activists, using tactics of civil disobedience in the tradition of other civil rights movements, blocked buses with their wheelchairs and bodies and brought traffic to a standstill on the corner of Broadway and Colfax in Denver: American Disabled for Accessible Public Transit was born (this was the original name for the acronym ADAPT).

Demonstrations branched out nationally and intensified. Between 1983 and 1990 alone, ADAPT organized more than 20 protest actions in nearly every major U.S. city. The American Public Transit Association (APTA) and the Urban Mass Transit Administration (UMTA), now the Federal Transit Administration (FTA), were the targets. "We Will Ride!" was the rallying cry. The Urban Mass Transit law, passed in 1970, required wheelchair-accessible lifts on public buses, but regulations for implementation were delayed by the transit industry for more than 20 years.

ADAPT continued to gain public awareness through tactics of civil disobedience until regulations were finally issued in 1990 with the passage of the Americans with Disabilities Act (ADA). ADAPT played a key role in applying pressure within Washington to pass the ADA. In one of the largest disability rights protests to date, the "Wheels of Justice March" brought more than 600 demonstrators to the Capitol in March of 1990. ADAPT national leader Mike Auberger addressed the crowd, "We will not permit these steps to continue to be a barrier to prevent us from the equality that is rightfully ours. The preamble of the Constitution does not say 'We the able-bodied people.' It says, 'We the People'" (Shapiro 1993:133). With those remarks, dozens of protesters threw themselves out of their wheelchairs and began crawling up the 83 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day, 150 ADAPT protesters gathered in the center of the Capitol rotunda. Locking their wheelchairs together, they engaged in a sit-in until police carried away the protesters one by one. With the combined efforts of many individuals and organizations, the ADA moved quickly through Congress and was signed into law by President George H. W. Bush on July 26, 1990. On the second anniversary of the ADA, a plaque was dedicated by the city of Denver at the intersection of Broadway and Colfax, honoring the names of "The Gang of Nineteen"; a large mural on the inside wall of the transit station now memorializes the legacy of Wade Blank.

Following the victory around accessible transportation in 1990, ADAPT refocused its political objectives. Returning to foundational roots, ADAPT decided to tackle the issue of community-based personal assistance services. The acronym ADAPT was creatively reconfigured to stand for American Disabled for Attendant Programs Today. Many individuals active within ADAPT have lived, or still live, in nursing homes or other institutions. The struggle for community-based personal assistance services lies at the heart of the independent living movement. ADAPT has raised awareness concerning the "institutional bias" that exists within the United States long-term care system. Medicaid is the primary funding source of long-term care services within the United

States. Approximately 75 percent of Medicaid spending on long-term care funds services in nursing homes and other institutions. Nursing home services are mandatory for states participating in the Medicaid program, while community-based attendant supports and services are optional.

To correct the institutional bias in the delivery of long-term care, ADAPT has worked with legislators at the national level to introduce a number of pieces of legislation. The first bill (H.R. 2020 of the 105th U.S. Congress) was introduced on June 24, 1997, in the House of Representatives by Newt Gingrich. The bill was titled the Medicaid Community Attendant Services Act, commonly referred to as MiCASA. The MiCASA proposal required states to provide the option of community-based attendant services for individuals entitled to nursing facility or intermediate care facility services under the Medicaid program. Cost-effectiveness limits were embedded, so that aggregate spending on community-based services did not exceed what would have been spent on institutional services. Also, transitional money was proposed for states to change their systems of delivery. MiCASA was referred to the House Subcommittee on Health and Environment and garnered bipartisan support from 77 cosponsors. Congressional hearings were held in March 1998; however, the bill did not make it out of committee.

Subsequent versions of the legislation were reintroduced in the 106th, 107th, 108th, and 109th U.S. Congresses in both the Senate and House of Representatives. These versions became known as the Medicaid Community-Based Attendant Services and Supports Act, or MiCASSA. Senators Tom Harkin (D-IA) and Arlen Specter (R-PA) and Representative Danny Davis (D-IL) were among the members of Congress instrumental in developing MiCASSA with ADAPT. While each version has become more politically savvy, using federal reimbursement incentives, the general goals of the original version have not drastically changed. However, later versions of MiCASSA have embraced a more cross-disability perspective of disability, for example, incorporating mechanisms to address the needs of individuals who may require more support. In addition to MiCASSA, ADAPT has also been successful in getting another piece of legislation introduced known as "Money Follows the Person." This legislation also aims to rebalance the institutional bias in long-term care through demonstration projects that would allow individuals to move from institutional to community-based settings of their choice. While MiCASSA and Money Follows the Person have obtained administration and bipartisan support, they have not passed through Congress.

ADAPT continues to use tactics of civil disobedience to raise awareness of MiCASSA. Since 1990, more than 45 major actions have been organized by ADAPT around issues of community-based attendant services and supports. Examples of recent actions include the "Stolen Lives Campaign," in which more than 500 demonstrators converged on the White House to demand a presidential apology for individuals who have been forced to live in institutional settings due to lack of available community-based supports, and the 144-mile "Free Our People March" from Philadelphia to Washington, D.C., on the 20th anniversary of the Civil Rights March of 1963. Under the leadership of Bob Kafka and ADAPT at the national level, individuals with diverse disabilities and ages have united in solidarity. Hundreds of individuals have participated in direct actions at the national level, and hundreds of disability-related organizations at the local, state, and national level have signed on in support of MiCASSA. ADAPT's efforts have successfully led to some enactment of principles within MiCASSA through systems change grants under the Clinton and Bush administrations. As a single-issue grassroots organization, ADAPT has been extremely successful in uniting the disability community; and if the history of ADAPT is telling, the fight will continue until the rallying cry of "Free Our People!" is heard.

—Joe Caldwell and Larry Biondi

See also Advocacy; Americans with Disabilities Act of 1990 (United States); Independent Living; Ed Roberts.

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ADLs

See Activities of Daily Living

ADOPTION AND FOSTER CARE

Most children with disabilities are raised in the homes of one or both of their biological parents, but some grow up in other environments including adoptive and foster care homes. Although historically children with disabilities were considered not to be adoptable, by the end of the twentieth century that had changed. Greater recognition of the rights of persons with disabilities combined with the decreased adoption availability of healthy infants helped public attitudes to become more favorable toward adoption of special-needs children—those who were older, of minority race or ethnicity, who were members of sibling groups of three or more, or who had disabilities. These more favorable attitudes were reflected in federal laws in the United States such as the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 and the Adoption Assistance and Child Welfare Act of 1980. This legislation expedited the adoption process by establishing adoption exchanges, training adoption workers, and offering financial subsidies for adoptive families, all of which promoted the adoption of children with special needs, including disabilities. In 2000 in the United States, 11.8 percent of all adopted children ages 5 to 17 had at least one disability, in contrast to only 5.2 percent of biological children.

Children with many types of disabilities have been adopted. Some disabilities are mild and correctable, whereas others are severe and life threatening. Although severity of disability and prognosis for a very limited lifespan are deterrents for some potential adopters, at least one-third of women currently seeking to adopt consider adopting a child with a severe physical or mental disability, and approximately 5 percent actually prefer to adopt this kind of special-needs child. As an example, in the 1980s and 1990s in the United States, the AIDS pandemic began to orphan children, some of whom were HIV-positive and therefore at high risk for both disability and early death. Many of these children were placed with foster families, became available for adoption, and were adopted. Although the number of pediatric AIDS cases in the United States is declining, worldwide it is increasing rapidly, and U.S. families who adopt internationally are at some risk for unknowingly adopting an HIV-infected child.

Children with disabilities become available for adoption in two ways. Some are relinquished voluntarily by their birth parents with the disability as a contributing factor, and others are removed involuntarily because of abuse and/or neglect. For example, several studies have yielded estimates that approximately 20 percent of children with Down syndrome are voluntarily relinquished for adoption by their birth parents, almost always immediately after diagnosis. This relatively high percentage results in a fairly large number of children with Down syndrome available for adoption, and some individuals and agencies have specialized in finding homes for them. Nonetheless, infants with Down syndrome are much in demand and agencies frequently report that potential adoptive families may need to wait for several years before one becomes available.

Many children with disabilities are adopted by their foster families, especially since 1997 in the United States when Public Law 105–89, the Adoption and Safe Families Act, was enacted. This legislation is quite complex, but it and state regulations and policies related to it have resulted in a number of improvements in children's welfare: The amount of time that children spend in foster care waiting for reunification with birth parents has decreased and the number of adoptions from foster care has increased, in some states by as much as 50 percent or more in just one year. Nationally, foster care adoptions grew from approximately 31,000 children in 1997 to 50,000 in 2001. Because many children in foster care have disabilities, it is anticipated that increasing the number of adoptions from foster care will also increase the number of adoptions of children with disabilities.

From the adoptive parent perspective, the rewards of adopting children with disabilities seem to far outweigh the difficulties. Many parents speak of the life-changing experiences of their adoptions and report positive changes in their marriages, their other children, and their understanding of life meaning. Parents also describe that they are proud of their child's achievements and that they delight in their child's positive characteristics such as an affectionate nature, a contagious sense of humor, and an optimistic outlook on life. One indication of the success of adoptions is that many families choose to do it again. It is not unusual for families to have adopted more than one child with a disability, and some families described in published research studies have, over their lifetimes, adopted more than 20 children with disabilities.

Nonetheless, there are also challenges in adopting children with disabilities. Along with rewards, many parents report problems, including a variety of negative child characteristics; worry, anxiety, or guilt relating to the child; an increase in family disharmony as a result of the child's adoption; and lack of emotional bonding to and from the child. Medical emergencies may be a common occurrence, and dealing with service providers can be a chronic source of stress.

Because many adopted children with disabilities have suffered neglect and physical and/or sexual abuse in their families of origin, psychological and behavioral issues related to these experiences arise and can cause problems such as oversexualized behaviors or a victim mentality. Identity issues also arise, sometimes exacerbated if the adoption is transracial or transethnic. However, there is no indication that disability, in general, is related to adoption disruption (termination before finalization) or dissolution (termination after finalization). Many studies, however, do confirm that both adoption dissatisfaction and disruption or dissolution are predicted by the children's behavioral disorders. Externalizing or acting-out behavior, in particular, is linked to adoption breakdown.

The adoption process consists of several phases. Family recruitment is often the first step because there are more children with disabilities waiting to be adopted than potential adoptive families for them. Children who are older and have emotional or behavioral problems in addition to other disabilities are particularly hard to place. Photo books and media presentations of waiting children are useful strategies, as are national recruitment efforts with children frequently adopted across state lines. Many potential adoptive families have initial preferences for the type of child they would like to adopt, but to expedite placements, agency workers may encourage parents to consider children who do not match those preferences, a practice called "stretching." Many successful adoptions result from some stretching, but disrupted and dissolved adoptions are likely to be poor matches between child and family.

Although there is no typical or ideal family for a child with disabilities, some characteristics are usually found in successful adoptive families. These include familiarity with child rearing and with disability; a family-centered approach, including high cohesiveness; and flexible parenting style. Neither higher parental education nor greater family income appears to be positively related to good outcomes, and some studies have actually found that families with lower incomes and less education are more successful, perhaps because their expectations for child achievement are less likely to be unrealistically high.

The adoption process is not complete even after placement and finalization. Postadoption services are essential for families adopting children with disabilities, and use of these services is known to be associated with low disruption. Postadoption service providers can help families identify, locate, and obtain assistance of a financial, educational, therapeutic, or medical nature. Issues related to child and family adjustment change as the child and the family enter different life stages, and access to ongoing or periodic treatment is important.

Although a permanent placement is the ultimate goal for all children, including those with disabilities, it is not always achievable. At the beginning of the twenty-first century in the United States, more than a half million children are in foster care, with an average stay of almost three years. Although some of these children will return to their families of origin, and some will be adopted, others will remain in the foster care system throughout their childhood. Years in foster care usually result in multiple placements, which put the child at additional risk for emotional and behavioral problems.

Research has shown that a majority of foster children have developmental delays and a variety of disability conditions. For children with extensive special needs including psychiatric care, treatment or therapeutic foster care has emerged as a viable option to residential care. Therapeutic foster parents are experienced and mature, and they are trained to be responsive to many of the difficulties that the children require. Typically, there are consultant clinical/psychiatric services available and utilized. Although the majority of children in foster care have multiple risk factors for poor outcomes, an enduring relationship with at least one supportive adult is protective. Thus, it is important that children in foster care be returned to biological homes if possible or be placed for adoption as soon as is feasible. If they remain in foster care until the age of majority, the transition to adulthood, including coordination with agencies serving adults with disabilities, needs to be managed.

—Laraine Masters Glidden

See also Behavioral Disorders; Childhood, Youth, and Adolescence; Developmental Disabilities; Down Syndrome; Early Childhood Intervention; Parenting.

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ADVERTISING

Advertising is defined as a paid, mass media-driven attempt to persuade selected audiences. Advertising messages, whether carried on traditional media (television, radio, newspaper and magazines) or nontraditional channels (e.g., Internet, kiosks in malls, signs in malls), are designed to provide the public with brand information, change their perception about a particular product, or motivate them to take action.

Although the definition seems simple, advertising is anything but simple. In the United States alone, more than $300 billion is spent each year on advertising campaigns targeted to various market segments. According to the National Organization on Disability (NOD) (Cheng 2002), the disability community is a market segment worth $220 billion in collective spending power each year. The 54 million people making up this segment represent 20 percent of the U.S. population. It is not surprising therefore that advertising and disability are linked. According to a 1999 report (Farnall and Smith 1999), more than 100 corporations producing general consumer goods were including people with disabilities in their television advertising campaigns. *Advertising Age,* a major trade publication in the advertising industry, addressed the connection between people with disabilities and major corporations by claiming it is just "good business sense" to use ability-integrated advertising. While these facts might be interpreted as an acceptance of people with disabilities in advertising executions, it is important to remember the percentage of people with disabilities in advertising is approximately 2–3 percent, well below the population percentage.

The debate over the social impact of advertising is particularly appropriate to this discussion. Advertising is first and foremost a business activity designed to improve the bottom line for companies, yet some research on advertising featuring people with disabilities supports the idea that there can be societal benefits to positive portrayal in advertising. Other social science studies have found either no effect or negative impact such as when the portrayal included physically disabled females interacting with nondisabled males.

The history of advertising targeting people with disabilities is fraught with many of the same ethical issues (stereotypical representations, absence from the media) other minorities have encountered. And the power of a message that is intended to persuade cannot be overlooked in a discussion of that history.

HISTORICAL DEVELOPMENT

The association between advertising and the disability community can be segmented into two major periods approximately separated by passage of the 1990 Americans with Disabilities Act (ADA). Prior to the ADA, advertising featuring people with disabilities was either promoting a product developed specifically for that target and placed in disability media or designed to raise money for various causes. About the time Congress was considering passage of the ADA, marketers began to acknowledge the economic potential of the disabled community. Consequently, the appearance of disabled characters in consumer goods advertising mushroomed and ability-integrated advertising became much more commonplace.

Examples of Early Advertising

A search of the archives of the National Museum of Advertising History at the Smithsonian Institution uncovered a limited number of examples of early-twentieth-century advertising containing images of people with disabilities. The examples that were found fit into one of two groups. The first group of ads dates back to the 1920s and is the most unflattering portrayal of people with disabilities. It is characterized by line drawings of disfigured bodies just waiting for replacement limbs and raucous posters of sideshow attractions such as General Tom Thumb and the Fiji Mermaid. Often these same posters exaggerated the physical differences of the celebrity, such as one poster that enlarged the head of the famous general to make his body appear even smaller than his 3-foot frame.

The other group of ads could be labeled as charity advertising. Typical of this group are the "poster child" print ads for nonprofit organizations and the heart-breaking TV spots aired during the telethons of the 1970s. In these advertising executions, the visuals usually featured a child in a wheelchair or with braces and crutches. The voice-over copy was usually dramatic and poignant. In its most bold form, the copy portrayed a person whose life needed to be changed and who was condemned to a pitiful existence without contributions.

Fortunately, the trend in charity advertising shifted away from that approach to a more positive theme in the 1990s. For example, in 1995 the National Easter Seals fund-raising event moved away from the old-style "telethon" to a 20-hour televised program featuring more entertainment and theme segments on acceptance of children and family members with disabilities. In 1998, the marathon event was dropped completely by the group.

Transition to Ability-Integrated Advertising

The phrase "ability-integrated advertising" refers to the practice of including roles for people with disabilities in advertising for products that are not exclusively intended for the disability community. There is some disagreement among experts about which national company was the first to recognize the potential of including people with disabilities in its overall promotional efforts. Some researchers claim that discount retailer Target Stores was the first major marketer to insert people with disabilities in its print ads. Others point to a 1983 CBS television promotional spot featuring a paraplegic wheelchair racer.

No matter who led the charge, the number of print ads and television commercials with disabled roles increased to the point of being noticed in the late 1980s and early 1990s. Major manufacturers including Levi's Jeans, McDonald's, Kodak, Kellogg's, Mattel, and Plymouth were including representations of people with disabilities in their advertising campaigns. Marketers were beginning to recognize and address a market estimated in 1985 to be 43 million strong. The use of disabled actors and actresses in the ads also suggested that society might be ready to start to look at people with disabilities as individuals able to lead normal lives and as promoters and consumers of products.

MARKETING STRATEGIES FOR ABILITY-INTEGRATED ADVERTISING

The inclusion of people with disabilities in advertising has not occurred without some pitfalls in both execution and strategy. Organizations such as the Media Access Office (MAO) and NOD provide advertising strategies and guidance to producers, directors, agency creative directors, and talent. In addition, organizations such as the National Easter Seals Society (NESS) have stressed the need to portray people with disabilities in positive, yet realistic, situations.

Examples of advertising from general products companies that successfully communicated the positive, realistic approach focused on normal characters in daily life experiences. The executions were emotional, but not too emotional. Plot lines included such things as one child learning sign language from his computer so that he could communicate with the "new kid" on a school bus who happened to be deaf or two brothers who wake up to the smell or sound of their mother preparing sausage (one brother was deaf), or the famous Nike ad portraying a man with an artificial limb getting knocked around in a street basketball game. Of course, humor was also used, as in the campaign for Airtouch Cellular featuring blind actor Rick Boggs. In all these examples, the ad worked because it did not pity the person with the disability or depict that person as achieving unrealistic feats.

Execution Pitfalls

It is not surprising that advertising executions do not always succeed in the area of positive portrayal for the disabled. Even with the best of intentions, it is easy to fall into one of the negative stereotypical portrayals of people with disabilities such as the "supercrip" or "one to be cared for." When writers, producers, and directors include characters with disabilities only to make sure that the group is represented, there is a greater chance the ad will actually alienate disabled consumers instead of embracing them.

In the relatively short history of disability-integrated advertising, the faux pas most often cited is the use of nondisabled actors to play disabled roles. Many have been guilty of that error, but no case better illustrates how easily it can happen than the Maryland Planning Council on Developmental Disabilities campaign. In 1988, a Baltimore agency produced a set of 30- and 60-second TV spots for the council featuring a nondisabled actor portraying a man in a wheelchair. The agency said a last-minute rewrite at the request of the council changed the script from one in which the actor got up from the wheelchair to one in which the actor did not reveal his ability to walk. The casting had already been done. The spots brought an avalanche of letters to professional publications and the council from activist groups and individuals who were aware of the production.

Examples of other campaigns that used disabled actors but still failed to capture the desired effect include a series of actor Christopher Reeve ads for an investment company, a retailer that showed a disabled shopper receiving help from the store's staff, and a shoe manufacturer's use of insensitive language about people with mobility impairment in its shoe ads.

ORGANIZATIONS SUPPORTING ADVERTISING EFFORTS

There are a number of private companies and consultancies that have experience in helping companies target consumers with disabilities. But on a national scale, three not-for-profit organizations lead the way.

National Organization on Disability

The NOD has a much broader mission, but it also provides support through its website for marketers interested in reaching people with disabilities. NOD efforts in this area include articles offering marketing strategy tips, information, and resource lists, and even partnership programs with corporate sponsors interested in the disability community. One recent example of sponsorship programs was the 2004 special advertising section in *Motor Trend* magazine. The 15-page spread was the largest mass-market effort to publicize automotive industry achievements in the field of mobility equipment.

Media Access Office

The purpose of the MAO is "to actively promote the employment and accurate portrayal of persons with disabilities in all areas of the media and entertainment industry, ensuring that the industry recognizes people with disabilities as part of cultural diversity" (California Governor's Committee 2004). The California Governor's Committee on Employment of People with Disabilities and entertainment and media industry professionals established the MAO in 1980. In addition to promoting ability-integrated advertising, this group works with writers, producers, and directors to advocate the use of actors with disabilities in disabled roles and promote a more positive portrayal of people with disabilities in the entertainment industry. Programs and services of the MAO include casting, talent development, talent support, project development, community education, and awards.

NESS Equality, Dignity, and Independence Awards

The emergence of ability-integrated advertising was a positive step toward gaining respect for the disability community. For 10 years, a primary force in supporting this role was the NESS. From 1989 to 2000, NESS recognized and encouraged realistic media portrayals of people with disabilities by presenting EDI Awards to members of the media, entertainment, and advertising industry. In the advertising category, both print and broadcast executions were judged with the best receiving recognition. In 1989, only five entries were received in the advertising category. By 1992, the number of entries had increased by 300 percent.

—*Olan F. Farnall*

See also Easter Seals; Poster Child; Telethon.

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▣ ADVOCACY

Advocacy refers to actions taken to express one's view, to further a cause or belief, and/or to exercise rights. Advocacy is used by people with disabilities (as individuals or organized groups) to increase their influence and obtain their rights. Advocates, people who take advocacy actions, may focus their actions on themselves, other individuals, families, organizations, communities, and/or public policies. Self-advocacy activities are those practices that involve individuals taking the initiative to request, pursue, obtain, and, if necessary, demand particular things they need in their daily lives to attain and exercise their rights. Community-based or other systems-level advocacy efforts target larger shared concerns that individuals may have with organizations or social movement building. Examples of advocacy of this nature include community outreach and education, community organizing, and public policy initiatives. Systems-directed advocacy can cover a wide range of disability-related issues such as education and youth services, transportation and housing, health care and personal assistance, and human and civil rights.

Within the disability rights movement (DRM), self-advocacy has been a key strategy in changing social conditions. In the context of the DRM, the term *self-advocacy* has sometimes been used as synonymous with the movement through which people with disabilities seek human, civil, and legal rights. In using self-advocacy as synonymous with the DRM, it becomes difficult to differentiate among other terms such as *advocacy, community movement,* and *self-help organization.* This entry will consider *self-advocacy* as advocacy that entails those individual actions directed at attaining better conditions for the self and *advocacy* as actions often taken by groups directed at improving conditions for others, groups, communities, and larger social systems. Advocacy and self-advocacy have become important means by which people with disabilities (along with their allies and families) have been able to gain rights. Another meaning of self-advocacy that is common in the DRM, especially among individuals with intellectual disabilities, is advocacy done by people with disabilities themselves.

A *social or community movement* occurs when a number of individuals work together to address important social problems with the purpose of producing social change. These efforts often involve increasing access to opportunities, civil rights, and stronger government support for exercising group member civil rights. Social movements rely on collective efforts by individuals, groups, and/or organizations that share similar values and common goals. Community movements are considered "bottom up" efforts that can produce changes in the structure and mindset of societies. Five defining elements of social movements include that they are joint efforts, have a common goal to produce change, are organized, continue across time, and use a combination of actions both within and external to existing institutions.

Within the DRM, structured settings in which people with disabilities meet and discuss common issues as well as plan advocacy actions are organizations known as *self-help organizations.* The primary goal of self-help organizations is to provide members with a supportive social network that can offer both instrumental and emotional support. Self-help organizations also tend to have a defined mission of change and strategies to obtain that change. The group's purpose may range from personal change to social change, or it may include both approaches to advocacy, self and system, as part of its change agenda. Members of self-help groups are often trying to address a particular issue and may join the group in an effort to gain personal control. Self-help groups operate within informal settings in which marginalized individuals who have similar concerns, experiences, or living conditions can give and receive support. Self-help organizations are often organized in a nonhierarchical manner with group members leading the group; professionals rarely have an active role in the group unless they participate as members or nondirective advisers. Membership is usually open to anyone who has the focal problem, situation, or identity in common with other group members.

Across time, self-help organizations have served diverse purposes and taken a variety of forms to achieve their goals. Different types of self-help organizations include local self-help groups, local advocacy and program centers, local single-issue advocacy groups, public policy groups, single-issue national advocacy groups, national membership organizations, national coalitions, federations of groups, national single-disability organizations, regional organizations, and international organizations.

Self-help organizations can be viewed along two dimensions, political and personal, with high and low gradations of foci on either dimension. Successful self-help organizations can take at least three forms: (1) a primary emphasis on political issues, (2) a prominent emphasis on personal issues, or (3) a significant dual emphasis on both. Organizations that reflect this latter dual focus on personal and political issues include centers for independent living, which have both national and local agencies; each branch of the organization may differ on its emphasis depending on whether it is a national or a local organization. Members of these organizations are both highly involved in political advocacy as well as seek and provide individual assistance and support through the organization.

Other organizations have a high political component and a moderate to low individual element such as Self-Advocates Becoming Empowered, the national federation of statewide advocacy organizations of, by, and for people with intellectual disabilities. Organizations such as these tend to be more focused on policy issues and engage in actions such as lobbying of policy makers. Other organizations have a strong personal component with a less active political agenda. These types of organizations tend to focus on individual needs. For example, a local chapter of People First for people with intellectual disabilities or another single-disability organization (i.e., an organization dedicated to only one form of disability) may focus exclusively on personal issues such as social support and interpersonal relationships. Within this high-low two-dimensional framework, there might be organizations that have both low political and individual agendas.

These organizations might be starting up, dying down, or in transition. Given the nature of grassroots organizing, it is typical for self-help organizations to be in this stage briefly at certain points in their development. Self-help organizations may shift their emphasis throughout time. The high-low two-dimensional framework includes all combinations of emphasis on the political and the personal and recognizes that today's personal concern may become tomorrow's political issue. It is dynamic in that the mix of personal and political can vary at different times in the life cycle of a self-help organization.

It may be that self-help organizations that recognize the personal as political and vice versa are most successful. For example, an individual who participates in self-help organizations might engage in political activities because it becomes personally rewarding to speak on behalf of others. In this context, the personal experience is affirmed because it has broader implications. Thus, when individuals in a self-help organization integrate the personal and political, the self-help organization may become stronger and serve multiple purposes.

All self-help organizations provide environments in which people have the opportunity to organize, develop self-advocacy skills, and receive support. These environments allow individuals to obtain public (e.g., taking a political stand) and private (e.g., establishing friendships) goals.

THREE INTERRELATED CONCEPTS

The focus of advocacy actions by advocacy, social movement, or self-help organizations can be placed on a continuum of different levels or units of analysis. This continuum includes actions that are directed at the self to actions directed at society. Examples of advocacy at the individual or family end of this "levels of analysis" continuum of advocacy include a parent who advocates at a school to obtain needed supports for his or her child and a disabled person who advocates at a rehabilitation services center for better service provision. In the middle of the continuum, at the community level, a group of residents may advocate for accessible parking. On the other end, actions taken to change legislation or public policy such as building codes or services are considered advocacy at a systems level. It is critical to note that placing advocacy actions on this continuum does not mean that advocacy efforts do not overlap or flow between these levels. Indeed, advocates and their organizations often move along this continuum. For example, a person with a disability may advocate for himself or herself as a self-advocate; however, while the person can advocate on an individual level (e.g., for adequate personal attendant care) he or she can also advocate at a systems level (e.g., lobbying legislators).

Advocacy serves as an empowering force through which people with disabilities obtain social change. In the 1970s, an international disability social movement emerged based on self-advocacy and advocacy efforts. The social movement known as the DRM began when people with disabilities started organizing themselves with the intent of speaking out and demanding their rights. For people with disabilities, the process of forming self-help organizations provided an infrastructure for self-advocacy development by providing a setting in which people could share their experiences and knowledge and receive support.

As part of the empowerment and self-determination movement, different organizations and groups of individuals drafted their own definitions of self-advocacy. For example, in 1991 People First, an advocacy organization of and for people with intellectual disabilities, defined self-advocacy as

> independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination. It teaches us how to make decisions and choices that

> affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn about our responsibilities. The way we learn about advocating for ourselves is supporting each other and helping each other gain confidence in themselves to speak out for what they believe in. (Dybwad 1996:2)

Definitions of self-advocacy reference common factors such as empowerment, self-determination, self-help, independence, and integration. In addition, they call for a reconceptualization of what it is to be a person with a disability by pushing for a change in society's view of disability from a medical and individual impairment to a socially created experience. The advocacy and self-advocacy efforts that have occurred over time across disabilities and specific historical developments led to the community movement known as the DRM.

HISTORY

Early Origins

People with disabilities have organized for centuries. Historians have been able to trace the existence of self-help organizations to medieval China and Europe. There, people with disabilities, especially those who were blind, were marginalized by society and then organized for self-protection and economic support. In China, informal organizations became guilds and associations composed exclusively of blind people. In at least one guild, members earned a living by singing and entertaining. The guild was self-governed, and all the members of the board were blind except the secretary. Board members decided on all issues including recruitment of new members and discipline of members. Children who entered the guild learned skills for specific trades. As members acquired skills, they ascended the hierarchy of the guild.

During the Middle Ages in Europe, blind people also formed guilds for the purpose of self-protection. Group membership provided status and a means of expression, participation in the community, and demonstration of self-sufficiency. Guilds were known as "free brotherhoods of the blind." In Paris, a group called the "Congregation and House of the Three Hundred" was formed composed of blind men and women. These early associations provided members emotional support and sometimes access to economic self-sufficiency. Despite these early associations, later historical events impeded the further development of these organizations. Nonetheless, the existence of these associations is important to be noted; men and women with disabilities who participated in these organizations were self-advocates of their time.

In the 1800s in the United States, advocates spoke out and demanded changes, particularly in laws and education. One of the first organizations to promote collective advocacy was the National Association of the Deaf, which advocated for the right to include sign language as part of education for people with hearing disabilities at a time when mainstream society opposed sign language. Similarly, in the nineteenth and first half of the twentieth centuries, there was an increase in the population of psychiatric hospitals. Initially, mental institutions were conceptualized as places to care for mentally ill individuals. However, they quickly became a means for social control. Mental institutions were often used as means to discipline and alienate those who were different.

Fortunately, successful advocacy strategies brought the problem of institutionalization to the public's attention. In 1866, Elizabeth Packard was committed to a psychiatric hospital against her will. She wrote a book on her experience and advocated for the creation of the Packard Law, which stipulated that a jury must decide whether to commit a person to a psychiatric hospital against his or her will. In the early 1900s Clifford Beers, a former inmate at a psychiatric hospital, authored a book on his experience. His book, *A Mind That Found Itself,* made public the experience of abuse while committed to a mental hospital. These instances of advocacy through written experiences reflect early efforts and success in changing public views towards mental illness.

Modern Advocacy Organizations

The first modern advocacy organization for the blind, the National Federation of the Blind, was founded in 1940. Around this time, parents of people with intellectual disabilities also began to organize to advocate for services for their children. After World War II, as the population increased, there was an increase in the number of children with disabilities. Other single-disability organizations arose such as the National Association for Retarded Children (formerly named the National Association of Parents and Friends of Mentally Retarded Children; *Children* was later replaced with *Citizen* and now the organization's name is the acronym ARC.). The ARC pushed forward the concerns of parents of children with intellectual disabilities including their children's exclusion from public education, the dearth of community and residential services, and dissatisfaction with extant conditions for employment of people with intellectual disabilities. The ARC has served as a leader in advancing public policy for people with intellectual disabilities including steps toward deinstitutionalization. Its success may be linked to the high social status of its members and effective, grassroots social action strategies.

During this same time period, a group of ex-patients publicly criticized institutions by bringing attention to issues of human rights violations in mental institutions. In doing so, ex-patients formed self-help groups and demanded changes in policy. In the mid-1960s, the mental health patients' movement slowly emerged. Simultaneously, the population of psychiatric hospitals was dropping due largely to the availability of medications that helped people live in the community, literature that improved social beliefs about mental illness, and concomitant shifts in public policy. Interplay among science, culture, society, and government began to produce changes that remain today. Literary examples that worked to induce these changes include Thomas Szasz's *The Manufacture of Madness* (1970) and Ken Kesey's *One Flew over the Cuckoo's Nest* (1962).Within the policy arena, President John F. Kennedy signed laws regarding mental health issues. For example, the 1963 Community Mental Health Act contributed to having people live and receive treatment in the community. In addition, the Kennedy administration contributed to setting the stage for attention to intellectual disabilities. Influenced by a sister with intellectual disabilities, Kennedy advanced the cause of providing public school services for people with disabilities by commissioning a presidential panel on mental retardation and creating a bureau for special education.

A group of parents filed a lawsuit to get their children with disabilities educated. Their advocacy efforts led to the passing of the federal law known as The Education for All Handicapped Children in 1975. Signed by President Gerald Ford, it guaranteed education in "the least restrictive environment" for children with disabilities. The original law has been revised over the years and has since been renamed the Individuals with Disabilities Education Act or IDEA.

The independent living movement was one of the first movements that provided tangible gains for people with disabilities by demonstrating that people with disabilities were capable of living and being leaders in their communities. In the early 1970s, the Berkeley Center for Independent Living opened. Centers for independent living (CILs) are nonresidential, not-for-profit organizations that do advocacy, service, and educational activities. CILs are cross disability, and the majority of the members on the board of directors are people with disabilities.

Similarly, in the 1970s, a group of individuals with intellectual disabilities founded People First, the first self-advocacy group for people with intellectual disabilities. The name was developed as an initial step in speaking out and demonstrating a sense of identity defined first by their humanity and second by their disability. The purpose of People First is to help members learn to advocate for themselves. The 1974 convention of People First in Oregon provided a setting to discuss issues in self-advocacy and served as a propelling force for the self-advocacy movement. As a result, many organizations flourished. By 1994, approximately 11,600 people with intellectual disabilities were involved in self-advocacy groups. Early issues addressed by advocates centered on public transportation, lack of accessible and affordable housing, institutionalizing of the poor, inclusion of students with disabilities in the classroom, and changing the understanding of disabilities.

In the mid-1970s, diverse advocacy groups led by ex-patients and mental health consumers were formed. These groups used strategies such as awareness raising, organizing, and political action techniques to effect change. The most radical of the groups viewed psychiatry as the oppressor and were suspicious of professional advocates. Others viewed some professionals who supported change as valued collaborators. The differences of opinion were often strongly held, which sometimes made it difficult to establish synergy among mental health advocacy groups.

Mental health advocates championed changes in policies through a variety of approaches, and various advocacy groups were created such as the National Alliance for the Mentally Ill (NAMI), founded in 1979. NAMI originated as a network of mutual support groups and expanded to include national public education efforts as well as legislative lobbying at the local, state, and federal levels. NAMI is an advocacy and education organization that now has hundreds of affiliates and represents thousands of families. Advocacy organizations such as NAMI have increased awareness of mental health issues and affected policy and legislation. Early impacts on legislation resulted in the right of a person with a mental disability to receive treatment, in the least restrictive environment, protected from intrusive procedures and from involuntary commitment without appropriate procedures.

ADVOCATE DEVELOPMENT AND ADVISORY

Since the initiation of the DRM, people with disabilities have obtained and been more able to exercise their rights through advocacy efforts. Many have initiated their advocacy activities as a result of personal experiences with disability whether as a person with a disability or as a family member or other loved one of a person with a disability. Other individuals have initiated advocacy activities from a shared interest in promoting equality. Some researchers have suggested stages of advocate development ranging from starting to be involved to being highly involved. Balcazar, Keys, Bertram, and Rizzo (1996) identified three developmental stages: beginner, involved, and activist. At the beginner stage, a person belongs to an organization and acts as a relatively passive member, receiving few services and taking few advocacy actions. In the involved stage, a person is a more active member of at least one organization, obtains services as needed, and takes more advocacy actions to address personal needs. An activist, however, likely belongs to several organizations, including those at the state and/or national levels, and has taken leadership roles in at least one advocacy organization. An activist also works to obtain services for local group members and takes a significant number of advocacy actions on a regular basis. By understanding advocate development, advocacy actions can be tailored according to the expertise, interests, and activity level of advocates. Advocacy training can be developed that is appropriate to participants' present level of involvement.

Many recognize a need to enhance and support advocate development in order to affect policy and society. Advocacy training programs have been designed to enhance the skills of advocates with the intention of maximizing the roles of people with disabilities and family members. Many advocacy training programs have been developed. One example is Partners in Policy Making. Partners is a training program designed to empower people with developmental disabilities and their families to pursue their cause. By introducing trainees to disability policy, advocacy skills, and state-of-the-art services, Partners in Policy Making promotes involvement in positive and progressive advocacy activities by program graduates. The program has been very successful in developing advocacy leaders in many states in the United States.

Advocacy training programs offer participants intensive training in advocacy skills and provide an opportunity for diverse people to become advocates. In a study with participants of different levels of advocacy activity, researchers found that advocates that already had a high level of participation in advocacy activity increased their participation the most and their family members with disabilities received three times more services when compared to people with medium or low levels of participation. In addition, researchers found that people can move beyond personal interest to address the needs of others similar to themselves. Results from this study shed light on the benefits of advocacy involvement and training.

In one program, participants in advocacy training programs delineated supports and barriers to successful advocacy. Participants identified elements such as empowered voices, networking, courage, and leadership as essential factors for successful advocacy efforts. Participants also outlined barriers to advocacy including lack of time, lack of financial resources, and the interference of emotions. By identifying and sharing the supports and barriers that advocates encounter, advocacy development trainings can build a sense of universality among advocates. That is, these training programs can increase participants' awareness that others share struggles and benefit from supports similar to their own. Universality can lead to greater solidarity among disability advocates. It can motivate participants to enhance their skills and collaborate to develop and share strategies to combat barriers to effective advocacy.

In general, individuals who participate in self-advocacy efforts become empowered, or gain greater control over things that affect their lives. Models of empowerment suggest that self-advocacy and advocacy provides a setting for people to become empowered by gaining awareness of society and self, emphasizing one's strengths, taking action, engaging in collaborative relationships, and effecting social change. Through participation in advocacy activities, including advocacy trainings, individuals gain a sense of awareness of their roles as advocates. For example, people with intellectual disabilities who participate in self-advocacy activities learn that social and physical structures are often discriminatory. They see that changes to systems must occur to meet and integrate individuals with disabilities to society. Once individuals become aware of barriers that impede the integration of people with disabilities, individuals are often more able to acknowledge that people with disabilities are persons with strengths and capable of contributing to society. In addition, individuals who participate in advocacy efforts are able to take action and gain greater control over their lives. Furthermore, members of self-advocacy groups gain peer and public support and a sense of self-confidence.

ADVOCATE ADVISERS

The DRM pushes for a shift from a traditional deficit model of disabilities to a social model that is strengths based, supportive, and collaborative. Collaboration occurs when members of different groups work together for a common cause or bring in nonmembers as consultants to provide specific expertise or guidance. For example, many self-advocacy groups of people with intellectual disabilities include a nondisabled member as an adviser. Advisers are usually community members or professionals who work in the disabilities field. The role of the adviser is to facilitate and provide assistance in various areas. Advisers are not experts but rather collaborators. It is important to note that advisers are not necessary for a self-advocacy organization and that there are advantages and disadvantages of having an adviser. One advantage of having an adviser is that it permits groups to access knowledge or expertise that may be less available within their current membership. One disadvantage is that some advisers can act beyond their advisory role and counteract members' advocacy by promoting disempowering relationships between the adviser and organization members.

To facilitate collaboration between an advocacy organization and advisers, it is important for advisers to be committed to the philosophy and realization of empowerment and self-determination. Effective advisers work to facilitate personal and collective changes, incorporate creative ideas, and recognize individual worth, equality, and skills of organization members. The role of advisers and nondisabled advocates is not without controversy: There is the potential for many to not fully understand their role within the DRM and to not fully appreciate the social role of people with disabilities.

CHALLENGES TO ADVOCACY MOVEMENTS

In addition to controversy over the role of advisers and participation of able-bodied individuals, there are several other challenges to the success of advocacy efforts. Many times, advocacy efforts have had difficulty finding a common cause given the broad scope of disabilities and individual needs related to this diversity. A second barrier might be that different models of disability are used as a basis for action and change. Differences among these approaches can present a barrier for a successful advocacy. For example, some people may incorporate the medical model and work within this framework to increase access to traditional services. However, others may feel that the legal rights model is a more adequate framework and work within this framework to change the services available and how they are delivered. Thus, those following the more traditional approach would ask for individual student services offices in universities to provide more readers or individual supports to make texts more readily available to blind college students in a timely manner. Others, noting the inadequacy for print access through these offices on campus, might focus instead on developing a policy with publishers or a law for them. For example, all publishers would make computer-readable versions of texts and journals available to blind students at a reasonable cost. These variations in perspectives on disability can affect the tactics and strategies used for advocating as well as present a challenge if consensus is not reached.

ADVOCACY TACTICS AND STRATEGIES

There are diverse tactics and strategies that advocates adopt to pursue change. As mentioned earlier, differences in these strategies might present challenges in pushing forward any particular agenda. However, many agree that the milestones reached in the contemporary DRM were obtained through the use of multiple advocacy strategies including the most action oriented of all, activism. Advocacy practices are geared toward changing services, promoting inclusion in society, and influencing legislation and policy. Advocacy efforts can be speaking out in the community, serving on boards and committees, communicating with decision makers, lobbying, writing letters, and participating in the development and implementation of programs, among many other tactics. There are also many tactics available to advocates such as peer advocacy, parent advocacy, professional advocacy, and self-advocacy.

An illustrative example of using multiple advocacy strategies occurred in 1973 when Section 504 of the Rehabilitation Act was passed. This act prohibited discrimination against disabled individuals from organizations receiving federal financial assistance. Regulations were passed thanks to cross-disability advocacy efforts. Multiple advocacy tactics were used ranging from single phone calls to a sit-in at federal buildings. Different advocacy approaches such as writing letters, lobbying, and media appearances made the promulgation possible. Another example of the success of multiple advocacy tactics is that of individuals with psychiatric disabilities issuing a public statement, called the "Highlander Statement of Concern and Call for Action on March 25, 2000." In this statement, a call for a mental health system founded on self-determination, respect, ethical behavior, and humane services and supports was made. Similar cross-disabilities, multifaceted advocacy efforts helped pass the Americans with Disabilities Act of 1990 (ADA). There are fundamental elements necessary to obtain a successful advocacy effort: Set goals, develop a strategy, gather information including asking questions, and use other support to establish your place in the process. Using these advocacy elements can bolster the effectiveness of the effort.

CONCLUSION

Overall, anecdotal accounts and research have established that appropriate advocacy strategies are effective in implementing change and can provide benefits at many levels, including to individuals, communities, and societies. Through advocacy, empowered groups have greater potential to have an impact on society and terminate the long history of unequal treatment against individual with disabilities. Advocacy, self-help, and social movement activities will continue to be integral to attaining social justice for people with disabilities in the twenty-first century.

—Yari Colon, Christopher B. Keys, and Katherine E. McDonald

See also Advocacy, International; Advocacy Movements: France; Advocacy Movements: Germany; Empowerment and Emancipation; Individuals with Disabilities Education Act of 1990 (United States); Lobbying; Parental Advocacy; People First.

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Websites

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National Alliance for the Mentally Ill, http://www.nami.org
National Federation of the Blind, www.nfb.org

ADVOCACY, INTERNATIONAL

Advocacy refers to actions taken to express one's view, to further a cause or belief, and/or to exercise rights. Advocacy is the practice, in this context, by people with disabilities (as individuals or groups), to increase their influence and independence. Self-advocacy activities are those practices that involve individuals taking the initiative to demand and pursue particular things they need in their daily life. Community-based or systemic advocacy efforts dovetail with organization and movement building. These efforts may include community outreach and education, community organizing, and public policy. They can cover a wide range of disability-related issues such as education and youth services, transportation and housing, health care and personal assistance, and human and civil rights. It is with the latter notion of advocacy and its connection to organization and movement building that this entry is concerned, although there are many connections between self-advocacy and community-based advocacy.

PHILOSOPHY AND PRACTICE

The philosophy and practice of advocacy, self-help, and social movement building have evolved out of an emerging consciousness of political activists worldwide that is informed both by their own particular local experiences and the reach of the international disability movement. They incorporate the interconnected principles of empowerment and human rights, integration and independence, self-help and self-determination. The meaning of these concepts and where they programmatically lead can, not surprisingly, be different and, more noticeably, can have different strategic movement or organizational importance. This reflects the divergent and often conflictual politics of the movement's activists.

DISABILITY RIGHTS AS A NEW SOCIAL MOVEMENT

The building of a disability movement rooted in self-help organization and advocacy reflects many of the traits of other new social movements that emphasize identity. These social movements focus on new forms of social and collective action, involve personal intimate needs, and are not centralized but loose and diffuse. There has been much debate among activists and scholars about how similar the disability movement(s) is to other new social movements such as women's, human rights, landless peoples', and environmental movements. In arguing that the disability rights movement is a new social movement, two British disability rights scholars, Mike Oliver and Gerry Zarb, argued that the critical traits of new social movements mirror those of the disability rights/advocacy movement: "To varying degrees and in varying ways the new movements also seek to connect the personal (or cultural) and political realms, or at least they raise psychological issues that were often submerged or ignored." Oliver and Zarb (1989:237) go so far as to make the assertion, "Hence, the disability movement will come to have a central role in counter-hegemonic politics and the social transformation upon which this will eventually be based." This assertion contrasts with the lack of interest most sociologists who study social movements have shown in the advocacy, community movement, and self-organization of people with disabilities.

CONTEXT OF ADVOCACY, MOVEMENT, ORGANIZATION

Out of the different and often hard realities of everyday life, advocacy organizations of people with disabilities have appeared in virtually every country in the world. These organizations form the core of the international disability rights movement. Although this development touches only a relatively small portion of people with disabilities, it nevertheless parallels the process of consciousness and organization that has given rise to many kinds of community-based advocacy and self-help organizations and social movements.

Many of these organizations started as a response to the simple need for survival—food, shelter, and work—and their goals were limited to economic self-help and self-sufficiency. Others started as political groups that wished to mobilize people with disabilities in their communities, cities, countries, or regions. These groups and purposes have gradually merged. All seek to link their work with the struggle for self-determination and human rights. With few exceptions, this struggle is their common denominator.

Although the development of disabled persons advocacy and self-help organizations has been uneven, it is undeniable. Within the past 25 years, self-help groups have formed in leprosy communities in southern Africa, in refugee camps in Kampuchea and Mexico, and on remote islands in the Philippines, Palau, and Fiji. A village in the mountains of Mexico has become the center of a self-organization of and by people disabled from drug-related violence and has attracted hundreds of people with disabilities from throughout the country.

Advocacy activists have made different choices over the years on how and what to organize around. In southern Africa, activists took a perspective that national and regional federations had to be organized that would in turn promote locally based economic development projects. For example, the National Council of Disabled Persons Zimbabwe fostered the establishment of a supermarket in a township outside Bulawayo and collective gardens outside Harare. In Southeast Asia, various individuals who had returned from international conferences banded together to form chapters of Disabled Peoples' International because they understood all policy and services were mandated by a number of connected politicians in their countries' capitals. Indeed, Disabled Peoples' International–Thailand quickly established a national presence by staging demonstrations criticizing the Thai government for dismissing a deputy cabinet member who used a wheelchair. In many places in the third world, the lack of rehabilitation services and mobility aids for those with physical disabilities created both an impetus to organize and goals of newly formed groups. In Nicaragua, one of the first things the Organization of Disabled Revolutionaries (ORD) did after the Sandinista revolution was to set up a wheelchair production and distribution system using locally available materials in their wheelchair design. Other activists, especially in the United States and Japan, out of a perceived overarching need to create community and employment, opted to concentrate on establishing centers for independent living.

HISTORY

Most of these groups are relatively new, small, and fragile. Most exist with little or no funding. As indicated, the 1980s were the first time people with disabilities and their supporters founded a large number of advocacy organizations. The National Council of Disabled Persons Zimbabwe, initially registered as a welfare organization, became a national disability rights group in 1981. The Organization of Disabled Revolutionaries was set up in the wake of the Sandinista victory in 1979. The Self Help Association of Paraplegics of Soweto was started in 1981 as an economic development project. The Program of Rehabilitation Organized by Disabled Youth of Western Mexico also began in 1981 as a rural community-based rehabilitation program. DPI-Thailand was established in 1983, and the Southern Africa Federation of the Disabled was formed in 1986 as a federation of nongovernmental organizations (NGOs) of disabled persons. It was during this time that many disability rights and advocacy groups were established including the Disability Rights and Education Defense Fund, ADAPT (American Disabled for Accessible Public Transit, also called American Disabled for Attendant Programs Today), and France's Groupement Francais de Personnes Handicapees. Also begun during this period were England's British Council of Disabled People (BCODP), Greater London Action on Disability, and Disability Awareness in Action; Cuba's Asociacion Cubana de Limitados Fisicos Motores; and many European advocacy groups.

Often these organizations have reached across borders to establish similar groups in neighboring countries. For example, members of DPI-Thailand, based in Bangkok, made numerous trips to Vietnam, Laos, and Kampuchea to spread the philosophy of disability rights and to initiate activities. There have been international exchanges between Hong Kong and the People's Republic of China. Some of these NGOs have very close connections to the governing party. Close connections have historically been the case in Vietnam, Mozambique, Angola, Cuba, Indonesia, Nicaragua, and the People's Republic of China among other countries, particularly in the third world. In other instances, disability rights and advocacy-oriented NGOs have been allied with opposition forces in their countries such as in Brazil (with the Workers Party), South Africa (with the African National Congress), and Japan. In most cases, disability rights and advocacy-oriented groups have stayed out of national politics, focusing instead on narrow disability issues.

A TYPOLOGY OF ORGANIZATION

Reviewing the various structures and strategies of international advocacy groups, we could group them by the following typology: (1) local self-help and advocacy groups, (2) national advocacy organizations and coalitions/federations, and (3) worldwide organizations.

Local Self-Help Groups

Local self-help groups vary from small collectives of people providing peer counseling and moral support to small plot gardening and agricultural ventures to larger projects involving a significant level of support, production, and revenue. Some are cross disability, cutting across many different kinds of disabilities, and others focus more on persons with a single disability or cluster of similar disabilities. The experiences and lessons from the hundreds of self-help groups are diverse. The peer relationships and friendships, material aid and support, and sense of control they engender have significantly contributed to the health and sustenance of hundreds of thousands of people. These groups are the easiest to establish but the hardest to maintain. In South Africa, for example, there are more than 175 revenue-generating self-help projects, most associated with Disabled People South Africa. Most employ fewer than 30 people and yield little revenue. However, the projects generate a minimal level of food or income for their members, which often is the margin between life and death. The largest and best known is the Self Help Association of Paraplegics (SHAP) established in 1981 by a group of Soweto paraplegics (primarily spinal cord injured).

Probably the most important local advocacy groups are centers for independent living (CILs). The first CILs appeared in the United States in the early 1970s, and there was a large increase in the number of CILs in the 1980s and early 1990s in the United States (now more than 400) as well as Japan (now exceeding 100) and Europe (where there are dozens in Northern Europe and England). Activists in Brazil set up Latin America's first CIL in Rio de Janeiro (Centro de Vida Independente). Later, in the late 1990s, CILs spread to a number of cities throughout Latin America. Efforts to establish CILs in Africa and Asia have been sporadic and less successful.

National and Regional Advocacy Organizations

National and regional advocacy organizations have local chapters throughout or across countries, and their membership participates in advocacy and program activities as well as in organizational business.

Most of the national advocacy groups are quite democratic, although there is a strong tendency to follow the same leadership over extended periods of time. Most countries have such organizations, although examples offer divergent pictures. For example, the constitution of the National Council of Disabled Persons Zimbabwe (NCDPZ) spells out the organization's mission: "[to] promote full integration into Zimbabwean society of all disabled persons and active participation by the disabled in the planning and decision-making processes that affect their own lives." The work of NCDPZ involves advocacy, grassroots organizing, services, and leadership development training. NCDPZ has been able to obtain funding from foundations located in Northern Europe. These foundations support specific programs or purchases, such as personal computers or agency vans. Another national organization is the BCOPD, the United Kingdom's national organization of disabled people. BCOPD was set up in 1981 by disabled people to promote their full equality and participation in UK society. By 2003, BCOPD included 126 groups run by disabled people in the UK. Between them, their member groups have a total membership of around 350,000 disabled people throughout England, Wales, and Scotland and is affiliated with Disabled Peoples' International.

An example of a regional organization is the Southern Africa Federation of the Disabled (SAFOD), which represents disability rights groups from a number of countries in southern Africa including Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe. The aims of SAFOD are to provide a forum for disability rights activists to meet, share common concerns, and coordinate regional projects. SAFOD has a secretariat in Bulawayo, Zimbabwe, with a small staff headed by a secretary general. SAFOD is a member organization of Disabled Peoples' International. SAFOD is governed by an executive committee, elected at each biannual general assembly and drawn from the national organizations. It also widely circulates its newsletter, *Disability Frontline*. The creation of SAFOD eventually led to the founding of the Pan-African Federation of the Disabled for the entire continent more than a decade later.

International Advocacy Efforts

There are a growing number of disability rights organizations that do international exchange work. Some, such as Mobility International, based in Eugene, Oregon, provide opportunities for advocacy activists to visit other countries. These exchanges have been successful in spreading the experiences of independent living, peer counseling, self-help projects, and an awareness of the politics of disability across many cultures. Worldwide organizations such as Disabled Peoples' International and the World Institute on Disability (WID) focus on international advocacy, networking, public policy, research, and training. WID has developed educational and leadership training programs throughout the world from Latin America to the former Soviet Republics. Many of WID's staff have spent considerable time outside the United States promoting disability rights. WID has convened international forums and foreign exchanges on personal assistance, leadership training, and disability rights philosophy. Other important international organizations in Europe include the Institute on Independent Living in Stockholm and Disability Awareness in Action based in London, which has established contacts in 158 countries, most of which are in underdeveloped countries and whose newsletter, *Disability Tribune*, reaches readers throughout the world. There has been a great deal written about Disabled Peoples' International, the most important of these organizations.

FUTURE DIRECTIONS IN ADVOCACY AND COMMUNITY ORGANIZATION

The disability rights movement has always situated self-control and community control at the center of its agenda. The history of the movement has been the growing consciousness and activism of greater numbers of people with disabilities. For the first time in history, millions of people with disabilities have seen or heard about other people with disabilities who are struggling for a better life. This is a beacon of hope for many. The practice of empowerment means and has meant creating, increasing, and improving the options available to people with disabilities in their everyday lives.

There is an abundance of challenges and a scarcity of choices. The dilemma most people with disabilities throughout the world face is how to use their meager resources to attend to this condition. So the most obvious challenge is the most elementary: how people with disabilities secure the basic needs to survive. For the vast majority of the 375 million people with disabilities living in the third world, meeting basic needs can be a matter of life and death. For those of us living in the developed world, achieving a level of self-sufficiency goes directly to the question of quality of life. In the course of grappling with an array of complex and burdensome issues, the fundamental challenge is how the movement develops politically. What kind of analysis and political program will its leaders and activists bring to their struggle? What is the strategic goal of the disability rights movement? Is it strictly human rights, or is it liberation and freedom? There are many questions with many answers. The answers will strongly inform the future of disability advocacy and community organization.

—James Charlton

See also Advocacy; Disability in Contemporary Africa; Disabled Peoples' International.

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ADVOCACY MOVEMENTS: FRANCE

The topic of French advocacy movements for the disabled is explored in this entry from two perspectives: first, the chronology and history of movements that have emerged from the disabled world and, second, the political and social situation of these movements. The phrase "disabled world" is justified by the fact that in recent times the representation of disabled persons and the effort to enhance their visibility in society were, with some few exceptions, more the work of parents and support circles than of the people who were directly concerned. *Movements* is an intentionally broad term even though most of the initiatives that have been and are being taken fall within the framework created by the French law of 1901 concerning associations.

Three historical waves can be identified. The earliest goes back in part to the first appearance of large numbers of work-related accidents in the nineteenth century and stimulated the creation in 1921 of the National Federation of Injured Workers (the French acronym is FNAT) and also others such as the National Union of the Disabled and Injured Workers (UNIAT), focused essentially on the protection of rights. Another contributing factor was the wounded veterans of World War I (1914–1918). These veterans founded dozens of organizations with a generally similar mission, for example, the National Union of the War-Wounded and Rehabilitated, but were also committed to the defense of very specific categories of the injured such as those with lung trauma, those with head injuries requiring surgery, and wounded agricultural workers.

These two great losses of life, marginalizing the economic activity of thousands of people, caused disability to be transformed from purely natural status to a form of socialization, in which society was seen as the agent that produced this multitude of injured persons. As a consequence, there emerged the idea that relief from, and compensation for, these prejudices was a collective responsibility, requiring a solidarity organized through the medium of social security. This right to compensation and the desire to recover a place in community life would form the basis for the claims of FNAT, of the *gueules casées* (a nickname that referred to severe facial injury), and with a similar thrust, of tuberculosis patients, who considered themselves the victims of a blight that was social in nature and not simply a health issue.

Numerous groups of disabled people, or the "diminished" as they called themselves at the time, were created, although in quantitative terms relatively small numbers of people were involved. Along with FNAT and federations and unions for war veterans, there appeared Auxilia (1924), dedicated to the retraining of the hospitalized disabled; Ladapt, or League for the Rehabilitation for Work of the Physically Disabled (1929), whose name spells out its program; and Clair-Vivre, a residential village for the rehabilitation of tuberculosis patients (1924), soon followed in the mid-1930s by the Association of the Paralyzed of France (APF) and the Marine Cross associations (which would become the Marine Cross Federation for Assistance in Mental Health in 1952).

This is not an exhaustive list. To be emphasized is the degree to which these movements and organizations were principally concerned with physical disability, except for the Marine Crosses. These movements were more the achievement of those affected than would be the case in the period that followed. It should also be noted that institutions that went back to the French Revolution and were not the creations of disabled people themselves continued their work, but they were fundamentally concerned with children and therefore addressed chiefly disabled children with prominent distinguishing features such as blindness, deafness, or mental retardation.

The second wave dates from the period after World War II. The great majority of the initiatives were the work of families and addressed the mentally disabled or "handicapped" as they were then known, or at least disabilities that caused difficulties or slow progress at school. In the face of the inertia of the public school system and the scarcity of appropriate institutions, parent groups formed, initially less to constitute a lobby than to create schools and training facilities, supplemented, as required, by lifelong vocational support structures. The families became the administrators. This is the case with the White Butterflies, regional or local associations that in 1960 joined to form the national Union of Associations of Parents of Maladjusted Children (UNAPEI).

Between 1950 and 1970, initiatives multiplied and it would be fruitless to attempt an enumeration. An exemplary case is the APAJH, initially created as the Association for Assistance and Vocational Placement for Disabled Adolescents (AAPAJH, 1962), then renamed Association for Vocational Placement and Assistance for Disabled Youth (APAJH, 1963), and last, Association for Disabled Adults and Youth (APAJH, 1981). This evolution illustrates that the connection between disabled adults and youngsters is a recent development. It also shows that two years after UNAPEI (1962), the French term *inadapté* (maladjusted) was dropped in favor of *handicapé* (handicapped or, more currently in English, disabled). The FNAT would become the FNATH and, last, the associations would become increasingly polyvalent and ambitious, tending to take the form of large national entities, powerful in the face of the authorities, rich in endowments and staff numbers.

This was also the path followed by associations that were formed between the wars (Ladapt, APF). Today, a group called the Committee of Understanding encompasses upwards of 50 national associations, and it is politics that effectively determines the dozen or so that are counted as heavyweights, such as those named above. In the course of this period, roughly the 30 years after World War II—three glorious decades for France because of economic expansion, full employment, implementation of far-reaching social policies, and the importance of the government's economic advisory committee—the overwhelming majority of associations wished (UNAPEI) or were obliged (APAJH) to manage their own operations. There were some exceptions such as the National Federation of the Ill, Disabled and Paralyzed (FNMIP, 1945), which engaged in the protection of rights, training, and advocacy but administered no facilities or services of its own.

In chronological terms, we may speak of a third wave of newly established movements or organizations concerned with disabled people. Here it is not so much a flood of new creations as a gradual emergence in the sense that antiestablishment groups coalesced, opposed both to existing institutional and legislative arrangements, and to earlier associations. These groups in general count fewer members in comparison with the others, adopt theoretical stands, and are inspired by movements already under way outside France. This rather heterogeneous assembly ranges from highly politicized movements such as the "mean crips" (*handicaps méchants*) of the mid-1970s to associations of disabled researchers (GIHP), which would eventually become an association of services, in particular as concerns adaptive transportation for the disabled. In the central range of the spectrum is the move toward emancipation from specialized institutions, such as Living Upright (*Vivre Debout*), which would lead to the creation of the association's first group living facility in 1977, and the initial establishment in France of Disabled Peoples' International (DPI).

From this hasty overview, reference may be made to the typology proposed by Catherine Barral (1998):

> The French association landscape has taken shape around three broad tendencies: associations that administer specialized facilities dominate the picture in terms of number, reputation, and representativity; a second group is made up of associations of the trade union kind, such as FNATH . . . ; the third type is represented by user-advocate associations on the model of consumer rights movements.

But to this typology, which readily permits each of the groups of associations to be situated in social and political terms, should be added an analysis that identifies the relationship between this nebula of associations and the authorities. In the case of every association that administers any kind of service or facility, financing comes in very large part from public funds or at least nonprivate sources. In fact, there is a near equilibrium today between state funding and, increasingly, funding by regional collectivities and funding from social security agencies. Self-generated funding or independent revenues are of only marginal importance. These associations thereby assume a public mission, what in France is called "subsidiarity": What is normally considered a responsibility of the state is delegated by it to private organizations.

This situation has very specific features in France. What is less specific is the degree to which the authorities respect but also restrain these agencies: They are partners; they cannot oppose the establishment, or can do so only to a limited degree. One example will suffice, the drafting of new legislation to replace that of 1975, in which associations that ran their own operations played the primary role, silencing the voices of those that refused any special legislation. In the reform of 2004, there was a moment when the government's approach to disability satisfied no one. The associations gathered under the heading Committee of Understanding could have required the lawmakers to rewrite the legislation completely but they preferred, as in the past, to settle for amendments.

But it would be wrong to give the impression that the organizations administering their own operations were incapable of evolution and innovation. They have developed a number of alternatives to the single route of specialized establishments. They do, however, remain hegemonistic when confronted with movements and associations that seek to position themselves differently, preferring to play on the generalized principle of nondiscrimination and a strengthened desire for democratic recognition.

In conclusion, all French organizations are today confronted by what comes from beyond, in particular European developments and recommendations that will become more constraining as Europe refashions itself into a tighter union. The European constitution, if adopted, will further this process.

—*Henri-Jacques Stiker*

See also Advocacy; Disability Law: Europe.

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▣ ADVOCACY MOVEMENTS: GERMANY

The German disabled people's disability rights movement began at the end of the 1970s in West Germany. Disabled people in East Germany (then German Democratic Republic) had to wait until the reunification of Germany in 1989 before they could be actively involved. After the catastrophe of national socialism and the horrible experiences of compulsory sterilization and euthanasia earlier in the twentieth century, followed by decades of silence about these atrocities and also decades of being put away in institutions and homes, German people with disabilities started to set up their own groups. The time seemed to be ripe: Disabled people profited from the political, societal, and cultural changes that had been initiated by student revolutions at the end of the 1960s. Ever since, Germany has been gradually turning into a more liberal, pluralistic, and individualistic society. "Self help" was the key concept of these and the following years.

Undoubtedly, when the disability rights movement started, disabled people in Germany could look back on a long tradition of self-help organization, which can be traced back to the beginning of the twentieth century. Blind and deaf people as well as war victims of World War I (1914–1918) were among the first who had their own interest groups. An early self-help organization of the physically disabled was founded by Otto Perl (1882–1951) in 1919. After World War II (1939–1945), organizations of war victims grew even bigger and were quite successful in political lobbying. Since the end of the 1950s, parents of disabled children began to build up their own disability-related organizations and services. The Bundesvereinigung Lebenshilfe (Confederation Help to Life) for mentally disabled children, founded in 1958 in Marburg, is one prominent example of a parent group.

Despite these activities, until the late 1970s a cross-disability rights movement did not exist in Germany. But the end of that decade saw the emergence of something new: So-called cripples' groups sprang up in several places. Their members came together solely because of their disabilities, but their specific impairments did not matter. Principally, the meetings were open for all people who defined themselves as being disabled. In contrast to the already existing organizations, the new groups excluded nondisabled people from their ranks. These new groups founded the "Krüppelzeitung" ("cripples' newsletter") and adopted a radical position: the "cripples' standpoint," which had been formulated by Franz Christoph (1953–1996), a major activist of the new movement. This philosophy was directed against professionals and experts, who took charge of and oppressed disabled people, and against do-gooders and what was viewed as their denigrating compassion. The new disability standpoint was full of angry protest against the ideologies of partnership and integration propagated by the traditional disability organizations. Instead, the new disability rights movement followed the example set by the women's liberation movement and women's consciousness-raising groups. Its aim was to accept and value disability as a specific form of life. Radical changes in living conditions were demanded as political rights and not as charity.

After that first phase in which angry young men and women with disabilities protested, for example, against the charity approach officially adopted in Germany for the 1981 International Year of Disabled Persons, a more pragmatic period followed. During the 1980s, German activists in the disability rights movement were busy organizing peer counseling services, giving each other legal advice and psychosocial support, protesting against inadequate public transport, and political lobbying. They built up their own infrastructure, consisting of counseling and advocacy facilities as well as job creation programs all over the country.

Gradually, the "cripples' movement" turned into the independent living movement in which the principle of self-representation continued to play an important role. The magazine *die randschau* (*from the margin*) became the new mouthpiece. Inspired by the American philosophy of independent living, German disabled people started their own independent living centers. Consequently, personal assistance became an important issue. In 1990, the nationwide umbrella organization Interessenvertretung Selbstbestimmt Leben (Independent Living Interest Group) was founded. A further field of intensive campaigning were bioethics and the effects of genetic engineering and reproductive technologies on the lives of disabled people. Female activists especially were involved in this issue. Disabled women also managed to build up their own feminist networks, and they gained a self-confident voice within the movement. Furthermore, the 1990s saw people with learning difficulties starting their own networks. A new phase began when the issue of equal rights and opportunities was put on the agenda.

Since the beginnings of the 1990s, the legal approach has dominated and both old and new disability organizations have started to work more closely together instead of competing against each other. In 1994, the disability rights movement was successful in using for its own aims the reform of the German constitution, which had been made necessary by the reunification of Germany. Since that year, an amendment to the constitution forbids discrimination on the ground of disability. Other laws, such as the Rehabilitation and Participation Law (2001) and the Federal Equal Rights Law (2002), have been formulated with the active contribution of disability rights activists. In 2003, the official German program of the European Year of People with Disabilities was organized by a prominent activist of the disability rights movement, and a summer school on critical disability studies took place. It seems as if disabled people finally have taken their place in German society, but at the same time discrimination continues and new issues arise on the disability agenda requiring new approaches and policies.

—Anne Waldschmidt

See also Advocacy; Franz Christoph; *Cripple*; Independent Living.

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AESOP

(Seventh- or sixth-century BCE; possibly legendary) Greek fabulist

Although the fables attributed to Aesop, such as "The Ant and the Grasshopper" and "The Tortoise and the Hare," are as well known as any of Hans Christian Andersen's tales, little is known of this early poet or even whether he existed. Aesop was connected with the Greek island of Samos in some way, either by birth or later residence. The sources for Aesop's life are very late, written many centuries later, thus unreliable. One tale tells us that he was born mute but granted not only speech but also eloquence by the goddess Isis. Another dubious piece of information—dubious because it was recorded so many centuries later—is that Aesop was lame or hunchbacked. Robert Garland, in *The Eye of the Beholder* (1995:11), tenuously identified as Aesop a disfigured man in conversation with a fox on a charming red-figure drinking cup from the classical Greek period.

—M. Lynn Rose

See also Folk Belief.

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AESTHETIC SURGERY

From the close of the nineteenth century to the present, aesthetic surgery has come to be ever more widely practiced. It has also become the focus of ongoing criticism of what limits society and the individual can or should set, with respect to control over our own bodies and the bodies of others. These debates are often undertaken in complete ignorance of the history of aesthetic surgery, which is seen as being an American (read: Hollywood), patriarchal form of the oppression that women were (and are) subject to. The reality is that aesthetic surgery is a classic product of the modern world, with all of its advantages and disadvantages, including our claim to control our bodies. It is the test case for all of the claims about human autonomy that the Enlightenment defined as "modernity."

The technology of aesthetic surgery, in its modern form, arose out of the anxiety about the visibility of the diseased and damaged body that forms its common history with reconstructive surgery. Wounds of war, lesions of diseases from syphilis to smallpox, and congenital malformations all formed the background to the beginning of aesthetic surgery at the close of the nineteenth century. The Berlin surgeon Johann Friedrich Dieffenbach (1792–1847), a central figure in nineteenth-century facial surgery, wrote in 1834 that

> a man without a nose arouses horror and loathing and people are apt to regard the deformity as a just punishment for his sins. This division of diseases, or even more their consequences, into blameworthy and blameless is strange. . . . As if all people with noses were always guiltless! No one ever asks whether the nose was lost because a beam fell on it, or whether it was destroyed by scrofula or syphilis. (Dieffenbach 1829–1834: Vol. 3, p. 39)

Disability was the product of the physical malformation and (equally important) the stigma associated with it. This the surgeon could remedy.

Here there was little question of the nature of the disability associated with the body. For early "reconstructive" surgeons, disability was defined as lack of function coupled with the stigma associated with perceived deformity. With the introduction of the technologies of anesthetics and antisepsis, the potential of a human being, through surgical intervention, to change his or her body became both imaginable and practicable. Yet the idea of a perceived difference from an implicit norm remains central to this new aesthetic surgery. From the first patients in the 1870s and 1880s to the millions (perhaps billions) having aesthetic surgery across the world today, the idea of surgical manipulation of the body has become commonplace. But at its center is the sense of our desire (through the agency of medicine) to give us the bodies that we want rather than those that we have in order to combat the stigma we associate with those aspects of our bodies that we wish to change.

Given the predilections of our desire to control our bodies, the history of aesthetic surgery can be rather neatly divided into the world before the end of the nineteenth century and the world afterwards. It is between 1870 and 1900 that virtually all of the present procedures for the aesthetic alternation of the body are introduced. They build, of course, on earlier developments in surgery. The initial patients, with few exceptions, were men, a fact seemingly lost in the history of aesthetic surgery. But why was there an explosion of both patient interest and surgical innovation at that specific time? Such surgery prior to the nineteenth century, before the introduction of antisepsis (no infection) and anesthesia (no pain), was undertaken only when it was truly a functional necessity. Aesthetic surgery demanded something in addition.

Anesthesia became generally accepted and central to the practice of surgery after the discovery of ether anesthesia by William Thomas Green Morton (1819–1868) in 1846. The further development by the 1880s of local anesthesia, in the form of cocaine for surgery of the eye as well as spinal (subarachnoid) anesthesia and epidural anesthesia, meant that the greater risk of dying under general anesthesia could be avoided. Local anesthesia has played a central part in the development of aesthetic surgery as a widely practiced specialty. It is one of the primary factors in the successful outcome of the patient, who can follow the procedure and, unlike the patient under general anesthesia, does not morbidly fantasize about the opening of the body while unconscious. Under local anesthesia, aesthetic surgery can be experienced as a procedure a patient actively chooses, not a cure to which he or she passively submits under general anesthesia, giving up all control of the self. The patient's perception of autonomy is central to the popularity of aesthetic surgery.

The movement toward antisepsis paralleled the development of anesthesia. In 1867, Joseph Lister (1827–1912) provided a model for antisepsis, which became generally accepted by the end of the century. The potential avoidance of infection meant that patients' anxiety about cutting the skin was lessened. The acceptance of antisepsis for all surgery was relatively slow but was strongly encouraged by aesthetic surgeons. On November 26, 1877, Robert F. Weir (1838–1894), one of the major figures in the creation of American aesthetic surgery, said in a talk before the New York Medical Association that the British and German acceptance of this procedure had outpaced that of the United States. He urged that the smallest detail of the cleansing of patient, surgeon, instruments, and surgical theater be carried out so as not to place the patient at needless risk. Once this was done, the risks attendant on aesthetic surgery decreased sharply because of the reduction in the high incidence of infection.

With pain and infection removed or reduced, aesthetic surgery came into its own. Yet anesthesia and antisepsis were necessary but not sufficient to mark the beginning of the modern history of aesthetic surgery. It was the Enlightenment ideology that each individual could remake himself or herself in the pursuit of happiness that provided the basis for the modern culture of aesthetic surgery. Indeed it is remarkable how often aesthetic surgeons describe "happiness" as the goal of the surgery. "Happiness" for aesthetic surgeons is a utilitarian notion of happiness, such as that espoused by John Stuart Mill (1806–1873), who placed the idea of happiness within the definition of individual autonomy. You can make yourself happy by being able to actively participate in the world. This was mirrored in the rise of modern notions of the citizen as well as the revolutionary potential of the individual.

Autonomy stands as the central principle in the shaping of aesthetic surgery. "'Dare to use your own reason,'" wrote Immanuel Kant (1724–1804), "is the motto of the Enlightenment" (1963:3). And it is the ability to remake one's self that is the heart of the matter. Aesthetic surgery is therefore a truly modern phenomenon that demanded not only a set of specific technical innovations in surgery but also a cultural presupposition that you have the inalienable right to alter, reshape, control, augment, or diminish your body (with, of course, the help of the surgeon). The autonomy that aesthetic surgery represents is truly a modern one: You can act as you desire to become happy, but only with the aid of and comfort provided by the technocrats whose expertise you can employ.

In the course of the nineteenth century and the movement from a functional to a transformative model of aesthetic surgery, the stigma of race had its impact. Some male Jews in Germany wished to vanish into the nonracial world of unracialized men. And in Berlin in the 1890s, there was Jacques Joseph (1865–1934). Joseph had been a highly acculturated young German Jewish surgeon practicing in fin-de-siècle Berlin**.** Born Jakob Joseph, he had altered his too-Jewish name when he studied medicine in Berlin and Leipzig. Joseph was a typical acculturated Jew of the period. He developed the first procedure of reducing the size and shape of the "Jewish" nose at the moment when political anti-Semitism first became a potent force in Germany.

In January 1898, a 28-year-old man came to him, having heard of a successful operation on a child's ears. He complained that

> his nose was the source of considerable annoyance. Wherever he went, everybody stared at him; often, he was the target of remarks or ridiculing gestures. On account of this he became melancholic, withdrew almost completely from social life, and had the earnest desire to be relieved of this deformity. (Joseph 1898 in Aufricht 1970:178)

The psychological symptoms were analogous to those of the young boy whose ears Joseph had repaired.

Joseph took the young man's case and proceeded to perform his first reduction rhinoplasty, cutting through the skin of the nose to reduce its size and alter its shape by chipping away the bone and removing the cartilage. On May 11, 1898, he reported on this operation before the Berlin Medical Society. In that report, Joseph provided a detailed "scientific" rationale for performing a medical procedure on an otherwise completely healthy individual:

> The psychological effect of the operation is of utmost importance. The depressed attitude of the patient subsided completely. He is happy to move around unnoticed. His happiness in life has increased, his wife was glad to report; the patient who formerly avoided social contact now wishes to attend and give parties. In other words, he is happy over the results. (Joseph 1898 in Aufricht 1970:178)

The patient no longer felt himself marked by the form of his nose. He was cured of the "disease" of "nostrility." In his own eyes, he looked less different from the group he desired to join—the non-Jews. Joseph had undertaken a surgical procedure that had cured his patient's psychological disorder. Yet he had left scars, which pointed to the procedure itself, and this became a major concern of Joseph's. He warned his colleagues that "disclosure to the patient on the problem of scarring is very important. Many patients, however, will consider even simple scars too conspicuous." He raised the specter of a court case in which the "unsightly scar might represent a greater degree of disfigurement than the enlarged cartilage of the nose presented previously." More centrally though, surgical scars, unlike scars obtained through socially acceptable and manly activities such as dueling, reveal the inauthencity of the body and the effort to "pass" via medical intervention.

The general claim that the surgery creates some form of happiness remains central to aesthetic surgery. In the nineteenth century, surgeons claimed that they were altering the body to change the psyche. In 1887, John Orlando Roe in Rochester, New York, developed a procedure to alter the shape of the "pug nose." Roe did not only claim to cure the pug nose, he claimed to be also curing his patient's unhappiness. His comprehension of the relationship between mind and body was clear:

> We are able to relieve patients of a condition which would remain a lifelong mark of disfigurement, constantly observed, forming a never ceasing source of embarrassment and mental distress to themselves, amounting, in many cases, to a positive torture, as well as often causing them to be objects of greater or lesser aversion to others. . . . The effect upon the mind of such physical defects is readily seen reflected in the face, which invariably conforms to the mental attitude, and leads after a time to a permanent distortion of the countenance. (quoted in McDowell 1977:114)

The surgeon in curing the deformity makes the patient happy, which in turn alters the physiognomy of sadness.

At the beginning of the twenty-first century, we have a resurgence in the idea that men (too) desire to shape their bodes through surgery to provide them with new, younger bodies. It is not actually much of a change. The bodybuilding culture for men that stressed the muscular, shaped body arose in the 1890s at the same time as the origin of modern aesthetic surgical procedures. Shaping or cutting can reform the male body by the desire of the individual in concert with the professional (either bodybuilder or surgeon).

Today, we have come not much further in the popular understanding of aesthetic surgery. Columnist Anne Duggan in Australia wrote in 2002:

> What man or woman is ever truly happy with every part of their face or body? Even if you are quite comfortable with your appearance, you probably think there is room for improvement. Cosmetic surgery can be a great adjunct to your health and fitness regime, improving those areas that diet and exercise won't. According to cosmetic surgery specialists, having a nip or a tuck is catching on in Australia, as the procedures become more acceptable and accessible for all Australians. Whether you'd like a smaller nose, fewer

> wrinkles or bigger breasts, there is a cosmetic surgery procedure that can help. (p. A7)

Can we truly become happy? And what does that happiness come to mean for us when we achieve it through surgery? Is happiness an appropriate goal for life or does it demand too much?

—Sander L. Gilman

See also Body, Theories of; Deformity; Identity.

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AESTHETICS

Disability aesthetics is a critical approach to thinking and making of art through a disability perspective. It is an approach that revises and resists the ways in which mainstream society has marginalized the disabled person as well as disability art. In part, this work has centered on the efforts of arts scholars to critique traditional notions of aesthetics that emphasize an ideal body and simultaneously discount, minimize, or erase disability. Cultural assumptions about disability inform many artistic artifacts and performance, and the analysis of these assumptions helps us to understand how disability has been historically and socially construed as well as how these parameters on disability limit the possibilities for new artistic practices. Consequently, a disability perspective foregrounds the value and power of human variegation, and it challenges the ways in which disability has typically been viewed as a deficit.

It is important to grapple with how art reinscribes and helps maintain traditional societal frames for disability, work that has been undertaken by such scholars as Lennard Davis, David Mitchell and Sharon Snyder, and Rosemarie Garland Thomson. This work helps us understand how disability and its figures have worked as the hidden partners in supporting what are deemed important cultural messages that are disseminated through art. Davis's work on the deafened moment looks at "deafness as a critical modality"—more specifically at the sites and ways in which the emphasis on hearing and sound falls out and there is a reliance on nonverbal signs. There are, as he demonstrates, cultural and artistic practices that emphasize moments of deafness without fully acknowledging the ways in which the practice rests on deafness itself. Mitchell and Snyder show the ways in which disability is used as a narrative prosthesis in literature, how images of disability act to jumpstart engagement with the text through a problem or crisis. It sets in motion the storyline, but by the end of the narrative, the disability most often gives way to some triumph of the able-bodiedness or the normal. Thomson has addressed how freak shows, photographs of the disabled, and other cultural evidence rely on the audience response of staring and thus communicate a set of coded messages about disability and its place in society.

The representation of disability is, of course, not new. Historically, a number of performing artists, as a result of their investment in challenging traditional modes of representation, have incorporated the presence of the disabled in their works. These numerous approaches include disabled characters in plays, sensory frames of reference from a position of "as if" disabled (such as Robert Wilson's early work, *Deafman Glance,* with African American deaf-mute Raymond Andrews), the use of sign language in modern dance works, or an entire aesthetic of modernity based on what could be called a disability perspective, such as the work of Antonin Artaud. In fact modernist (as well as postmodernist) aesthetics has often drawn on the seemingly unstable and often unclassifiable bodies of the disabled to bring new life to art practices. While a number of these examples open up new aesthetic frames, they also have worked to reinscribe the abnormal phenomena back within the regime of normalcy.

All too often the disabled person has fallen out of the picture. This maneuver reflects the larger sociocultural malaise toward dealing with disability—of disappearing or marginalizing the disabled—as well as the ways in which art claims to rest on the position of the ideal body. The disabled person, in these cases, does not play the disabled character. Robert Wilson, for instance, continues his work with its complex visual textures and "deafened" tones without his counterpart, and we still go to see modern dance that uses sign language but does not include deaf dancers.

More recently, disability aesthetics has also begun to account for how disability itself produces art, what those art practices are, and how those endeavors lead to a new aesthetics—revising what we have typically and traditionally considered aesthetics with its emphasis on the beautiful. This account can help us understand how the incidents of the anomalous body in a vast amount of art history are not simply always an effort to discount the lives of the disabled and the ways in which the unusual reinvigorates artistic practice. But, even more significantly, disability art today bypasses traditional modes of representation and demands new practices of engagement.

Artistic practice relies on the manipulation of sensory frames of reference, and these sensory amalgamations carry with them emotional and conceptual implications. Consequently, disability aesthetics as practice provides a rich frame for articulating different ways of existing as persons in the world.

The disabled are privy to all sorts of sensory experience not accessible to the able-bodied. Disability art is one way of providing access to this unfamiliar territory and of creating space for the emergence of new concepts and experiences of artistic creation. This pattern not only challenges traditional representations of the body, but it also unsettles conventional ways of knowing and communicating. And the increasing number of arts organizations, dance companies, and performance companies that generate work giving direct voice to the disabled gives witness to the growing interest in disability arts.

There are a number of challenges regarding the disability perspective. Feminist disability theorist Thomson (1997b) noted: "Disability, perhaps more than other forms of alterity, demands a reckoning with the messiness of bodily variegation, with literal individuation run amok. . . . [D]isability foregrounds embodiment's specificity" (p. 283). The question of "embodiment's specificity" finds particular cogency in disability arts with its emphasis on corporeal particularity and the unpredictable and unfamiliar. In performances of various sorts, disability invites the audience to engage with art and performance in new ways as they provide us with what Petra Kuppers, following dance choreographer Deborah Hay, calls "perceptual challenges." Examples include, but are not limited to, the inclusion of dancers in wheelchairs (AXIS and Infinity USA, CandoCo Britain), dancers with cerebral palsy and cognitive differences in Restless Dance (Australia), performers with sensory and physical impairments in Graeae Theater (Britain), deaf dancers in Common Ground Sign Dancer Theater (Britain), or the recent inclusion of deaf dancers in Nancy Hauser's Company (United States), as well as a choreographer and dancer who has dystonia, Neil Marcus (United States). This variety not only changes the look of what's staged but also the feel, as these perceptual challenges often create an emergent space of experience and understanding. Consequently, we engage with disability as difference rather than deficit as it bypasses the usual representational circuitry.

Contact improvisation, a dance form where the participants rely on the exchange of energies between a variety of physical contact points and shifts in body weight both individually and shared, has a well-developed history in including disabled performers. Part of the reason for this occurrence is that the form itself does not rely on the typical cultural expectations of upright physicality and presentational qualities; it relies on the feel of the dancing rather than its look.

This radical, liminal space unsettles expected transactions between performer and audience, and it creates an arena of instability. In this arena, previous assumptions and significations become unmoored; new possibilities emerge. Confronted with the material world of disabled performers, the present and palpable bodies of physical difference the audience also faces its own phantasms of disability—questions of illness or weakness, physical appearance, or suffering that are often dismissed or rejected by society at large. This body is unpredictable, unstable. Unleashing ourselves from the proclivity of bracketing the anomalous body helps to generate space not only of visibility for the disabled but also a space for grappling with the inherent hybridity of our physicality—its concomitant sensory and emotional variety.

In the National Theatre of the Deaf, for example, the deaf performers use sign language, which is a visual-kinetic mode of language and often referred to as "silent poetry," but voicing actors also interpret their performances. This work challenges the traditional limits of language, poetry, and the use of voice; deaf individuals speak visually and kinesthetically in ways that the hearing population is not accustomed to hearing. The location of deaf poetry—and by implication deaf poetry as it occurs in theatrical performance—within the larger discussion of the ways we have moved from a textually based model of communication to a performance-based model of communication indicates an emphasis on a visual-spatial field rather than that of sound. Consequently, the use of American Sign Language (ASL) in performance is a valuable site for grappling with an aesthetic that valorizes the position of deafness.

It is important, furthermore, to note that several well-known ASL poets, such as Clayton Valli and Ella Mae Lentz, have chosen not to have their work sound-interpreted as a matter of a political statement to the hearing community. This work invites a consideration of how "think-hearing" is what Michael Davidson has called "a subject of aesthetic critique while utilizing ASL as a powerful discourse to phonocentric models for literature." Davidson has addressed the ways in which the work of Flying Circus, with deaf performer Peter Cook and hearing performer Kenny Lerner, use speech as well as vocalization in their performances to challenge and revise the ways in which the use of speech tends to signal specific meanings for the hearing. Davidson also critiques the work of Deaf performance artist Aaron Williamson and the ways in which he uses the visual channels to render the in-between status and states of a late-deafened adult—the ways in which meaning slides between image, object, body, and voice. For Williamson, Davidson concluded that he critiques the organizing cultural metaphor for meaning as the ear rather than the voice. Work of this sort serves to locate disability artists within the nexus of a broad range of concerns that provides a powerful critique of how the construct of disability operates across a range of questions about human experience.

Street performer Bill Shannon, aka "Crutchmaster," with strong ties to both the hip-hop dance scene and the disability arts scene, has developed an entire dance aesthetic out of his need to use crutches to move around. In his street improvisations, Shannon uses both his crutches and a skateboard to maneuver in and around people passing by on the streets. This approach plays off of and with people's discomfort and confusion about how to deal with someone moving through public space in unfamiliar ways. Consequently, Shannon's prowess in moving invites spectators to revise their expectations about how disabled individuals can navigate public spaces. It also inserts the generation of a new movement aesthetic into the experience of everyday life.

In addition to innovative engagement with how mainstream notions of aesthetics can be changed through the development of new practices for staging the moving body and various sensory frames, the use of storytelling has also helped to further disability aesthetics by investigating new ways to look at narrative. For example, Anne Basting's TimeSlips (U.S. based) is an interactive project on storytelling for Alzheimer's patients. Bastings has developed a process for doing storytelling circles with these patients that centers on telling a story in the present through the impetus of a visual stimulus. The stories that emerge out of these workshops emphasize the power of image rather than the linearity of traditional storytelling. This work has led to the development of an interactive component on the TimeSlips website, installation work, and a TimeSlips play, as well as growing interest in the creative possibilities of dementia.

There are a number of other groups that have used storytelling in innovative ways. Artistic director Ruth Collett's project Stalking Histories (Britain based) explores lost stories from the disability culture, in relationship to such events as the Holocaust in Germany or the impact of Mendel (1822–1884; a botanist and monk who developed the study of genetics) and integrates the use of new technologies and nontraditional sites for the sharing of the stories. As they continue to explore the implications of new technology for disability performance and storytelling, they are making progressive use of their website as a gallery space for the sharing of stories.

Other disability artists exploring how the new technologies make the production and access to artwork more available for disabled artists include Bilderwerfer's (Austria) web-based collaboration area and Petra Kuppers, director of Olimpias Performance Research Project. She explores the connections between story, mental health system survivors, disability arts, and the new media. The projects take a variety of forms: installations, film, and CD-ROM. Each of these examples develops an alternative venue to the traditional structures of the presentational stage, allowing a more mobile approach to be taken to the making and sharing of art. In addition, cultural expectations about looking at a performance are disrupted or challenged and the audience members must adopt a more participatory and nonlinear approach to experiencing the artwork.

These unfamiliar moments are not easy to analyze or to live through with complete lucidity, yet, as new spaces of exchange open up, new identities and geographies can unfold. Consequently, as we attend to the embodied traces of disabled identity in the mobile landscape of the everyday, performance provides a medium par excellence for mapping new identities. The fixities of personal and social identity, the traumas of history, and the obsessively repeated stories give way to the possibilities of other narratives, new viewpoints. The body shape-shifts, and as it responds to the creative charges and unexpected changes it is suddenly engaged in a new storyline, a different angle in the aesthetic trajectory brought on by the mobilizing of communal energies.

—Kanta Kochhar-Lindgren

See also Body, Theories of; Culture; Dance; Deaf Culture; Drama and Performance; National Theatre of the Deaf; Sign Poetry.

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World Institute on Disability, http://www.wid.org

AFFIRMATIVE ACTION

See Quota Hiring Policy

AFFIRMATIVE BUSINESSES

Affirmative businesses provide employment opportunities for people with disabilities. They operate as regular businesses, producing goods and services for sale within the broader community. Affirmative businesses have typically emerged from nonprofit organizations and have developed through a collaboration between people with disabilities, vocational rehabilitation professionals, and businesspeople. This collaboration is directed toward the creation of a business organization that is sensitive to the needs and aspirations of persons with disabilities, constructs a working environment that can meet diverse needs for training and job accommodations, and operates using sound business principles and practices. In this way, affirmative businesses are structured to neutralize the individualism and competition that disadvantage individuals with disabilities in the open labor market.

The exact nature of an affirmative business will depend on the interests and skills of the potential workforce and on the market prospects in the local community. Examples include businesses that have focused on industrial subcontracting, cafés and catering, desktop publishing and video production, car washes, greenhouses, laundry services, and retail convenience and gift outlets. Since they are designed as true businesses, they provide workers with either the opportunity for long-term employment or a place to develop their work capacities before they move on to other jobs in the open labor market.

The effectiveness of the affirmative business is measured by its commercial success. A primary objective is to reduce reliance on funding from government or philanthropic organizations. They are also expected to offer wages that are consistent with standards in the open labor market and opportunities for advancement. Effectiveness is also measured by the extent to which the working environment facilitates participation and ownership by individuals with disabilities.

The affirmative business approach to job development has been applied broadly to people who are disadvantaged with respect to employment. John Durand is widely credited for its application to persons with disabilities in the 1960s. The approach is one of many commercially oriented ventures that attempt to develop business practices that promote a socially responsible and sustainable economy.

Community integration in this employment approach is realized at the level of the business. Employees connect with the broader community in the day-to-day context of offering goods and services to the public, ordering supplies, and participating in local business networks. It is expected that the financial rewards and personal connections made in the context of work will facilitate opportunities for community participation outside of the business.

Critics of the approach have argued that this is segregated employment and is minimized as a credible business model in the open labor market. There are also concerns that these businesses typically provide only entry-level jobs with poor prospects for financial compensation and opportunities for advancement. Finally, it has been argued that the structure of the organization will favor employment of professionals from the human services sectors in key management positions, undermining full ownership by persons with disabilities.

—Terry Krupa

See also Consumer-Run Businesses; Employment; Sheltered Workshop.

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AFRICA

See Deaf People in African Histories;
Disability in Contemporary Africa;
Experience of Disability: Sub-Saharan Africa

AFRICANS, DEAF

See Deaf People in African Histories

AGASSIZ, (JEAN) LOUIS (RODOLPHE) (1807–1873)

American (Swiss-born) naturalist

The naturalist Louis Agassiz began his career working on fish fossils and studying under Georges Cuvier (1831). In 1847, he became a professor at Harvard University where he founded and directed the Museum of Comparative Zoology until his death in 1873. Furthering Cuvier's work on geological catastrophism and classification of animals, Agassiz developed the glacial theory of the Ice Age (1840) and a classification of biological life forms (1851–1855). Similar work on biological order led Charles Darwin and Ernst Haeckel to theories of evolution and natural selection. Agassiz rejected these theories and, instead, adhered to natural science as a combination of empirical methodology and natural theology. In 1847, he advocated polygenesis, basing his support on new geological evidence. Polygenesis, the theory that at least some races had separate origins, was also employed as a defense of Christianity and eventually as a social doctrine (1850). He advocated the permanence of different races and worried about the "tenacious influences of physical disability" if races were mixed (1863). While his teaching and early research brought unprecedented national and international recognition for the field of natural science, his antievolution position and support of polygenesis were controversial throughout his life and contributed to his marginalization in subsequent years.

—Jee Yoon Lee

See also Race and Ethnicity.

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AGING

Conceptions and definitions of *old age* and *disability* vary in different cultures. These include chronological age, functional limitations (activities of daily living and instrumental activities of daily living), social performance, or work capacity. One approach is to define aging as an ongoing process that includes age-related changes related to physiological processes occurring at certain stages in life (e.g., puberty and menopause) and age-related conditions that occur as individuals age (e.g., hypertension and coronary artery disease). Criticism of these definitions of aging and disability center on their failure to measure the impact of social, political, economic, and cultural factors on a person's ability to perform or engage in social roles. Common barriers to participating in social roles include architectural barriers and attitudinal barriers that can impede active community participation. The Americans with Disabilities Act of 1990 (ADA) acknowledges that people with impairments (even in the absence of any limitation) may face discrimination due to social forces, such as stigmatization, fears, or myths regarding disability. According to the ADA, a person with a disability is someone who meets at least one of the following criteria: (1) has a physical or mental impairment that substantially limits one or more major life activities, such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, or working; (2) has a history or record of such an impairment; or (3) is perceived by others as having such an impairment.

The onset of disability for most people occurs at older ages and the duration is short. These individuals experience disability with aging. Adults who acquire their disability in childhood, before the age of 20 (about 7–9 percent in the United States), experience aging with a disability. The terms *disability with aging* and *aging with a disability* have generated stereotypical views about aging and disability in that the onsets of disability is an issue for older persons and "aging" is an issue for younger adults with permanent disabilities.

GLOBAL AGING AND AGING IN THE UNITED STATES

Human longevity climbed in the twentieth century due to changes in public health policies (e.g., improved sanitation and food and water safety), advances in medical practice (e.g., antibiotics and insulin), and greater emphasis on health promotion and disease preventive. The older population of persons aged 60 years or older is growing faster than the total population in almost every region of the world.

Data from the United Nations Department of Economic and Social Affairs (2002) indicate that over the past 50 years, the number of older persons has tripled from 205 million persons in 1950 to 606 million in 2000 and is projected to triple again by 2050 to approximately 2 billion persons aged 60 or older. People who are 80 years or older are the fastest-growing group of older individuals; this cohort is projected to increase five-fold from 69 million in 2000 to 379 million in 2050.

In the United States, according to the U.S. Bureau of Census (2002), 35.1 million persons are over the age of 65 years (12.4 percent of the total population). Of these, 21 million are women and 14 million are men. The 2003 "American Community Survey (ACS) Data Profile" (U.S. Bureau of the Census 2003) reported that 20 million (12 percent) people 21–64 years old have a disability and 14 million (40 percent) persons age 65 and older have a disability. The likelihood of acquiring a disability increases as people live longer. Age-associated disabilities include impairments in mobility, hearing, vision, cognition, and loss of function due to medical conditions such as congestive heart failure, stroke, and chronic obstructive pulmonary disease. In the United States, the number of people aging with a disability also is increasing. Today, the population over age 60 years includes more than half the persons with disabilities in the United States.

LIFE EXPECTANCY

The average life expectancy in the United States for infant girls is now 79.7 years and 74.1 years for boys. While the life expectancy for persons with disabilities acquired early in life has increased significantly, in general, disabled people have a life expectancy that is 15 to 20 years less than the rest of the population. With advances in medical treatment and living conditions, life expectancy for some people with disabilities (e.g., people with developmental disabilities and spinal cord injury) has risen dramatically and is only slightly lower than that of the general population. Individuals with spinal cord injuries have the highest mortality rate in the first year after injury, and those who have greater neurological deficits tend to die earlier. For people with Down syndrome, cerebral palsy (particularly individuals with lower functional levels), and severe intellectual disabilities, life expectancy is significantly lower than for the general population. In addition, life expectancy for persons with intellectual and developmental disabilities is significantly lower than that of the general population in the presence of the following impairments: severe mobility impairment (requiring a wheelchair and assistance for propulsion), severe manual dexterity impairment (unable to feed and dress without assistance), and severe intellectual disability (IQ < 50).

VIEWS OF AGING AND DISABILITY

Perceptions of aging and disability in any era and culture are influenced by lifespan, economic conditions, social expectations, and images presented in contemporary media, arts, and literature. During the past several centuries in the United States, the religious and secular movements have transformed our views of aging and disability. In the seventeenth century, Puritans revered people who were aged and saw aging as a sacred pilgrimage to God. Similarly, reformers motivated by religious principles worked to help people with disabilities, as they helped children and heathens. During the Victorian age, youth became a symbol of growth and expansion, and people with disabilities, who were increasingly sent to live in mental asylums, state schools, and homes for the feebleminded, had little control over their lives. As the need to provide for a rapidly growing population increased, youthful energy, westward migration, and technological advances made the elderly seem out touch and their traditions seemed cumbersome and a hindrance to progress. In addition, medical advances during the twentieth century promised to eliminate much disability. Though this promise was overstated, people with disabilities were less visible in our communities as many people continued to be placed in institutions or special schools or kept out of sight at home.

In the past 20 years, portrayals of aging have shifted from viewing aged individuals as victims or those to be pitied, shunned, or ridiculed to seeing robust images of aging adults maintaining active lifestyles within their communities. Images of people with disabilities have also transformed from depicting them as broken people who need fixing to people who want the right to live, work, and engage in recreational activities within their communities. Increasingly, we are recognizing and confronting the negative assumptions and values our culture has held about old age and disability.

As more persons are living longer with a disability, whether the disability onset is earlier or later in life, the intersection of the fields of disability and gerontology is greater. Biological, sociological, and psychological theories seek to understand the determinants of mortality, morbidity, and well-being in later life. These determinants include individual biological and lifestyle issues as well as environmental aspects, including support services and the physical environment.

THEORIES OF AGING

Historical Perspectives

The concept of aging represents a phenomenon of populations and individuals. On a *population* level, aging represents the success of a society based on the outcome of human discoveries and developments in hygiene, nutrition, biomedical technology, and sociopsychological and political advancements. Aging also reflects societal challenges, given the costs required of social and health programs in modern societies. On an *individual* level, aging takes into account three main aspects: biomedical, psychological, and social well-being, though throughout the history of the study of aging, the biomedical discipline has predominated, compared with psychology or any of the other social sciences.

Theories related to the universal human phenomenon of aging have been debated since early philosopher-scientists. According to Ebersole, Hess, and Luggen (2004), Aristotle believed that aging was a period of disengagement and interiority, whereas Cicero and Montaigne saw aging as a period of self-discovery, pursuit of gentility, and complexity. Plato viewed aging as the development of wisdom and a metamorphosis of the soul. Leonardo da Vinci saw aging as a time of coping with the reality of physical decline, and Charcot viewed aging as a latency period of diseases that appeared only in old age. While Galen asserted that old age is not a "disease," Benjamin Rush stressed the importance of heredity and behavior on aging and Louis Cornaro believed that restricted diet and moderation were necessary for a long life. Alasdair Fothergill linked the effects of mind on body by recommending the benefits of positive attitudes on aging. Arnald of Villanova thought that moderation and humoral balance were critical to vitality.

Contemporary Theories on Aging

As scientists expanded their knowledge, improved their research methods, and discovered more about aging, they came to view aging as a complex and variable process. During the twentieth century, biologists, sociologists, and psychologists developed theories to explain the phenomenon of aging. These theories fall into several broad categories such as biological (encompassing measures of functional capacities of vital or life-limiting organ systems), sociological (involving the roles and age-graded behaviors of people in response to the society of which they are a part), and psychological (referring to the behavioral capacities of people to adapt to changing environmental demands).

Biological Theories

Although aging and disease are independent processes, aging clearly includes increased vulnerability to disease. Early medical theories focused on the relationship between disease and aging. More recent medical theory focuses on assessing and improving the functional health of aging individuals. Evolving theories addressing not only longevity but also active life expectancy and functional health explain the recent emphasis on health promotion interventions and provide goals for healthy aging.

All organ systems undergo a gradual decrease in reserve capacity, although at different rates. This rate depends on the genetic composition, such as the presence of genetic syndromes or disease-resistant genes, and on "wear and tear" brought on by a stressful lifestyle and environmental factors (e.g., smoking, poor diet, alcohol abuse, muscular strain). Diminished immunity increases susceptibility to chronic conditions such as cancer, infections, lupus, and rheumatoid arthritis. When little reserve capacity remains, the likelihood of developing a disease increases. People with disabilities may have less reserve capacity remaining. For example, a person who had polio is unlikely to reach the same peak pulmonary capacity as a nondisabled person. Persons who have been nonambulatory for many years are unlikely to reach the same peak bone density as other persons.

Sociological Theories

Early sociological theories of aging (in the 1960s) focused on the adjustment of older people to losses within the context of their roles in society. Examples of these theories are the disengagement and activity theories. In the 1970s, the perspective broadened to also examine the complex interrelationships between older persons and their physical, political, and socioeconomic environments.

The premise of the disengagement theory proposed by Cumming and Henry is that aging is a time of mutual withdrawal and gradual reduction of roles and responsibilities so that the older person could be replaced. This view depicted the older person as preoccupied with himself or herself and with decreasing emotional involvement with others. Criticism of this theory posits that such disengagement is neither natural nor inevitable and presents a one-sided view of older persons, as many persons remain active throughout old age.

Robert Havighurst's activity theory conceptualized aging in terms of the developmental tasks of later life. Using a lifespan perspective, he suggested that these developmental tasks include (1) coping with physical changes; (2) redirecting energy to new roles and activities such as grandparenting, retirement, and widowhood; (3) accepting one's own life; and (4) developing a point of view about death. The premise is that to maintain a positive sense of self, elderly persons must substitute new roles for those lost in old age.

Lawton proposed the concept of the person-environment fit that examines the interrelationship between personal competence and environment; for each level of competence, there is an optimal level of environmental demand (environmental press) that is most advantageous to a person's function. Those persons with a low level of competence can tolerate only a low-level press, and those with higher levels of competence can tolerate increased demands. This paradigm is useful in planning suitable interventions for older adults with disabilities who reside in private homes and institutional settings.

Psychological Theories

Psychological theories of aging address old age within the context of a person's life cycle, wherein one moves through stages in certain patterns. Successful aging occurs when people fulfill life tasks that they consider important despite reduced energy in later life.

Erik Erickson's original theory in the 1960s described the last life stages as ego integrity (vs. despair) followed by life review activities that result in wisdom. He believed that mastery in an earlier stage laid the groundwork for success in the next stage. In the 1980s, Paul Baltes distinguished between normal, pathological, and optimal-developmental enhancing and age-friendly environments. He viewed aging as (1) a lifelong process that influences and in turn is influenced by social processes and (2) that is perceived differently by each age cohort. Among individuals, latent reserve capacity is highly variable. Individual and social knowledge can help compensate for age-related decline in fluid intelligence. Aging is a lifelong process of selective optimization with compensation allowing people to age successfully and to engage in life tasks that are important to them.

Successful Aging

For years, gerontology promulgated the "decline and loss" paradigm: that aging encompasses a series of decrements or losses in the individual to which elders and society needed to adapt. Rowe and Kahn's notion of *successful aging* used the concept of physiological reserve to make a distinction between "usual" aging and "successful" aging. People who age *successfully* have a great amount of physiological reserve. Successful aging outcomes include (1) low probability of disease and disease-related disability, (2) high cognitive and physical functioning, and (3) active engagement with life through involvement in close relationships and in meaningful activities (paid or unpaid). It stresses that much of the feared losses with aging are preventable and that many functional losses can be regained. This perspective attributes many of the problems associated with "normal" aging to a high-risk lifestyle. Hence, health promotion activities are seen as a way to lower the risk for disease and disability in later life.

Although this perspective offers a more positive image of aging than do the models focusing on decline and losses, this conceptualization does not take into account early-onset disabilities. People with disabilities can age well. The successful aging model also pays scant attention to (1) aging over the life course; (2) race, class, and gender inequities; (3) implications of losses and gains in later life to older persons with disabilities; (4) stigma associated with disability when viewed as a failure; and (5) limitations of the concept when applied to people with disabilities.

This model fails to adequately address heterogeneity of experiences for people with long-term disabilities whose views of effective functioning may differ from that of other people. People with disabilities may view success as the degree to which the environment changes to accommodate their changing bodies and needs. Hence, stigma is shifted from the old to the disabled, who may be more likely to experience lower adaptive functioning and may be less able to fully participate in community life.

A need exists for a broader environmental approach that stresses environmental accommodations, societal attitudes, and policy changes. People with disabilities have low employment rates (less than one-third in the United States) according to the 1994 "Survey of Income and Program Participation" (McNeil 1994; Yamaki and Fujiura 2002). They are also twice as likely to live alone (19.6 vs. 8.4 percent). Lower income is associated with poorer diet and less exercise. Consequently, people with disabilities need access to programs and policies that promote a higher standard of living, greater participation in society, improved health behaviors, and decreases in inaccessible environments and poverty.

AGING AND AGING WITH A DISABILITY

Age-Related Changes

A common misconception is that age changes indicate illness or disease. Universal changes occur for all people, but the rates of change are different depending on individual circumstances. The gradual wearing down of essential organs and systems is largely related to unmodifiable changes that lead to anatomic and physiological changes. The Baltimore Longitudinal Study (Shock et al. 1984) identified the following normal changes of aging that were not associated with disease:

- Loss of height (1 cm for every 20 years of aging) and weight (peaks in mid-50s for men and mid-60s for women and then declines)
- Reduced cerebral blood flow (20 percent), cardiac reserve (decrease from 4.6 to 3.3 times resting cardiac output), and lung vital capacity (17 percent)
- Decreased muscle mass (30 percent decrease) and bone density
- Diminished smell and taste receptors (smoking, dental problems, medications, or illnesses may contribute to the loss)
- Diminished pain and tactile perception
- Decreased vision (amount of light reaching the retina decreases by 70 percent) and hearing (environmental noise, genetic disease, ototoxic agents contribute to the loss)
- Increased susceptibility to disease

Age-related changes can be categorized as *usual aging* (e.g., combined effects related to the aging process, disease, adverse environmental and lifestyle factors) and *successful aging* (e.g., changes from the aging process uncomplicated by damage from environment, lifestyle, or disease). Individual variations across the lifespan and in every bodily system are tremendous. Moreover, lifelong use and abuse of the body through diet and physical and psychological trauma through accidents and injuries are thought to be related to wear-and-tear changes. Significant changes in structure, function, and biochemistry, along with genetics and lifestyle, are responsible for changes in tissue elasticity, subcutaneous fat, gastrointestinal function and motility, muscle, bone, immunity, and the senses.

Aging with a Disability

A majority of persons aging with a disability will experience a multitude of premature medical, functional, and psychosocial problems as they age. Chronic disability is not stable over the lifespan, and an *aging gap* is becoming evident as many persons with disabilities present with functional changes that are customarily not seen in nondisabled persons until much later in life. Recent studies have documented higher rates of morbidity and mortality for adults aging with disabilities in comparison with the general population for a number of health conditions, such as dental disease, gastroesophageal reflux, esophagitis, and constipation. Several chronic conditions seem to be more prevalent among individuals with disabilities than in the general population, including non-atherosclerotic heart disease, hypertension, hypercholesteremia, obesity, heart disease, diabetes, respiratory illness, osteoporosis, and pressure sores. Also, obesity, mobility impairment, thyroid disease, psychotropic drug polypharmacy, and deaths due to pneumonia, gastrointestinal cancer, bowel obstruction, and intestinal perforation have a higher prevalence among groups of people with various disabilities.

Individuals with disabilities have a higher risk of developing chronic health compromises at younger ages than other adults, due to the confluence of biological factors related to syndromes and associated developmental disabilities, access to adequate health care, and lifestyle and environmental issues. Although people aging with early-onset disabilities (including developmental disabilities, spinal cord injury, polio, diabetes, and rheumatoid arthritis) can now expect to live late in life along with their nondisabled peers, many experience major changes in health, function, and psychosocial status at much earlier ages. The new problems reported by people aging with a disability as early as in their 30s and 40s include the onset of age-related chronic health conditions, pain, loss of endurance, changes in employment, discouragement, and worry. These changes, suggestive of *premature aging,* have a major impact on family and friends.

Age-related health problems of women are often overlooked though they have higher rates of osteoporosis (for people with Down syndrome, epilepsy, and cerebral palsy), earlier onset of menopause for women with Down syndrome, and inadequate screening for breast, cervical cancer, and heart disease. People with Down syndrome have an earlier onset of Alzheimer's disease.

People aging with spinal cord injury (SCI) have a greater risk for pressure ulcers, decreased muscular strength, decline in immune system function/increase in incidence of infection, decreased flexibility of soft tissues (e.g., skin, ligaments, tendons, joint capsules), osteoarthritis, osteoporosis (related to immobility), diminished sensation, and spasticity. Individuals with SCI may also experience overuse and degenerative changes in the shoulder and lower extremities due to repetitive use of these joints and nerve entrapment due to repetitive use from wheeling their wheelchairs.

An estimated 25–50 percent of polio survivors are developing post-polio syndrome (PPS), which is a condition affecting polio survivors anywhere from 10 to 40 years after recovery from an initial paralytic attack of the poliomyelitis virus. PPS may affect more than 300,000 polio survivors in the United States according to the National Institute of Neurological Disorders and Stroke (NINDS). While the cause is unknown, new research is starting to clarify the mechanisms of this complex syndrome. With PPS, some of the initial problems that polio survivors had with polio are reappearing. Increasing numbers of polio survivors are reporting the onset of new symptoms, including increased muscle weakness, fatigue, swallowing difficulties (dysphagia), breathing difficulty (breathing capacity declines twice as fast compared to their nondisabled peers), and muscle joint pain, after years of stable functioning. Polio survivors are also reporting functional difficulties related to climbing stairs, making transfers, and dressing.

Persons aging with cerebral palsy may experience earlier-onset arthritis related to excessive joint wear and tear, chronic pain, gastroesophageal reflux (heartburn), contractures, and bowel and bladder problems. Women with cerebral palsy are three times more likely to die from breast cancer than nondisabled women. Adults with cerebral palsy are more likely to die from brain cancer, trauma, and diseases of the circulatory and digestive systems than their nondisabled peers. Health care services for these adults are often inadequate in addressing the need for accessible examination tables, increased time for communication, and primary care providers knowledgeable about their health conditions.

Syndrome-specific effects (e.g., Down syndrome, Williams syndrome, autism spectrum disorders, PKU, Smith-Lemli-Opitz syndrome, Prader-Willi syndrome) link to special risk factors. For example, among adults with cerebral palsy, later-life morbidity and functional declines seem to be related to the long-standing effect of movement patterns on the musculoskeletal system. Also, recent studies of older persons with autism spectrum disorders suggest that at least some threats to health maintenance and social isolation respond to health promotion approaches.

SUPPORTS TO MAINTAIN COMMUNITY PARTICIPATION

People with long-term disabilities or those who acquire a disability later in life can experience a severe sense of personal loss if they lack adequate family and community resources that allow them to maintain the degree of independence and community participation they desire. Age-related declines in health and functioning and psychosocial losses necessitate accessing an array of potential supportive services. As one ages and has more difficulties with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), it becomes more difficult to maintain a household or employment and there are greater needs for assistive technologies, environmental accommodations, therapeutic and nursing services, and respite and other housing and vocational supports. In addition to care provided by families, a range of public programs can provide these types of support. In comparison with other older adults, older adults with long-term disabilities are more likely to have received some type of housing supports, to have been unemployed or underemployed, and to have lived in poverty most of their lives with little retirement pensions. Some adults with disability, such as those with polio or Down syndrome, may experience earlier age-related physical decline and may experience loss of function, fatigue, and pain, which could result in leaving one's job or current residence, if adequate supports are not in place.

Families

Families have a pivotal role in meeting the increased needs for care by persons with disability as they age. In the United States, up to 80 percent of care, including physical, emotional, psychological, and financial, is provided by family caregivers. Over three-quarters of adults with intellectual and developmental disabilities live with families.

As function changes with age, families are called on even more frequently. With longer life expectancy, parents of persons with a long-term disability have a longer period of responsibility. There is also a greater likelihood of the disabled member outliving his or her parents. These parents are more likely to face dealing with their own aging in addition to the aging of their adult children. Another challenge is planning for future caregiving. Earlier aging of the family member with disabilities has implications for family caregiving. For spouses and parents, the changing roles can be stressful as one of the members develops a disability with aging resulting in increased needs for assistance from family members.

Caregiving can affect the nature of a relationship. For example, a spouse providing personal care can result in a change in the intimate relationship. Caregivers are the main providers of support, including instrumental support (e.g., personal care, transportation, and money) and socioemotional support. Caregivers are mostly women, who often give up, cut back, or lose job opportunities. The consequences can be stressful. The incidence of psychological disturbances among spouses of stroke survivors and of brain injury survivors is high. Cognitive changes (such as in Alzheimer's disease) are particularly difficult for families, who often lack adequate services and experience the loss of shared activities and their own independence.

Public Programs

Strong traditions of public support programs serving for both elderly and disabled persons exist in the United States. In colonial times, almshouses provided care jointly to persons who were elderly, poor, disabled, and mentally impaired. Over time, separate systems of care developed for each of these groups. More recent ongoing efforts seek to build bridges between the aging and disability networks.

The aging and disability programs differ in their philosophical approaches, systems of care, and histories of political lobbying. This divergence can serve as a barrier to merging the two programs. The elderly services focus on retirement and dealing with age-related losses, whereas the disability programs tend to focus on development of skills and rehabilitation. Rather than referring to older persons as *disabled*, they are often described as *frail* or *impaired*. *Caregivers* provide care to elderly persons, while *attendants* provide assistance to people with disabilities. Frequently, elderly persons do not want to associate with disabled and younger adults who do not share many common interests with them.

Aging Programs

Aging programs aim to assist and compensate elderly persons who experience age-related declines in function. Services tend to focus on financial support, disease management, assistance with adaptive functioning, and promoting social well-being. These programs are typically age based rather than need based.

In the United States, Social Security and Supplemental Security Income (1972) provide financial support to elderly, disabled, and poor persons. These programs were also expanded to cover spouses, widows, children of deceased or disabled workers, and parents of children with disabilities. The Older Americans Acts (1965) offers service delivery and support including compensatory services, in-home assistance, and congregate services such as recreation and meals delivered through senior centers. Medicare and Medicaid (established in 1965) provide national health insurance for both elderly (over age 65 years) and disabled persons. It includes hospital, nursing home, and home health care, hence covering both acute and long-term services.

Disability Programs

Disability programs focus on education, job training, and residential services. The emphasis tends to be on rehabilitation and vocational training. In the United States, the Rehabilitation Act (1973) laid the foundation for the disability rights movement. Its Section 504 asserted that people with disabilities had equal rights that prevented discrimination based on their disability. The civil rights of persons with a disability were further protected with the landmark American with Disabilities Act (ADA) (1990). It established equal access for people with disabilities through accommodation in the workplace and in the community. It has helped decrease environmental barriers for both disabled and elderly persons experiencing age-related functional losses. In 1999, the U.S. Supreme Court issued a ruling in the case of *Olmstead v L.C.* that under Title II of the ADA unjustified institutionalization of persons with disabilities is discrimination. This ruling is likely to give momentum to the expansion of community-based care.

BUILDING A COALITION

As more people live longer and potentially develop disabilities and more persons with long-term disabilities live into older age, greater attention is being given to the overlapping needs and constituencies of elderly persons and those with disabilities. Commonalities exist in the needs for long-term care, housing, medical care, and home and attendant care services. Aging is now more likely to adopt the language of the disability rights movement in regard to consumer-directed home- and community-based services. In 1994, the two networks joined together to form the U.S. National Coalition on Aging and Disability in order to hold a series of state conferences in preparation for the White House Conference on Aging in 1995. More recently, policy makers and advocates have begun to see the benefits of some merging of services. Examples of commonalities in needs and services include the Medicaid/Medicare services, assistive technology and environmental accommodations, housing, and health care policies.

Medicaid/Medicare

In the United States as of 2001, more than 40 million people receive health insurance from Medicare and nearly as many receive Medicaid services for their acute and long-term care needs. Over 75 percent of Medicaid expenditures are for institutional care. The trend over the past couple decades has been to reduce institutional spending and to increase community spending. The program has expanded to include the Personal Care (PC) program and the Home and Community-Based Services (HCBS) waiver program in most states. The PC program includes home health care and assistance with personal care, ADLs, IADLs, and housekeeping chores. The HCBS program services include home modification, case management, and habilitation (pre-vocational, educational, and supported employment). Now both of these programs cover not only elderly people but also younger people with intellectual and developmental disabilities. Though this program has grown significantly since the 1990s, states can still limit the number enrolled.

Assistive Technology and Environmental Interventions

As individuals with long-term disabilities and other older adults face declines in health and function, there is a greater need for assistive technology (AT) and environmental interventions (EI) to help them maintain their independence and community participation. With earlier discharge from hospitals and greater emphasis on community living, there is a greater need for AT/EI approaches to help the older adult and the family caregiver.

New and highly personalized devices and technological advances can now aid aging individuals with disabilities in maintaining or increasing their independence, productivity, and quality of life. AT/EI innovations reduce their dependencies on others for assistance, lower their risk of secondary conditions, allow caregivers to provide assistance more easily, and forestall the need for nursing home care. Advances in microelectronics, computer science, communications, bioengineering, and health and rehabilitation sciences have led to the development of a host of physical and cognitive aids. These aids can help older adults function in work, home, recreational, and other community settings as they encounter age-related changes. Examples of the uses of such technologies include the following:

- Helping with planning, execution, attention, and memory (cognitive prosthetics and orthotics)
- Monitoring health and safety (tele-care, tele-health, alert systems)

- Assisting with ADLs and IADLs (robotics, personal digital assistants, adapted eating devices, handrails)
- Controlling the physical environmental in the home (environmental controls, ramps)
- Facilitating greater community participation (navigational systems, recreational aids, communication devices for social interaction)
- Improving mobility (wheelchairs)
- Providing communication and learning aids for educational and employment settings (augmentative communication devices)
- Using information technology (Internet, computers, adapted web browsers)
- Helping to improve vision (glasses) and hearing (hearing aids)

While many older individuals and their caregivers could benefit from such advances, often they are unaware or unable to access or pay for them. This is particularly true for individuals with intellectual disabilities who lag behind other disability groups in their use of technology. Older people and people with disabilities are less likely than other people to own or use computer technology. Barriers to use include lack of proper equipment, poor fit of mobility devices, lack of training in use of equipment, poor communication of needs, and reluctance to accept need for devices.

In the United States, the Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988, and 1994 amendments) provides financial assistance to the states to support programs of technology-related assistance for individuals with disabilities of all ages. These programs provide technical assistance, information, training, and public awareness activities relating to the provision of AT/EI devices and services. They also promote initiatives to increase the availability of funding for, access to, and provision of AT devices and AT/EI services.

Health Promotion and Health Care

Now that people are living longer with a disability, whether the disability occurs early or later in life, health promotion and disease prevention increase in importance. Key components of health promotion include adequate health care, diet and nutrition, and physical activities.

Although persons with a disability have a significant need for routine primary care screenings as they age, in general, for them surveillance and early detection of chronic health conditions is poor. Screening activities such as breast, pelvic, and prostrate examinations; blood pressure and cholesterol checks; urinalysis; and bowel analysis can lead to enhanced functioning, prevention of secondary conditions, and an increased quality of life for persons with disabilities. To provide people with disabilities more resources to age well across the lifespan, better diagnostic tools are needed, along with greater understanding of the physiological changes that occur as people age with disabilities.

Adults with disabilities are often disadvantaged when attempting to access social and health services. Much of this is due to several factors: (1) inadequate services capable of addressing their aging-related needs; (2) a need for supportive services, health surveillance and provision, and family assistance; (3) special problems facing women who often find themselves a disadvantaged class; (4) and health practitioners who generally fail to recognize special problems experienced by persons with lifelong disabilities who are aging.

Physical barriers often constitute a problem for many persons with disabilities. Older women with cerebral palsy report difficulties obtaining dental and gynecologic care because of accessibility problems. Health care facilities often are not accessible to individuals with disabilities who may have physical and sensory impairments. In addition, persons with disabilities often experience difficulties with examinations and procedures. For many people, the most important barrier to effective medical care is case complexity. They encounter a variety of medical subspecialists, dentists, mental health providers, and other health care professionals, often without sufficient guidance.

Because of age-related changes, the presence of chronic diseases that are prevalent in the aging population, feeding problems, multiple concurrent medications, cognitive and functional declines, and syndrome-specific morbidity and comorbidities, older persons with disabilities are a nutritionally vulnerable group. Adults with disabilities also have low fitness levels, a high incidence of obesity, and tend to lead sedentary lives. Hence, they are also at a higher risk than the general population of developing secondary conditions and age-related declines at an earlier age.

With the scant attention given to health promotion strategies for people with disabilities, there is a need for prevention strategies that account for their specific impairments and potential risks for developing new conditions for adults living with long-term disability. Specific guidelines pertaining to the types of exercises, nutritional requirements, and use of medications for various types of conditions or syndromes may be necessary. For example, for people with cerebral palsy, exercise prescriptions need to consider the potential for overuse resulting in pain, injury, and fatigue. Adults with Down syndrome are more prone to osteoporosis and are more likely than other people to require calcium and vitamin D supplements as they age. Coordination between various health care providers, patients, and families is critical. Many primary care physicians have little training in disability or geriatrics, and even fewer have training that crosses both of these areas. They may lack training in dealing with multiple conditions, interacting medicines, and unique aspects of various disabilities.

To improve the fitness capacity and psychosocial well-being of adults with intellectual or developmental disabilities, Heller and her colleagues (Heller, Hsieh, and Rimmer 2004; Rimmer et al. 2004) developed and demonstrated the effectiveness of an innovative fitness and health education program. Results of this program demonstrated improved physical fitness and psychosocial well-being for participants, including more positive attitudes toward exercise, higher life satisfaction, and less depression. The next challenge is to develop and test methods of delivering health promotion interventions within the individual's natural settings, such as where they live, work, or recreate. This would require developing methods of training staff and setting up on-site health promotion programs as well as using fitness and recreation centers in the community.

FUTURE NEEDS

According to the U.S. National Long-Term Care Survey, the proportion of older adults who report certain activity limitations has decreased. However, the absolute number of older Americans living with disabilities and chronic illness will likely grow, particularly as the baby-boom generation enters old age and life expectancy continues to increase. The aging and disability service systems will need to build more capacity to provide services to a growing number of persons with lifelong disabilities who are aging and to other older individuals with disabilities who will increasingly need more services and supports to maintain their health and independence. Communities will need to adapt to this population by designing environments that accommodate elders of diverse abilities and functional limits. This includes developing more accessible transportation, recreational facilities, and businesses. In addition, there is a need for better and more training of health care professionals on age-related changes in disability.

Finally, family caregivers, who provide the greatest amount of care—physically, emotionally, psychologically, and financially—themselves need supportive services.

—Tamar Heller and Beth Marks

See also Aging, International; Alzheimer's Disease; Cerebral Palsy; Down Syndrome; Family; Frailty; Mobility Aids.

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AGING, INTERNATIONAL

The term *aging* is broad and implies various concepts and dimensions including chronological, biological, and mental aging, which are applicable to persons with and without disabilities. The aging process occurs in the context of historical age. Chronological age is the lived time from birth, and administrative age is the age cutoff used by administrators, statisticians, and epidemiologists. Biological aging refers to the physical state of the body in its relation with biological processes of growth, ripening, disease, and decay of organ functioning and body functioning. Social, psychological, cognitive, and social ability also affect aging, and aging may be strongly influenced by legal, ethical, religious, and historical considerations. For instance, under the notion of legal age (categorization based on political considerations), the age category of 55 to 65 years reflects the period when some societies legislate or allow individuals to stop work and become pensioners.

Under the notion of social age, aging may be characterized as a period of changing lifestyle, preretirement, or other social determinants of growing older. As members of the greater society, older adults are more underprivileged when they are long-term disabled. They are often unemployed or underemployed; underprivileged in income and social status; segregated in a special system of work or activity, housing or leisure; and often dependent on the help of others. Scientific data about the impact on social aging of those indicators of low social economic status, segregation, and dependency on health and on the use of health services are very scarce.

Mental or cognitive age refers to intellectual and maturational capabilities. It can be very important in the analysis and interpretation of behavior. When a 2-year-old child repeatedly throws a drinking cup on the floor, it is usually interpreted as a sensory-motor game played by that child and his or her parents. The same behavior, exhibited by an older adult, is likely to be viewed as destructive, or even as psychopathological. Cohort effects require the researcher to consider the dimension of historical age in psychological, social, and epidemiological studies. One needs to analyse the impact of cohort effects in all aspects of human life of today's adults who are elderly. To explain today's behavior, adaptations, complaints, functioning, and health problems, one needs to take into account the different opportunity structures and socializing systems available to them when they were young. For example, as a group, young adults with disabilities of today will know much more about their heart, its function, irregularities, and heart failure when they are 60 years old compared to those adults who have already reached this age. In countries such as Germany and Austria, there are very few survivors with severe disabilities of the Nazi regime. Persons from the birth cohorts before the year 1945 are almost nonexistent in the disability statistics of those countries. In all countries, but especially in the developing countries, older adults are healthy survivors from limited opportunity structures in the past. This is the case for persons without lifelong disability, but is especially evident for persons with lifelong disabilities. For example, many of the children with Down syndrome born in the 1950s and 1960s with congenital heart disorder had a very limited life expectancy, whereas those from later birth cohorts were operated on successfully and have joined the ranks of today's adults.

COMMON TERMINOLOGY OF DISABILITY

Within and between countries the term *disability* has very different connotations. The World Health Organization (WHO 2001) has provided one common terminology by developing the International Classification of Impairments, Activities, and Participation (ICIDH-2). The WHO defines impairment as a "loss or abnormality of body structure or of a physiological or psychological function." This (physiological, psychological) impairment can lead to limitations in activities, which in turn can lead to restrictions in participation in society. An individual with an impairment may not experience any disability; alternatively, an individual may have a disability as a direct consequence of an impairment; or a disability may be a psychological response to an impairment.

The original ICIDH was based on a model where impairment, disability, and handicap were causally linked as consequences of diseases or disorders at the levels of the body, person, or society, respectively. The ICIDH-2 uses the human functioning approach. In this approach, there are no assumptions related to causality. The key components are body functions and structures, activities and participation, environmental factors, and personal factors. In this new classification, disability is a negative aspect of body functions and structures as well as activities, while impairment is defined as a negative aspect of body functions and structures only (but not of activities). The term *disability* is also used as a generic term for impairments, activity limitations, and participation restrictions.

NUMBER OF PERSONS WITH DISABILITY IN THE EUROPEAN UNION

In a report of the European Commission (EC) (2001), it is estimated that the number of people in the European Union with a disability varies from 8 to 14 percent. The group consists of disabled people with congenital and acquired impairments, with different degrees of disability, and with mental and physical, permanent and temporary disabilities. Among them are those who are able to work and those who are not; in most countries, a significant proportion of people with disabilities report a combination of impairments.

Labor Market Participation and Age

Disability has a reverse effect on labor market participation and on unemployment. Differences in sociodemographic characteristics such as age and education account for the relatively weak labor market position of people with disabilities. The report of the EC (2001) shows that their probability of being in employment is lower for almost all age categories and for all educational levels than for nondisabled persons. These effects reinforce each other. The labor market position of older people with disabilities is worse than the sum of the effects of being old and being disabled. Compared to other people with disabilities, working disabled people are younger and more likely to be male and better educated (EC 2001). However, compared with nondisabled people in employment, the pattern is reversed: Working disabled are older and slightly more likely to be female and less well educated than nondisabled workers. Employment rates vary greatly between types of disability. People with mental illnesses, learning disabilities, or psychological impairments are less likely to be employed than are people with physical impairments

(EC 2001). The majority of adults and older adults with intellectual disability in the EU have found employment in sheltered work settings.

AGE AND DISABILITY

There is a strong relationship between age and disability. Disability is much more prevalent among older people: 63 percent of people with disabilities are older than 45 years (EC 2001). For nondisabled people, the corresponding percentage is only 34 percent. Hence, the disabled population is relatively old. This is particularly so in Germany, Greece, Italy, and Spain. This pattern is mainly due to individuals' health conditioning deteriorating with age. Furthermore, many impairments leading to disability are acquired during a person's life. There may, in addition, be a generation factor or cohort effect insofar as younger age groups experience better health, education, and working conditions in their early life and better health care and rehabilitation provision than their predecessors in older generations. Also, the rising life expectancy for people in general and especially for persons with lifelong disabilities affects strongly the number, distribution, and level of participation in society of older adults with disabilities.

LIFE EXPECTANCY AND NUMBER OF OLDER PERSONS

Life expectancy has risen sharply in the past 100 years and is expected to continue to rise in virtually all populations throughout the world. The number of people reaching old age is therefore increasing. At the end of the twentieth century, there were about 580 million people in the world who were aged 60 years or older. This figure is expected to rise to 1,000 million by 2020—a 75 percent increase compared with 50 percent for the population as a whole (WHO 1999). Health is vital to maintain well-being and quality of life in older age, and it is essential if older citizens are to continue making active contributions to society. The vast majority of older people enjoy sound health and lead active lives. It is expected that from the 1,000 million older people in 2020, more than 700 million will live in the developing world. The reason for the increase of life expectancy is the sharp decline in premature mortality from many infections and chronic diseases. Improvements in sanitation, housing, nutrition, and medical innovations, including vaccinations and the discovery of antibiotics, have all contributed to the steep increase in the number of people reaching older age.

Health Status of Older People

As more people reach a "ripe old age," however, they also enter a period in their lives when they are at a higher risk of developing chronic diseases, which in turn may result in disability. In fact, chronic diseases, including cardiovascular diseases, diabetes, and cancer, are the main contributors to disease in older persons. However, there is mounting evidence from developed countries that people are maintaining better health in later life than ever before. It is estimated that in 1996, there were 1.4 million fewer disabled older persons in the United States than would have been expected if the health status of older people had not improved since the early 1980s (WHO 1999). The increase in life expectancy was most spectacular for persons with lifelong disabilities.

Effect of Incidence and Life Expectancy

The high proportion of older adults with lifelong disabilities in the population of countries is a function of incidence and life expectancy. Even when in Western countries the birth rates are declining in more recent years, the overall prevalence is increasing because of longer life expectancies of persons with disabilities born in the large birth cohorts after World War II. In developing countries, the prevalence rates as well as the number of elderly persons with disabilities have been increasing significantly during the past decades by the combined effect of high incidence rates of disability and of a longer life expectancy of affected persons.

DIVERSITY OF DISABILITY AT OLD AGE

"Older people" constitute a very diverse group. Many older people lead active and healthy lives, while some much younger adults are more passive and unhealthy. People age in unique ways, depending on a large variety of environmental and genetic factors.

Environmental Factors

Climate and geographic location can be a significant factor determining the incidence of disability, life expectancy and the process of aging.

Whereas iodine deficiency disorders are a major cause of disability, little is known about the life expectancy and the process of aging of persons with this condition in their community. As a consequence, iodine deficiency disorder can result in intellectual disability, deaf-mutism, spastic-diplegia, and squint. Between 600 and 1,000 million people are at risk of iodine deficiency in various regions of the world, mostly in developing countries. According to Dund and van der Haar (1990) about 710 million persons in Asia, 227 million in Africa, 60 million in Latin America, and 20–30 million in Europe are at risk of developing iodine deficiency disorder. At least 200–300 million of them have goiter or some other demonstrable consequence of iodine deficiency, and at least 6 million suffer from severe consequences of iodine deficiency. The most severe iodine deficiency occurs in inland mountainous areas, far from the sea, such as the Alps, the Andes, or the Himalayas. However, iodine deficiency is not confined to mountainous regions; it has also been associated with areas exposed to frequent flooding. In areas of iodine deficiency, 1 in 10 neonates has intellectual disability caused by the deficiency, and there are small pockets where the figure reaches 1 in 4.

Many young persons, especially those living in developing countries, have vision, hearing, speech, mobility, and/or intellectual functioning impairments. From the start of their life, these are not at all homogeneous groups of disabled persons. These individuals differ widely in genotype and phenotype, severity, and treatability of their impairment. Many of those persons have multiple disabilities, with various and different consequences.

Genetic Factors

For persons with intellectual disabilities, there are over 200 monogenetic causes. An increasing number of specific chromosomal and molecular-generic syndromes are associated with intellectual disability. For example, there are more than 60 chromosome-linked disorders. The interaction of genotype and phenotype is much more complex and shows much more variation between individuals than was expected.

Whereas the aging process is relatively well documented for persons with Down syndrome, there is scarce or nonexistent information about older adults with other causes of intellectual disability such as fragile-X syndrome and fetal alcohol syndrome (FAS). FAS is one of the most common causes of intellectual disability, ranking worldwide ahead of Down syndrome and spina bifida, and is characterized by intellectual disability, abnormalities in the central nervous system, growth retardation, and craniofacial and cardiac abnormalities. Abel and Sokol (1987), basing their estimate on 20 studies from Australia, Europe, and North America, which covered a total of more than 88,000 births, found a rate of 1.9 cases of FAS per 1,000 live births; rates were higher in the United States (2.2 per 1,000) than in Europe (1.8 per 1,000). This European rate will change with the extension of the EU.

AGING IN A LIFESPAN PERSPECTIVE

In his work, Plato (fourth century BC) emphasized the personal and lifespan experience of aging. His concepts have a strong educational and social basis. The feeling of "being old," as an aspect of psychological aging, is very much dependent on the person's view of young and old people. In Plato's view, to age "wisely" and peacefully, it is necessary to live a righteous life. For this reason, youths should be educated to live with a sense of duty in order to enjoy old age. The Platonist view of healthy aging is reflected in the modern conception of geroprophylaxis, as proposed by J. E. Birren and J. J. F. Schroots, which emphasizes educating people in healthy lifestyles, management of stress, the need for adequate exercise and nutrition, and the prevention of loss of autonomy as well as prevention of disease. This process must begin in young adulthood to be fully effective.

Life Course Development

Genetic components and early disabilities may contribute to how long persons live. However, health and activity in older age are largely an accumulation of the experiences, exposures, and actions of an individual during the whole span of life. The life course begins before birth. There is evidence that when fetuses are undernourished in the womb, they grow up to be adults more likely to suffer from a variety of diseases, including coronary heart disease and diabetes; they also seem to age faster than people who receive good nutrition during early life. Although aging begins in the womb, changes attributed to senescence usually begin in the postpubertal years. From age 20 years and older, cognitive functions such as fluid working memory and speed of processing show steady decline with each decade. However, crystallized knowledge does not. In fact, domain-specific knowledge among the intact elderly may exceed that for younger persons. There are differences in rate of decline between some physiological systems. For example, pulmonary function declines more rapidly than physical strength.

Aging is also associated with multiple changes wrought by illness. Some of these changes are gradual (e.g., the onset of osteoarthritis) and others are abrupt (e.g., diagnosis of life-threatening illness). Some have instant disabling consequences for the life of the individual; others will show symptoms in older years. Previous accidents and injuries make chronic and sometimes disabling diseases more likely in adult life. Lifestyle factors in adolescence and adulthood, such as smoking, excessive alcohol consumption, lack of exercise, and inadequate nutrition or obesity, greatly add to disease and disability at any age in adulthood.

Differences in education level, income, and social roles and expectations during all stages of a person's life increase the diversity of aging. Throughout the world, the average education of older people is below that of younger people, and this is especially the case for older adults with lifelong disabilities. Higher levels of education are important, because they are associated with better health and less social handicap. People with higher education levels at all ages tend to adopt and maintain healthier lifestyles and have better access to health care and health information.

Healthy Aging

Since the beginning of the 1980s, Paul B. Baltes and colleagues have conducted studies on the psychological processes of development and aging from a lifespan perspective. Their work resulted in a psychological model, called "selective optimization with compensation." The central focus of this lifespan model is the management of the dynamics between gains and losses (i.e., a general process of adaptation), consisting of three interacting elements: selection, optimization, and compensation. It is expected that the lifelong process of selective optimization with compensation allows people to age successfully (i.e., to engage in life tasks that are important to them despite a reduction in energy). This model does not fit well for persons with lifelong disabilities, because the three major components for healthy aging, low probability of disease or disease-related decline, high cognitive and physical function capacity, and active engagement with life, are valid only for a well-functioning minority. Lifelong disability need not impede healthy or successful aging of persons with lifelong disabilities if there are no significant medical aspects of the disability and if the person has productive coping and compensatory mechanisms during adulthood and has maintained control over his or her life activities.

AGING, DISABILITY, AND PLANNING OF SERVICES

Person-Centered Planning

Aging is a lifelong process of learning in taking responsibilities and making choices that can be optimized in the concept of person-centered planning. In Western countries, adequate planning of services for the older generation of people with lifelong disabilities is increasingly based on person-centered planning. Person-centered planning values the customer's views and preferences when defining which services to offer, the manner in which they should be offered, and the personnel providing them. To fulfill such requirements, rigorous changes are needed in the planning of services for older persons with disabilities—changes of goals and values as well as changes in the structure of service delivery and the distribution of financial means. With regard to goals and values, today's living situation of older persons with lifelong disabilities can still be characterized in many countries as dependent, segregated, custodial, patient-like, and without dignity.

UN PRINCIPLES FOR OLDER PERSONS

The UN Principles for Older Persons (United Nations 1992) offer a useful opportunity to stimulate alternative and more human goals and values not only in the field of general aging but also in the field of aging with lifelong disabilities. The UN resolution lists in this respect five principles: independence, participation, care, self-fulfillment, and dignity. Two other basic principles are least restrictive environment and self-determination. The independence principle calls for living in environments that are safe and suited to personal preferences and changing capacities. The participation principle requires that older adults remain integrated in society, participating actively in the formulation and implementation of policies that directly affect their well-being.

Under the principle of care, the United Nations urges that older adults should have the benefits and protection of family and community care. The principle of self-fulfillment promotes the ability of older people to pursue opportunities to develop their personhood through access to educational, cultural, spiritual, and recreational resources. The principle of dignity states that older people should be able to live with dignity and security, free of exploitation and physical or mental abuse. The principle of least restrictive alternative stimulates the reduction of unnecessary restriction in the lives of older adults with and without disabilities. The principle of self-determination enhances the wish of growth and autonomy for older adults with disabilities.

Based on these principles, the following structural changes in policy are recommended:

- Build up a developmental-oriented care system with stimulating but safe environments in which all facets of aging from childhood through senescence are addressed.
- Enhance service capacity for older adults with disabilities because of longevity and the demographic bulges due to the high birth rates in the 1950s and 1960s.
- Define an agenda for planning for the needs of an aging population considering demographics, changing ideologies and practicalities, and the changing needs of older adults with disabilities as they age.
- Develop a professional support system that is sensitive and directed toward personal goals, wishes, and choices of older adults with disabilities, a support system that works with realistic yet safe self- determined plans.
- Plan policies and programs for housing and physical infrastructure, health and hygiene, income security, education and training, social welfare, and family support.

It is still an open question whether the model of person-centered planning for older adults with disabilities can be and should be expanded to non-Western countries and cultures. It needs extensive adaptations when applied to countries with low-income economies or to cultures where identity primarily is defined by being member of a family, clan, or community. For successful implementation of a model of person-centered planning, it will be essential that aging and disability be viewed within the context of the local community, its values, priorities, and social and financial resources.

—Meindert Haveman

See also Aging; Family, International; Frailty.

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AGORAPHOBIA

Agoraphobia is a disabling complication of panic disorder. Although originally conceptualized as separate disorders, research suggests that panic disorder and agoraphobia actually represent a single illness. In fact, agoraphobia in the absence of panic is unusual. The term *agoraphobia* translates literally from Greek as “fear of the marketplace.” Although many patients with agoraphobia are uncomfortable in shops and markets, their true fear is to be separated from their source of security. Agoraphobic patients often fear having a panic attack in a public place and embarrassing themselves or having a panic attack and not being near their physician or medical clinic. They tend to avoid crowded places, such as shops, restaurants, theaters, and churches, because they feel trapped. Many have difficulty driving long distances (because they fear being away from help should a panic attack occur), crossing bridges, and driving through tunnels. Many agoraphobic patients insist on being accompanied to places they might otherwise avoid. At its most severe, agoraphobia leads many patients to become housebound. Common situations that provoke people with agoraphobia are public transport, crowding, and shopping malls. Panic disorder is prevalent among the general population between 1.5 and 3 percent. The prevalence of agoraphobia is slightly higher. Many patients, however, will report that panic attacks began after an illness, an accident, or the breakup of a relationship; developed postpartum; or occurred after taking mind-altering drugs such as lysergic acid diethylamide (LSD) or marijuana.

Panic disorder generally is treated with a combination of specific medication and individual psychotherapy. Cognitive-behavioral therapy (CBT), a form of individual psychotherapy, also appears to be effective in the treatment of panic disorder; its combination with medication may be even more powerful. CBT usually involves distraction and breathing exercises, along with education to help the patient make more appropriate attributions for distressing somatic symptoms. Patients with agoraphobia, with or without panic attacks, should receive behavior therapy. Exposure in vivo is the most effective intervention and in its most basic form may consist of gentle encouragement for patients to enter feared situations, such as shopping in a grocery store.

—Ahmed Okasha

See also Behavior Therapy; Panic Disorder.

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AIDS FOR ACTIVITIES OF DAILY LIVING

Aids for activities of daily living (AADLs) are products, devices, and equipment used within everyday functional activities. They are commonly included as a category of assistive technology. Other common terms for AADLs include adaptive equipment, ADL equipment, self-care equipment/aids, basic assistive technology, rehabilitation equipment or technology, and low technology.

The focus and purpose of these technologies are to adapt the environment, rather than the person, to support identified needs, choice, and control. These products may be used to compensate for impairments and functional limitations or to augment or assist in task performance, such as enabling quicker, safer, or more efficient performance of everyday activities. Products may address vision, hearing, fine and gross motor, sensory, proprioceptive, cognitive, communication, safety, and learning needs.

AADLs include a wide range of devices. Potential categories of equipment may span, but are not limited to, eating and meal preparation, grooming, bathing and showering, dressing, transferring, mobility, writing and basic communication, environmental control, home management, phone use, time management, organization and scheduling, money management, shopping, leisure/recreation/play, community living, and school and work activities. Common examples include tub benches, reachers, large-print or talking devices, and adapted utensils or utensil/tool holders that can be used across many activities.

AADLs are often distinguished from other assistive technologies as low, simple, or basic technology. However, this conceptualization can be misleading in that there is an increasing, rapidly changing pool of products and features from which to choose; many involve electronic components (e.g., phone systems); some involve custom fabrication or fitting to meet the specific person-task-environment demands (e.g., fabrication of a custom orthotic to hold a variety of everyday utensils); and in most cases, AADLs need to be considered as part of an accommodation package involving complex integration and environmental fit issues. For instance, AADLs are often combined with physical and social environment adaptations and strategies. An example is that commonly used ADL equipment in the bathroom includes tub benches/seats, long-handled reachers, raised toilet seats, and extended shower controls. These products are often used in combination with environmental modifications such as grab bars, roll-in or seated shower stall modifications, nonglare lighting, nonslip flooring, and offset temperature controls and sensors, which are then coupled with a set of individually customized strategies to manage and troubleshoot bathroom activities on a routine basis, such as strategies for transferring safely and efficiently.

Previously, AADLs were available only through medical or rehabilitation professionals, most commonly occupational and physical therapists, and required a physician's prescription to obtain and fund them through third-party reimbursement sources such as Medicare, Medicaid, or private insurance. Although rehabilitation remains a primary source for AADLs in the United States, particularly if third-party reimbursement is sought, the market for and availability of this equipment has broadened significantly. Given the functionality of these devices, many are now built into new homes and community environments and are widely available in department stores, consumer product catalogs, and Internet-based vendor sites. With the universal design movement, AADLs are being constantly redesigned and updated to increase their ease of use, efficiency, and ergonomics in response to the growing disability and aging consumer markets. As an example, the line of Good Grip products by OXO International, and other similar product lines on the market, represent a growing line of AADLs that not only support everyday activity but also look and feel good when using them, thus increasing their appeal and lowering their cost given the widespread market base. Thus, many types of AADLs are no longer considered "assistive," but rather are perceived as common tools and are available to the general public.

Research examining the effectiveness of assistive technologies, much of which would be categorized as AADLs, has shown the supportive role this equipment can play in maintaining, increasing, or delaying declines in everyday function for people with disabilities and older adults, particularly as they and significant others in their social world experience age-related issues. AADLs may also support the function and safety of family, personal attendants, and others who may work interdependently with people with disabilities during everyday activities. At the same time, however, research has shown that AADLs are often abandoned at rates from 20 to 50 percent. Reasons for abandonment include that the technology did not do what it was intended to do or did not match the person's needs, the consumer and important others' were not included in the decision-making process, the technology was not accepted due to aesthetics and issues surrounding being labeled as "disabled," a change in needs occurred that was not considered, and the technology was broken or needed to be updated.

These findings point to the critical need for consumer involvement in AADL decisions and to the complexity of factors influencing the fit between the person, the task, the AADL, the physical and social environment in which it will be used, and societal systems and policies involved in obtaining it. Despite the growing need, one of the primary barriers to obtaining needed or wanted AADLs is economic; that is, a large number of people with disabilities cannot afford AADLs and are not able to get reimbursed for them through existing funding systems. As an example, although tub benches have been found to support function and safety, they are typically not funded through third-party reimbursement systems as they are considered "optional," do not qualify as durable medical equipment (DME), and therefore do not meet eligibility criteria.

In response, a number of systems change initiatives have occurred to increase access to AADLs. In the United States, a national network of alternative financing programs offers a consumer-directed program and range of alternative financing strategies to increase access to funding for AADLs and other technologies. Several countries, such as Canada and Sweden, have implemented delivery systems that offer more extensive access to AADLs as part of integrated community living plans across the lifespan. In the United States, several states are using Home and Community-Based Waiver (HCBW) programs to provide needed AADLs as part of an integrated community support package, complying with the 1999 *Olmstead* decision that mandated the right to live in the least restrictive setting with reasonable accommodations.

—Joy Hammel

See also Assistive Technology; Home Modification.

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AIDS/HIV

See HIV/AIDS

AIR CARRIER ACCESS

While there is much in common between different countries' approaches in disability antidiscrimination legislation to employment and goods and services, there is considerable variation in approach to air carrier access throughout the world.

In the United States, for example, access is dealt with primarily by means of the Air Carrier Access Act (ACAA; 1986). The act provided for the U.S. Department of Transportation (DOT) to develop new regulations that ensure that disabled people would be treated without discrimination in a way consistent with the safe carriage of all passengers. The relevant regulations (the Air Carrier Access rules) were published in March 1990. The legislation and rules prohibit discrimination in air transportation by domestic and foreign air carriers against qualified individuals with physical or mental impairments. It applies only to air carriers that provide regularly scheduled services for hire to the public. Requirements address a wide range of issues including boarding assistance and certain accessibility features in newly built aircraft and new or altered airport facilities. People may enforce rights under the ACAA by filing a complaint with the DOT or by bringing a lawsuit in federal court (although recent decisions have cast doubt on the ability of individuals to bring a lawsuit under the ACAA—see *Love v. Delta Air Lines,* 310F 3d. 1347 11th Cir [2002], and the National Disability Council Position Paper on Amending the ACAA to Allow for Private Right of Action, July 8, 2004).

In January 2004, the DOT produced a report on the implementation of the ACAA, in which it detailed some of the ways it had dealt with a failure to comply with the act: "For example, the Enforcement Office has instituted an in-depth investigation of eight major air carriers for violations of the ACAA relating to boarding and wheelchair assistance based on formal and informal complaints. These investigations have resulted in separate consent orders under which a number of airlines were directed to cease and desist from further violations of the ACAA and Department regulations prohibiting discrimination against air travelers with a disability. These investigations also assessed civil penalties to $1.35 million" (*Implementing* 2004:1).

In Australia, the Australian Disability Discrimination Act (1992) makes it unlawful to discriminate in relation to access to premises, including public transportation. In addition—and perhaps as regards transport, more important—specific provision is made in the act for disability standards to be drawn up in relation to the provision of public transportation services and facilities. Failure to comply with these standards is made unlawful. Such standards have now been drawn up, although this has taken 10 years since passage of the ADA. The Disability Standards for Accessible Public Transport (2002) apply to public transport vehicles, conveyances, premises, and infrastructure and set out a timetable for adjustment by public transport operators over 30 years, with fixed milestones every 5 years. They list detailed accessibility requirements including access paths, ramps, boarding devices, allocated spaces, handrails, doorways, controls, signage, information provision, and much more. Given the late passage of the regulations, it is likely to be some time before significant improvements are seen in disability access to air carriers in Australia.

In Canada, provisions relating to accessible air transport are contained primarily in the Canada Transportation Act 1996, which covers, among other methods of transport, air travel. The act created the Canadian Transportation Agency (CTA), which has the power to remove "undue obstacles" from Canada's transportation network. The CTA also attempts to resolve passenger complaints regarding access to air travel. The Air Transportation Regulations make provision for services and information that air carriers are required to provide in relation to disabled people where they are Canadian air carriers operating services within Canada with aircraft of 30 or more passenger seats; while the Regulations on Personnel Training for the Assistance of Persons with Disabilities cover the training of staff—a vital aspect of ensuring accessible transport. There is also the Aircraft Code of Practice, which covers physical accessibility of equipment used in air transportation, although it applies in general only to fixed-wing aircraft with 30 or more passenger seats and only those areas of an aircraft that may be used by the general public.

According to the Council of Canadians with Disabilities, it is generally believed that the CTA has not been successful at tackling systemic issues through either its complaints mechanisms or its other work, although its response to individual complaints has in general been fairly good. Unlike the approach to air carrier access considered above, the European approach to air carrier access has been extremely limited. Very few European countries have antidiscrimination legislation dealing with goods and services at all, and those that do tend not to have addressed air travel. Disabled passengers have had to rely primarily on the International Air Transport Association Resolution 700 (Acceptance and Carriage of Incapacitated Persons) and the Airport Voluntary Commitment on Air Passenger Service—neither of which is based on any rights perspective or indeed has the force of law. However, on February 16, 2005, the European Commission tabled a proposal for a Regulation on the Rights of Passengers with Reduced Mobility When Travelling by Air, which will prohibit discrimination against disabled air passengers. This proposal, once it is adopted by the European Parliament and the Council of the European Union, will apply to all airlines, all airports (public and private), and all passengers. The regulation will prohibit refusal of booking or refusal of carriage to disabled persons because of their disability; prohibit charging disabled passengers for assistance needed; ensure provision of assistance for disabled passengers and establish a centralized charging system (the managing body of an airport will provide assistance free of charge to disabled passengers; costs of the centralized system will be covered by airlines, which will pay an amount proportional to the number of passengers they carry [based on all passengers, not just disabled passengers]); and quality standards will be set by the managing body of the airport in conjunction with airport users' committees. The regulation proposal contains mechanisms for complaints, sanctions, and enforcement in the regulation.

In the United Kingdom, which has had disability discrimination legislation since the 1995 Disability Discrimination Act was passed, anything consisting of the use of a means of transport is specifically excluded from the goods and services provisions of the act, although the infrastructure—such as stations and airports—is still covered by the act (and this exemption will be removed by the Disability Discrimination Act 2005 and regulations made under it, although it will not be covering aircraft for the foreseeable future). Although there are regulations governing the accessibility of trains, buses, and coaches, no such provision exists for air travel. There has, however, been a significant legal case involving assistance at an airport for a passenger. In the case of *Ross v. Ryanair and Stansted Airport Ltd.* (EWCA Civ 1751 [2004]), Mr. Ross—a disabled person with a mobility impairment who was not a wheelchair user—brought a claim relating to a charge of £18 that he had to pay for the provision of a wheelchair to get him from the check-in point at Stansted Airport to the departure gate. Mr. Ross succeeded in his case, with the court holding that Ryanair was responsible for providing the assistance and that it should have done so at no charge. It was particularly interesting that the court held that—despite the low cost of Mr. Ross's flights—it was nevertheless reasonable for Ryanair to provide the assistance required at no charge. Ryanair appealed against the decision, on the basis, and the Court of Appeal upheld the appeal purely in relation to who was responsible for providing the free assistance, holding that because of the particular circumstances of the case both Ryanair and the airport were 100 percent liable for ensuring that Mr. Ross and others in his position had access to wheelchair assistance free of charge.

As can be seen from the brief overview above, access to air travel for disabled people, and specifically the legislation and guidance that govern it, is extremely piecemeal. As with antidiscrimination legislation on disability more generally, the United States appears to lead the way in terms of both the comprehensiveness of its legislation and the activity of its enforcement agency—although this is, of course, no guarantee that disabled people as a whole can actually access flights more easily. Such an approach is perhaps a reflection of the reliance in countries such as the United States and Canada, which cover such vast geographic areas, on internal flights to ensure any degree of travel within the country—something that in Europe remains less prominent. Australia, though, has been slow to catch up, with its regulations being promulgated only as recently as 2002. Nevertheless, European countries will have significant ground to make up to ensure that their disabled citizens have the same rights of access as those in the United States, Canada, and Australia.

—Catherine Casserley

See also Disability in Contemporary Australia; Disability Discrimination Act of 1995 (United Kingdom); Disability Law: Canada.

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▣ ALIENATION

Alienation is the act of withdrawing a person's affections from something else. One can alienate another person, a group of persons, an idea or social reality, or even aspects of their own body or behaviors. Alienation often results in an indifference or outright aversion by an individual or group of individuals toward some aspect of life that might otherwise be attractive and significant. Ignoring others or treating them in a way that causes the other person or group discomfort or excludes them from participating in social aspects of life is an example of alienation. Some ethnic minorities in the United States, women, and people with disabilities have a history of being excluded from full participation in social life by others in power, and are examples of how groups in power can alienate those not in power. People can be alienated, or indifferent, to the products they make or promote in their work. Another example of alienation is when an individual withdraws emotional connection from aspects of themselves, such as a part of their body that has an impairment or illness. Often they consider that the impaired body part no longer is a part of them and is indifferently or negatively perceived by the disabled individual.

Alienation is a process that develops in an ongoing relationship between an individual and another person or group of people, or in an individual as he or she negotiates the emotional terrain of dealing with an unwanted aspect of the person's physical or psychological state. It involves an unexpected deterioration in the quality of interactions and outcomes between individual players, and it continues until the alienated individual or aspect of the individual remains spatially or psychologically separate from others or to the whole person. Alienation is the experience of being disconnected with one's self, with others, with one's gods, nature, or a transcendent realm of being. While alienation is not considered to be a mental disorder, it is recognized as an element of a condition called antisocial personality disorder. Often alienation overlaps with other major psychological symptoms such as boredom, depression, and loss of locus of control.

HISTORICAL ORIGINS

In its early intellectual roots in ancient philosophy and medieval theology, the concept of alienation originally contained a fullness of positive, neutral, and negative connotations. The term was first used by Hegel, who stated that human life easily becomes estranged from the natural world unless validated by the divine. It was a force of development, a mode of conciousness used to signify stepping outside oneself; as Hegel put it, "Alienation is the fundamental feature of consciousness throughout its history" and was considered a necessary precondition for man to realize the true self.

Alienation can be applied to different social circumstances. Judeo-Christian texts find the concept of alienation from one's source of transcendant being in both Old and New Testamants: "My God, my God, why hast thou forsaken me?" In its original Marxist sense, alienation referred to the process of labor whereby workers became estranged from the products they produced. Marx understood alienation in terms of social and historical forces that resulted in spritual disillusionment and the physical separation of labor from its products. Marx noted in his famous "alienation of labor" treatise that conditions in a capitalist society make it impossible for workers to live meaningfully in relation to each other, to the products of their labor, or even to themselves. Simone de Beauvoir and other feminist thinkers point out that women in a patriarchal culture undergo additional forms of alienation when they are pervasively treated as the objects of male sexual desire and effectively coerced into submitting to male-biased political, social, and intellectual norms. Goffman (1968) noted that alienation can also occur when people with disabilities feel stigmatized by their surrounding society as a result of their impairment.

PSYCHOLOGICAL PROCESS OF ALIENATION

The psychological component of alienation is a process of self-estrangement and is considered a failure of self-realization. Alienation causes an altered relationship with the self that takes three forms:

1. The "despised" self, a negatively evaluated discrepancy between the person's preferred ideal and the perceived actual self
2. The "disguised" self, a false consciousness that is out of touch with one's feelings
3. The "detached" self, a disjunction between activity and affect (i.e., the individual's engagements in activities that are not rewarding in themselves)

Alienation involves feelings of meaninglessness, powerlessness, being manipulated, social and self-isolation—a major theme in all of these feelings is a person's feeling of lack of power to eliminate the gap between the definition of the role he or she is playing and the one the person feels he or she should be playing in a situation. The intensity of the individual's feelings of powerlessness to achieve the rightful life role he or she has claimed also contributes to the degree of alienation realized. Other feelings of helplessness, loss of community, lack of understanding, and the opposite of commitment can also be present in alienation. Common symptoms of alienation may include the following:

- Loss of a sense of humor
- The conviction that life is without meaning
- Need to withdraw from social and familial circles
- Emotional disconnectivity or numbness
- Belief that one doesn't belong to formerly intimate groups
- Inability to care for others

Alienation is usually thought of in terms of an individual's emotional distance from social groups. However, alienation can also be thought of in terms of an individual's emotional distance from himself or herself—a term called *self-alienation*. This facet is closely associated with an individual's sense of identity. When self-alienation occurs, individuals may be confused about their identity and the role they are "supposed" to play in the context of their life. This disconnectedness serves to depersonalize events, interactions with others, feelings, and interpretations.

ALIENATION AND DISABILITY

In terms of disability, alienation occurs when the state of disability or impairment causes the individual to develop a state of disconnectedness with his or her personal identity, relating to the adaptation to the impairment within the framework of reconciling relations between mind and body expectations and realities. For instance, an athletic person loses his leg in an accident. While the reality is that he is now an amputee, he refuses to go to recommended therapy, stops going to the gym to work out, and drops completely out of his social society. He feels angry that his leg "betrayed him," that it makes him "less of a man," and he eventually considers his impaired leg as something that does not belong to him but is unfortunately attached and therefore must be accommodated. In this example, the man has alienated himself from his community, and he has alienated the impaired part of his body from his personal identity.

While there is research of alienation and how it manifests in the disabled population, it has primarily focused on physical illness or impairment. There is little known about alienation as it relates to individuals with cognitive impairments or mental illness, or whether the concept of alienation operates within impairment categories of this kind.

Individuals may ignore or minimize illness or impairment when they choose not to acknowledge its effects on their lives or their lack of control over those effects; by doing so, they hope to preserve the sense of unity between body and self that they had before disablement. The disabling condition, or impairment, is separated from the primary essence of the individual as it is perceived by the individual to "cause" the events and feelings of disconnect. Placing the disability or impairment "outside" of the individual identity and removing it from one's inner essence makes the disabling condition something external and foreign to the essential core being of the individual.

—Ann Cameron Williams

See also Depression; Isolation.

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ALTERNATIVE MEDICINE

See Complementary and Alternative Medicine

ALZHEIMER'S DISEASE

Alzheimer's disease is considered to be the commonest form of a group of illnesses that predominantly occur in later life and are referred to as "the dementias." These illnesses have in common a progressive loss of brain function leading to the development of impairments in a number of cognitive and functional abilities such as memory, the use and understanding of spoken language, and the ability to undertake complex tasks. As dementia progresses, these impairments become increasingly severe with the eventual loss of everyday living skills, resulting in an inability to care for oneself. Changes in personality and behavior are also apparent. The exact course and characteristics of the dementia in an individual varies depending on the cause for the dementia and also because of individual differences. The majority of the dementias are rare before the age of 60, but the prevalence rates increase steadily in older age groups. The general consensus is that the occurrence of Alzheimer's disease should not be considered inevitable with increasing age, but rather it is an illness that is age related and affects a proportion of people. Summarized below is a compilation of prevalence data published in the Alzheimer's Disease International (1999) "Factsheet 3." These figures are a conservative estimate with some studies suggesting that nearly 50 percent of people over the age of 85 have dementia.

Age group	*Prevalence rates (%)*
65–69	1.4
70–74	2.8
75–79	5.6
80–84	11.1

Alzheimer's disease was named after Alois Alzheimer, who in 1906 described the clinical features and postmortem findings of the brain from an elderly person who had suffered from particular mental experiences prior to her death. On postmortem, she had a significant loss of brain tissue and many microscopic *plaques* and *tangles* in her brain. Later research established that the plaques, containing beta amyloid, and the neurofibrillary tangles, containing aggregations of a modified form of another protein called tau, are together the characteristic brain changes of what is now called Alzheimer's disease. It was later established that there was a relationship between the severity of the symptoms of dementia prior to death and the extent to which these plaques and tangles were present in the brain at postmortem. While among Caucasians Alzheimer's disease is considered to be the cause of over half of the cases of dementia, this may not be so across all cultures. Globally, Alzheimer's disease is of increasing concern because the number of people over age 65 years, and therefore at risk of dementia, is increasing. For developed countries, mean life expectancy is now in the late 70s. It has been estimated in the United States that 4.5 million people have Alzheimer's disease at present and, if trends continue, it is estimated that 13.2 million will have Alzheimer's disease by 2050 (see Herbert et al. 2003).

PRESENTATION AND COURSE OF ALZHEIMER'S DISEASE

The clinical presentation and course of Alzheimer's disease reflect the progression of the underlying brain pathology. It has three stages. An early sign is memory loss for recent events. This goes beyond what would be considered normal for that person's age and is a result of the brain pathology starting in an area of the brain called the hippocampus. The person may be unable to remember how to get around, and disorientation becomes a serious problem. In the second stage, involvement of the surfaces (cortex) of the two lateral lobes (cerebral hemispheres) of the brain results in further problems, such as a deterioration in the understanding and use of language, an inability to recognize commonplace objects, and/or an inability to undertake complex tasks (such as brushing one's hair) even though the physical ability to move the necessary parts of the body remains intact. The person's personality may change during the course of the illness, and he or she may engaged in inappropriate and difficult behavior or suffer from frightening experiences more characteristic of major mental illnesses, such as experiencing auditory or visual hallucinations or paranoid ideas. In the final, third stage complete care is necessary as the person is unable to feed or care for himself or herself and to undertake the basic necessities of life. The average length of illness from diagnosis to death is between eight and ten years but can be longer.

DIAGNOSIS OF ALZHEIMER'S DISEASE

The diagnosis of dementia, and specifically of Alzheimer's disease, depends on evidence of the progressive development of the above clinical characteristics as set out in established diagnostic guidance, such as the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) or the International Classification of Diseases (ICD-10). Other causes of dementia (e.g., multi-infarct dementia) and also conditions that might mimic dementia (e.g., profound depression, endocrine disorders) are excluded on the basis of the clinical picture and as a result of clinical investigations, such as brain scans and specific blood tests. This process of *differential diagnosis* is crucial as it identifies possible treatable disorders mimicking dementia and guides subsequent interventions. Specific psychological tests are available to enable the systematic assessment of those areas of cognitive ability that are known to decline with dementia, such as memory, orientation, and language. The best known of these is the Mini Mental State Examination developed by Folstein and colleagues. Such established assessments can screen for and monitor the disorder's progression.

CAUSE OF ALZHEIMER'S DISEASE

The cause of Alzheimer's disease remains unknown. Research has focused on investigating the brain changes and also on identifying those factors that might affect the risk of developing the illness or modify its course. One very striking feature is that it is predominantly an illness of later life, increasing age being the most significant risk factor. Both the plaques and the tangles in the brain have been the focus for intensive study. There are those who argue that a protein called amyloid is central to the pathological process. The large amyloid precursor protein (APP) is found across the cell membrane of the brain cells (neurons), with parts inside and outside of these cells. It is a smaller extracellular part of this protein (beta amyloid) that appears to be the basis for the development of the microscopic plaques characteristic of Alzheimer's disease that subsequently accumulate in the brain in the space outside of the neurons. In contrast, there are those who see the formation of the abnormal neurofibrillary tangles (consisting of modified tau protein) inside of the nerve cells as being the crucial pathological event. These two processes must in some way relate to each other, leading to the accelerated atrophy of brain tissue and therefore the progressive course of the illness. The main, but not exclusive, brain neurotransmitter system affected is that of acetyl choline, and it is this observation that has been the focus for treatment developments.

In the rare cases of people developing Alzheimer's disease in middle age, genetic factors are important. In these families, subtle changes (mutations) in specific genes (amyloid precursor and presenilin genes) develop. People with Down syndrome also develop the brain changes and the clinical features of Alzheimer's disease relatively early in life. The gene that codes for the APP is located on chromosome 21, the chromosome that is inherited in triplicate rather than in duplicate in those with Down syndrome. Having the abnormal number of three copies of the APP gene and therefore too much of the protein amyloid is the possible process that leads ultimately to plaque and tangle formation in those with Down syndrome. Other genetic risk factors for Alzheimer's disease are not causative but either protect against or increase the risk of developing the disorder with increasing age. One example is the normal variation in the type of ApoE gene inherited by individuals. One variant (number 2) protects against and one (number 4) increases the risk. Lifestyle factors may also have some influence, such as level of past educational achievements and present activity, or the occurrence of previous serious head injuries.

TREATMENT OF ALZHEIMER'S DISEASE

An accurate diagnosis is the starting point for the development of an individualized package of care for the affected person, together with support for carers. The fact that at present there are no treatments that arrest or reverse the progressive brain atrophy can lead to a feeling of hopelessness. However, despite the absence of curative treatments much can be done to maintain the quality of life of the person concerned. Medications developed to date have a temporary modifying effect on the course. Their action is primarily to temporarily restore activity of the neurotransmitter acetyl choline, and by doing so temporarily improve cognitive and functional abilities. Other medication approaches have included the use of antioxidants such as vitamin E, anti-inflammatory medications, and hormone replacement therapy. None of these permanently arrest the course of the illness.

The main approaches to providing support for people with Alzheimer's disease remain maintaining good physical health; trying to ensure a consistent, predictable, and safe environment; and using strategies that help maximize memory and other cognitive functions. Nighttime can be a particular problem with erratic sleep patterns and the increased likelihood of confusion that darkness brings. Thus, changes to lighting and nighttime support are often crucial. Medications may be needed with the development of epilepsy or psychotic phenomena but should be used with care as they can add to a person's disorientation and state of confusion. Guidance from national Alzheimer's disease organizations is available.

—*Anthony Holland*

See also Aging; Dementia; Down Syndrome.

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AMERICAN DISABLED FOR ACCESSIBLE PUBLIC TRANSIT

See ADAPT

AMERICAN DISABLED FOR ATTENDANT PROGRAMS TODAY

See ADAPT

AMERICANS WITH DISABILITIES ACT OF 1990 (UNITED STATES)

The Americans with Disabilities Act of 1990 (ADA) is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States. Passed by the 101st Congress of the United States and signed into law by President George H. W. Bush on July 26, 1990, the statute prohibits disability discrimination by a wide range of private employers, businesses, and state and local government agencies.

ORIGINS AND ENACTMENT OF THE ADA

A shift in focus from asking for charity to demanding civil rights for people with disabilities in the United States in the late 1960s and 1970s prompted calls for federal statutory protection of the civil rights of individuals with disabilities. The Civil Rights Act of 1964, which prohibited discrimination on the basis of race, color, religion, or national origin, was a major inspiration for the concept of similar protection for people with disabilities. Bills to add disability or "handicap" to the grounds of discrimination prohibited by the

1964 act were periodically introduced in Congress, but most of them died in congressional committees. A partial success of such efforts occurred in 1973 with the enactment of Section 504 of the Rehabilitation Act; this provision, patterned on Title VI of the Civil Rights Act of 1964, prohibited discrimination on the basis of "handicap" in programs or activities that receive federal funding.

The first proposal in U.S. legal literature of a more comprehensive federal statute that would prohibit discrimination based on disability, other than by simply adding "handicap" to the Civil Rights Act of 1964, occurred in a 1984 article published in the American Bar Association's *Mental and Physical Disability Law Reporter* (Burgdorf and Bell 1984). The article presented a "statutory blueprint" for such a law, suggesting that it should provide a definition of discrimination on the basis of disability and should explicitly impose obligations to make reasonable accommodations; to remove architectural, transportation, and communication barriers; and to eliminate discriminatory qualification standards. It also advocated broad coverage of such a law, arguing that Congress should prohibit discrimination on the basis of disability in all contexts in which it had prohibited other types of discrimination and should broadly cover all entities whose activities affect interstate commerce.

These theoretical concepts took a major step toward realization when the National Council on the Handicapped, an independent federal agency comprised of 15 presidential appointees, published its 1986 report to the president and Congress, titled *Toward Independence.* Under the leadership of the Council's executive director, Lex Frieden, and informed by the input received in a nationwide series of consumer forums conducted by its vice chair, Justin Dart, the Council advanced 45 legislative recommendations in ten broad topic areas. The first recommendation in the report was that "Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap." Subsequent recommendations in the report described in detail what should be included in such a statute and suggested that the law should be called "the Americans with Disabilities Act."

In its 1988 follow-up report, *On the Threshold of Independence* (Farbman 1988), the council took the somewhat unusual step—at the insistent urging of the report's editor, Andrea Farbman—of publishing its own draft ADA bill, written for the council by its attorney staff member Robert L. Burgdorf Jr. With a few changes, the council's draft bill was introduced in the Senate by Senator Lowell Weicker (R-Conn.) on April 28, 1988, and in the House of Representatives by Representative Tony Coelho (D-Cal.) on April 29, 1988. After joint congressional hearings on the bills had been held on September 27, 1988, the 100th Congress expired without either house of Congress taking action on the proposed legislation.

Before reintroducing the ADA legislation in the 101st Congress, congressional supporters revised the proposal in consultation with national disability consumer organizations, adding specificity and some policy compromises. The revised ADA bills were introduced in the new Congress on May 9, 1989, with Senator Tom Harkin (D-Iowa) as the sponsor in the Senate and Representative Coelho in the House of Representatives. On August 2, 1989, the Senate Committee on Labor and Human Resources approved a substitute bill reflecting certain compromises and clarifications arrived at through negotiations between the Bush administration and Senate sponsors of the bill. The Senate passed the bill, with a few floor amendments, by a vote of 76 to 8 on September 7, 1989.

In the House of Representatives, the House Committee on Education and Labor reported out the House's version of the Senate bill, with some additional clarifying language, on November 14, 1989. After approval by the three other House committees to which the legislation was assigned, the full House passed the ADA bill on May 22, 1990, by a vote of 403 to 20. Two separate conference committees were required to work out final differences between the Senate and House versions, after which the House approved the final version of the bill on July 12, 1990, and the Senate followed suit on July 13, 1990.

In his remarks before the more than 3,000 people, predominantly individuals with disabilities, who gathered on the South Lawn of the White House for the signing ceremony, President George H. W. Bush described the act as a "historic new civil rights Act . . . the world's first comprehensive declaration of equality for people with disabilities." The president added that "with today's signing of the landmark Americans with Disabilities Act, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom" (Bush 1990:1–2). He also noted that other countries, including Sweden, Japan, the Soviet Union, and each of the 12 member nations of the European Economic Community, had announced their desire to enact similar legislation (p. 2).

CONTENT OF THE ADA

The long title of the ADA describes it as "an Act to establish a clear and comprehensive prohibition of discrimination on the basis of disability." The act is divided into five titles: I—Employment; II—Public Services; III—Public Accommodations and Services Operated by Private Entities; IV—Telecommunications Relay Services; and V—Miscellaneous Provisions. The substantive titles are preceded by preliminary sections providing the short title of the act, a table of contents, congressional findings and purposes, and certain definitions.

Title I applies to employers having 15 or more employees, and to employment agencies, labor organizations, and joint labor-management committees. It establishes a "general rule" that "no covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual." This applies broadly to various aspects of applying for, getting, retaining, and benefiting from employment, including compensation, promotion, and "other terms, conditions, and privileges of employment." Title I goes on to specify several forms of discrimination that are contained in the general prohibition, including such things as segregation; using standards, criteria, or methods of administration that have a discriminatory effect or perpetuate discrimination; discriminating against a person because of that individual's relationship to another individual who has a disability; not making "reasonable accommodations" to known limitations of a qualified individual with a disability; and using discriminatory standards, tests, or other selection criteria.

Title II of the ADA, styled "Public Services," prohibits discrimination by any "public entity," a term defined to include states, local governments, or departments, agencies, or instrumentalities of states or local governments; and Amtrak and entities providing commuter transportation services. Title II subjects all the activities, programs, and services of such entities to a prohibition of discrimination on the basis of disability, requiring that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of public entities." Previously, such a nondiscrimination requirement had been applicable pursuant to Section 504 of the Rehabilitation Act only to those activities, programs, and services of such entities that received federal financial assistance. Pursuant to Title II, all state and local government facilities, services, and communications are made subject to accessibility requirements established under Section 504 and to other requirements consistent with other parts of the act, including, specifically, obligations to make "reasonable modifications to rules, policies, or practices"; to achieve "the removal of architectural, communication, or transportation barriers"; and to ensure "the provision of auxiliary aids and services."

Title II also includes detailed provisions applicable to public transportation systems, Amtrak, and commuter transit authorities. These provisions resolved some of the controversial, contentious issues that had arisen from the ambiguity and inconsistency in prior statutes regarding the extent of accessibility obligations for public transportation systems, and had led to considerable litigation. Among other things, these provisions of Title II impose requirements and set standards for accessibility of new or refurbished buses and trains, for bus and train stations, and for paratransit services for people with disabilities unable to use fixed-route bus services.

Title III addresses "public accommodations," defined very broadly to encompass most types of privately owned businesses, including places of lodging, establishments serving food or drink, places of exhibition or entertainment, places of public gathering, sales or rental establishments, service establishments, transportation terminals and stations, places of public display or collection, parks and other places of recreation, schools and other places of education, social service establishments, and places of exercise or recreation. Title III contains a sweeping "general rule" that prohibits discrimination "on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation." Subsequent provisions identify forms of discrimination encompassed in the general prohibition; these include such things as imposing discriminatory eligibility criteria, failing to make reasonable modifications, failing to provide "auxiliary aids and services" necessary for equal participation of an individual with a disability, not providing opportunities in "the most integrated setting appropriate to the needs of the individual," and denying a person equal treatment because of that individual's relationship with an individual with a disability.

Title III also imposes certain requirements regarding architectural and communication accessibility. One provision requires public accommodations to remove architectural barriers and communication barriers from existing facilities, where doing so is "readily achievable." The act defines "readily achievable" to mean "easily accomplishable and able to be carried out without much difficulty or expense." One of the most far-reaching provisions of Title III is the requirement that newly constructed facilities or altered portions of facilities of "commercial facilities" must be accessible, except where it is "structurally impracticable." The term "commercial facilities" is defined extremely broadly as facilities "intended for nonresidential use . . . whose operations will affect commerce." Title III also prohibits discrimination by private companies that provide transportation services, other than by air, to the general public. In general, public accommodations that offer transportation must provide service to individuals with disabilities equivalent to that available to others. New fixed-route vehicles seating more than 16 passengers must be accessible.

Title IV establishes requirements regarding two types of telecommunications services: telephone transmissions and television public service announcements. Companies offering telephone services to the public must provide telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices throughout the areas that they serve. Any television public service announcement that is produced or funded in whole or in part by any agency or instrumentality of the federal government is required to "include closed captioning of the verbal content of such announcement." "Closed captioning" refers to a system that allows only viewers with a decoder to view the captions.

Title V of the ADA contains various provisions relating to procedural and enforcement issues. Among other matters, it addresses the coverage of Congress and legislative branch agencies by the act; the application of the act to the insurance industry; the availability of attorney's fees under the act; states' liability for being sued under the act; the process for issuing accessibility standards; and liability for acts of retaliation, interference, coercion, or intimidation against a person for exercising rights under the act.

INTERPRETATION AND APPLICATION OF THE ADA

The various titles of the ADA direct that implementing regulations be issued by the federal agencies with enforcement responsibilities under the respective titles. The Equal Employment Opportunity Commission (EEOC) was directed to issue regulations for implementing Title I, the employment provisions of the ADA. As the head of the Department of Justice (DOJ), the attorney general was charged with issuing regulations both for carrying out Title II's requirements regarding state and local government entities and for implementing the requirements Title III places on public accommodations. The secretary of transportation was made responsible for issuing regulations for the implementation of the ADA's transportation requirements both for state and local government entities under Title II and public accommodations under Title III. The Federal Communications Commission (FCC) was directed to issue and enforce regulations for carrying out Title IV's requirements regarding telephone relay services. These regulations and additional regulatory guidance issued by the federal agencies provide considerable guidance regarding the scope and substance of ADA provisions.

Despite the enforcement activities of the federal agencies and the guidance they have provided, many claims under the ADA have wound up in courts. The passage of the ADA provoked a great deal of litigation. In the lower courts, the results were disproportionately unfavorable (90 percent or higher in some studies) to those filing employment discrimination lawsuits, generally on the grounds that they had not adequately proven that they had a disability under the law.

Eventually, the cases began to make their way to the higher courts. By the end of its summer 2004 term, the Supreme Court of the United States had decided 19 cases interpreting and applying the ADA. It is difficult to draw many firm conclusions from these decisions, but they suggest some general patterns or trends. Examining the results according to which title of the ADA was at issue reveals that the Court decided cases under Title III (public accommodations) in favor of litigants with disabilities, ruled about evenly for and against litigants with disabilities in cases under Title II (activities of state and local governments), and came down against litigants with disabilities in a significant majority of the cases under Title I (employment).

The Supreme Court's decisions can also be classified according to types of legal issues raised. Thus, the decisions addressing the language of the ADA in terms of what things it covers—*Pennsylvania Department of Corrections v. Yeskey* (prisons); *Olmstead v. L.C.* (residential treatment facilities); *PGA Tour, Inc. v. Martin* (PGA Tour golf tournaments); *Clackamas Gastroenterology Associates, P. C. v. Wells* (medical clinic owned by physician director-shareholders); *Tennessee v. Lane* (state courthouse facilities)—have produced results generally favorable to litigants with disabilities. Decisions interpreting the substantive requirements of the ADA—*Olmstead v. L.C.* (prohibiting segregation); *U.S. Airways, Inc. v. Barnett* (reasonable accommodation)—have produced mixed results. The Court's rulings on the scope of defenses available under the act—*Bragdon v. Abbott* (direct threat to health or safety of others); *Albertson's, Inc. v. Kirkingburg* (application of a federal transportation safety regulation); *PGA Tour, Inc. v. Martin* (fundamental alteration); *Chevron U.S.A. Inc. v. Echazabal* (direct threat to the employee's health or safety); *Raytheon Co. v. Hernandez* (non-disability-based misconduct rules)—have also been mixed, although, in numerical terms at least, slightly more adverse than favorable to litigants with disabilities.

The decisions of the Court addressing procedural issues, such as attorney's fees—*Buckhannon Board and Care Home, Inc. v. West Virginia Department of Health and Human Resources* (applicability of "catalyst theory")—and availability of punitive damages—*Barnes v. Gorman* (under Title II and Section 504)—that disability rights law shares with other civil rights constituencies, have mainly been restrictive of the interests of litigants with disabilities. Decisions addressing the scope of congressional authority to enact the ADA (and other civil rights laws)—*Board of Trustees of University of Alabama v. Garrett* (state liability for monetary damages under Title I); *Tennessee v. Lane* (right of access to state courts under ADA Title II upheld as exercise of congressional authority under Fourteenth Amendment)—have produced mixed results but have not resolved some fundamental questions. Finally, cases addressing who can invoke the ADA's protection have been mixed, but increasingly limiting as time has gone on; some have taken an inclusive view of the definition of disability—*Bragdon v. Abbott* (asymptomatic HIV infection)—and who is "qualified"—*Cleveland v. Policy Management Systems Corp.* (extent of inconsistency between application or receipt of disability benefits and pursuing ADA action)—but some very significant decisions—*Sutton v. United Airlines* (consideration of mitigating measures in determining disability of individuals with severe myopia); *Murphy v. United Parcel Service* (consideration of mitigating measures in determining disability of a person with high blood pressure); *Albertson's, Inc. v. Kirkingburg* (whether monocular vision is automatically a disability); *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams* (whether carpal tunnel syndrome and painful condition of wrists, elbow, and shoulders substantially limited major life activity of performing manual tasks)—have taken a highly restrictive view of what it takes to demonstrate a disability under the ADA.

One of the most influential of the Supreme Court's ADA rulings occurred in the case of *Olmstead v. L.C.,* in which a six-justice plurality agreed that the integration provision of Title II of the ADA requires states to place individuals with mental disabilities in community-based facilities in appropriate circumstances. To the central issue in the case of whether the prohibition of discrimination in the ADA may require placement of persons with mental disabilities in community settings rather than in institutions, the Supreme Court answered with "a qualified yes." The Court concluded that "unjustified isolation," for example, institutionalization when consulting physicians deem community treatment equally beneficial, "is properly regarded as discrimination based on disability." No single opinion in its entirety, however, garnered the votes of a majority.

The effect of this ruling was magnified when President George W. Bush made the ADA's integration requirement a cornerstone of his administration's "New Freedom Initiative." In February 2001, the president formally announced the "New Freedom Initiative" and committed the administration to ensuring the rights and inclusion of persons with disabilities in all aspects of American life. By Executive Order No. 13217, issued on June 18, 2001, the president declared the commitment of the United States to community-based alternatives for individuals with disabilities, and required the attorney general, the secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the commissioner of the Social Security Administration to work cooperatively with the states to ensure that the *Olmstead v. L.C.* decision is implemented in a timely manner, including providing services to individuals with disabilities in community-based settings, whenever appropriate to the needs of the individuals. The executive order directed federal agencies to work together to tear down the barriers to community living. As a result, various federal departments entered into joint efforts with states and others to provide elderly persons and people with disabilities the necessary supports to participate more fully in community life.

A significant issue only partially resolved by the U.S. Supreme Court's ADA decisions through the end of 2004 is that of constitutional limits on congressional authority in relation to the ADA. In *Board of Trustees of University of Alabama v. Garrett* in 2001, the Supreme Court ruled that suits by employees of a state to recover money damages from a state for violations of Title I of the ADA were barred by the Eleventh Amendment to the U.S. Constitution. This followed the Court's decision in 2000 in *Kimel v. Florida Bd. of Regents,* in which the Court had ruled that another federal law, the Age Discrimination in Employment Act, did not validly abrogate states' Eleventh Amendment immunity from suits by private individuals. In *Garrett,* the Court indicated that in evaluating congressional authority to enact ADA provisions as part of its power to enforce the Fourteenth Amendment, the Court would require that legislation reaching beyond the scope of the Fourteenth Amendment's guarantees must exhibit "congruence and proportionality" between the constitutional injury being addressed and the means adopted to address it. Applying such standards to Title I of the ADA as it applies to state employment, the Court found that the evidence Congress assembled of unconstitutional state discrimination in employment was inadequate and that Congress had not imposed a remedy that was congruent and proportional to the targeted constitutional violation.

The scope of the Court's ruling in *Garrett* was relatively narrow; the ruling did not prevent lawsuits against state employers for injunctive relief, did not preclude suits initiated by the federal government for monetary damages, and did not bar suits for money damages against private employers or local governments. And despite the *Garrett* decision, most state workers still retained rights to sue for money damages under Title II of the ADA and under Section 504 of the Rehabilitation Act of 1973. The Court also expressly made clear in its *Garrett* decision that the same analysis might not apply to cases brought under Title II of the ADA. But the Court's ruling in *Garrett* raised substantial fears that the analytical standards applied to Title I would subsequently be applied to bar private suits for monetary damages against states under Title II, and fueled concerns that the *Garrett* decision was but a stepping-stone toward a broader effort by the Court to restrict congressional authority and to expand the rights of states.

Such concerns were allayed to some degree when the Supreme Court issued its decision in the case of *Tennessee v. Lane* in 2004. In the *Lane* ruling, the Court upheld provisions of Title II of the ADA as applied to create a right of access to the courts for individuals with disabilities. The state of Tennessee had raised questions regarding the authority of Congress to place accessibility obligations on states and state entities under Title II and to authorize monetary damages when they fail to comply with these obligations. The Court rejected these challenges and held that Title II of the ADA, as applied to cases implicating the fundamental right of access to the courts, constituted a valid exercise of Congress's enforcement power under the Fourteenth Amendment. The Court found that "Congress enacted Title II against a backdrop of pervasive unequal treatment in the administration of state services and programs, including systematic deprivations of fundamental rights." The Court ruled that the congressional finding in the ADA of persisting discrimination against individuals with disabilities in critical areas, including access to public services, "together with the extensive record of disability discrimination that underlies it, makes clear beyond peradventure that inadequate provision of public services and access to public facilities was an appropriate subject for prophylactic legislation." While recognizing a solid constitutional foundation for the basic thrust of Title II of the ADA, particularly in its application to access to state courts, the *Lane* decision does not fully resolve all questions about the legitimacy of congressional authorization of private lawsuits against states in situations where access to the courts or other "fundamental rights" may not be at issue.

PROBLEMS AND CHALLENGES

The National Council on Disability, which originally proposed the enactment of the ADA, has monitored progress under the law on an ongoing basis. In June 2000, the council issued a report addressing federal compliance, enforcement, technical assistance, and public information activities for Titles I through IV of the ADA. The report, *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act,* examined ADA enforcement activities of DOJ, the EEOC, the Department of Transportation (DOT), and the FCC. The National Council on Disability found that, although the executive branch had consistently asserted its strong support for the civil rights of people with disabilities, "the federal agencies charged with enforcement and policy development under the ADA, to varying degrees, had been overly cautious, reactive, and lacking any coherent and unifying national strategy." The report was critical of case-by-case enforcement efforts in lieu of ongoing compliance monitoring and cohesive, proactive enforcement strategies. It also criticized the federal agencies for not having taken leadership roles in clarifying frontier or emergent issues. Underlying causes of enforcement deficiencies were identified as including the "cultures" of particular agencies, their reluctance to expand their views of their missions and to take strong stands on issues, and, critically, chronic underfunding and understaffing of the responsible agencies. Such factors, according to the council, had undermined federal enforcement of the ADA in its first decade, allowing the destructive effects of discrimination to continue without sufficient challenge in some areas and contributing to problematic federal court ADA decisions unnecessarily narrowing the scope of the law's protections. The report included 104 specific recommendations for improvements to the ADA enforcement effort.

In addition to its oversight of federal agency ADA enforcement efforts, the National Council on Disability has monitored ADA cases in the courts. In 2002, the council inaugurated a major initiative to address serious problems created by court decisions interpreting and applying the ADA. Spurred by concerns expressed at a series of meetings with ADA stakeholders, the National Council on Disability had become increasingly troubled by decisions in which the U.S. Supreme Court took restrictive and antagonistic approaches to the ADA, resulting in significant diminishment of the civil rights of people with disabilities. Initially, the council developed a series of policy briefing papers explaining the problematic aspects of the decisions of the Supreme Court and describing their negative implications. Such papers were issued under the title *Policy Brief Series: Righting the ADA Papers,* and were published on the council's website.

On December 1, 2004, the National Council on Disability issued a final summary report, titled *Righting the ADA,* highlighting key material derived from the various specific topic papers and offering legislative proposals for addressing the problematic implications of the Supreme Court's ADA decisions. The report presented legislative proposals in a combined form to produce a draft "ADA Restoration Act of 2004." It explained that such drastic action was necessary to address "a series of negative court decisions [that] is returning [Americans with disabilities] to 'second-class citizen' status that the Americans with Disabilities Act (ADA) was supposed to remedy forever": "Like a boat that has been blown off course or has tipped over on its side, the ADA needs to be 'righted' so that it can proceed toward the accomplishment of the lofty and laudable objectives that led Congress to enact it." The ADA Restoration Act was designed to (1) reinstate the scope of protection the act affords, (2) restore certain previously available remedies to successful ADA claimants, and (3) repudiate or curtail certain inappropriate and harmful defenses that have been grafted onto the carefully crafted standards of the ADA.

Despite its concerns about some judicial interpretations and executive agency enforcement of the ADA, the council expressed in both its *Promises to Keep* and *Righting the ADA* reports its belief that the law has had numerous positive effects and has "begun to transform the social fabric of [the] nation":

> It has brought the principle of disability civil rights into the mainstream of public policy. The law, coupled with the disability rights movement that produced a climate where such legislation could be enacted, has impacted fundamentally the way Americans perceive disability. The placement of disability discrimination on a par with race or gender discrimination exposed the common experiences of prejudice and segregation and provided clear rationale for the elimination of disability discrimination in this country. The ADA has become a symbol, internationally, of the promise of human and civil rights, and a blueprint for policy development in other countries. It has changed permanently the architectural and telecommunications landscape of the United States. It has created increased recognition and understanding of the manner in which the physical and social environment can pose discriminatory barriers to people with disabilities. It is a vehicle through which people with disabilities have made their political influence felt, and it continues to be a unifying focus for the disability rights movement. (National Council on Disability 2000:1; 2004b:37–38)

These rosy sentiments are tempered with the observation that "implementation has been far from universal and much still remains to be done."

—Robert L. Burgdorf Jr.

See also ADAPT; Antidiscrimination Law: Judicial Interpretations; Communication: Law and Policy; Family: Law and Policy; Health Care and Disability; Housing: Law and Policy; Rehabilitation Act of 1973 (United States).

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AMOR HEREOS (LOVESICKNESS)

The term *amor hereos,* meaning lovesickness, stems from a twelfth-century Latin medical text by Constantine the African, a translator of Arabic treatises: "Amor qui et eros dicitur morbus est"—"The love, which is called 'eros,' is a disease." Lovesickness, as a concept, dates at least from ancient Greece and later Byzantium, continuing in academic medical treatises until the early modern period. Texts on *amor hereos* are found in Greek, Arabic, Latin, French, English, Italian, and many other vulgar languages (languages of the common people). Its life in popular culture continues today.

Amor hereos is a curious cultural condition; it had no social class basis in its early medical descriptions, but by the end of the thirteenth century became an illness of the elite, a transition characterized by modern scholars as one from *amor eros* to *amor heroicus.* This transition occurred in concert with the rise of chivalry; Geoffrey Chaucer refers to it thus in the *Knight's Tale.* Lovesickness was so important in this courtly context that later texts suggested ways of simulating its symptoms.

In its more classic evocation, the image of the loved one entered through the victim's eyes, causing a humoral alteration, particularly the two hot humors, blood and black bile. The disabling symptoms of lovesickness were variable, sudden, and chronic (lasting six months or more). Insomnia, pain, anxiety, a jaundiced color, and wasting were some of its symptoms. In one early modern case, a shoemaker fell limp and lost speech for a week, assuming a form of paralysis. Severe melancholy and even death were other potential outcomes.

Some treated the condition with wine, conversations with close friends, walks in nature, music, and observing the faces of beautiful women. Others recommended playing games and doing delightful things, and also fattening and moistening foods, jokes, intercourse with a woman who was not the cause of the condition (often a prostitute), or a purgation of the humors.

Initially, men were the typical victims of lovesickness, though Galen treated at least one woman with the condition in the second century. During the Renaissance, as chivalric culture declined, lovesickness became increasingly a condition of women. With its shifting gender, lovesickness's pathologic etiology changed from psychological to sexual, while therapy changed to regimenal and dietary interventions.

—Walton O. Schalick III

See also Galen; Hippocrates; Melancholy.

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AMPUTATION

To *amputate* is to cut off (e.g., a limb, arm) by a surgical operation (*American College Dictionary*). The term sometimes is used to refer to a traumatic event such as to have a leg or foot amputated by a land mine where salvage is impossible.

SOME CAUSES OF LIMB AMPUTATION

About 90 percent of lower-limb amputations in Western countries of the world are due to peripheral vascular disease (PVD), which is often connected with diabetes mellitus. Surgical attempts to salvage limbs (e.g., where there is PVD) may later have to go on to amputation. Not uncommonly, salvage failure causes patients and even some surgeons to feel that amputation signifies a failure. However, experienced clinicians look upon necessary amputation positively as a new opportunity for successful rehabilitation if the surgical amputation is handled expertly and if good pre- and postmanagement procedures are followed. Therefore, they believe that special attention should be placed on the techniques associated with amputation and that amputation should be thought of as a high art.

Elective amputation may be necessary following infections of various kinds. Infections frequently occur in the foot when that area has sensory deficits caused by diabetes or other medical conditions. Many amputations due to infections can be avoided if there is good patient compliance with foot management regimens (e.g., proper shoes, foot hygiene, skin care, proper nutrition, and periodic medical observation). Infections such as bacterial meningococcemia are particularly pernicious and may result in loss of multiple limbs or death even in healthy young persons.

Elective amputations can also result from tumors or from failure of limb salvage attempts during tumor removal. Under ordinary conditions, tumor-related amputations are not as common as amputations due to PVD or infection.

The general population probably thinks first of amputation caused by trauma. Leading trauma causes of amputation are farm machinery accidents, car accidents, industrial accidents, burns from high-voltage electrical accidents, frostbite, and military combat.

A small number of children are born with limb deficiencies. Years ago, before the fetus could be viewed in utero by ultrasonic methods, the birth of a child with a limb deficiency was often a shock to parents. This shock can now be ameliorated with counseling and preparations before the child's birth.

DEVELOPMENT OF AMPUTATION SURGERY AND ARTIFICIAL LIMBS

Amputation of body parts and their artificial replacements can be traced to antiquity. Ambroise Paré, a French Army surgeon of the sixteenth century, is often regarded as the father of amputation surgery, partly because of his development of the ligature, his selection of sites for amputations, and his interest in prostheses and outcomes. Development of the ligature and later the tourniquet, aseptic techniques, and anesthesia has been key to successful amputation surgery. With these techniques, amputation procedures developed rapidly during and following World War I, particularly by German surgeons exemplified by Krukenberg and Sauerbruch. In a number of countries, the end of World War II in 1945 ushered in the first organized research and development efforts in the field of amputation and prosthetics. Scientists, engineers, and prosthetists were brought together with surgeons to advance the field of amputation and prosthetics, as admonished by Sauerbruch around 1916.

This interdisciplinary approach has been productive, and significant advances are being made, but adequate replacement of human limbs remains a daunting task. It seems clear that technology is not enough. Surgeons need to be important members of research teams in this field, not only to perform amputations but also sometimes to reorganize body tissues in ways that make it possible to design and build completely new kinds of limb replacements that may be superior to what has been known previously.

PEOPLE WITH AMPUTATIONS

People who have had amputations, like many other persons with disabilities, are not sick. Whether famous or infamous, many people who have had amputations have been achievers throughout history. The Netherlands'

Peter Stuyvesant wore a wooden leg and was governor of New York. England's Admiral Horatio Nelson was a right-arm amputee. Blind in his right eye, Nelson ended his naval career—and life—with a spinal cord injury from a sniper's shot in 1805. Look carefully at Nelson's statue on the tall column in Trafalgar Square in London and you will be able to see that his right sleeve is empty. Confederate General Thomas J. "Stonewall" Jackson was accidentally shot in the left arm by his own troops as evening fell at Chancellorsville. When he died from blood poisoning a few days after amputation of his arm, General Robert E. Lee, leader of the Confederate forces in the American Civil War said, "Jackson has lost his left arm, and I have lost my right arm."

French actress Sarah Bernhardt, "the Divine Sarah," had a leg amputation. John Wesley Powell was an intrepid explorer of the Colorado River without a right arm. Bernhard Schmidt was not inhibited by amputation of his arm when he was 15 years old. Known in Germany as "the optician," his famous telescope design and his ability to make mirrors and lenses to high accuracy is legendary. "Peg Leg" Bates was a dancer in New York City, even though he had lost part of his left leg in an auger accident. He became a star tap dancer using an artificial leg. Harold Russell, who lost both hands in a military training accident, received two Academy Awards—one for Best Supporting Actor and a second, honorary, award for "bringing hope and courage to his fellow veterans"—for his acting role in the 1946 movie *The Best Years of Our Lives*. That event led him to become an important American advocate for persons with a disability.

Two unlikely amputations occurred in 2003. A young woman, Bethany Hamilton, lost her left arm in a shark attack while surfing. A hiker/climber, Aron Ralston, 27, had to amputate his own arm below the elbow using his pocketknife to escape death when he became caught by a boulder in a remote area of Utah.

The previous paragraphs illustrate how the lives of some widely known people have been altered by amputation of limbs. Their stories are compelling but really no more compelling than the stories of many others with amputations who are just less well known.

—Dudley Childress

See also Accidents; Biomechanics; Burns; Diabetes; Phantom Limb Pain; Harold Russell; Surgery; Veterans.

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AMPUTEES AT PERSEPOLIS

As Alexander the Great advanced to take Persepolis in southwestern Persia in January 330 BCE, he met a large, desperate group of released Greek prisoners whose hands, feet, ears, or noses had been cut off by their captors. In one account, there were 800 men who had been trained in various skills or crafts, "then their other extremities had been amputated and they were left only those which were vital to their profession." In another version, nearly 4,000 men had had parts amputated and then were "branded with letters from the Persian alphabet" to amuse their captors: "They looked more like outlandish phantoms than men."

The group begged Alexander to save them from their tormentors. Shaken by the spectacle, Alexander promised help. The men withdrew to discuss what to ask. The key issue was whether to return to Greece and disperse to their villages, facing an uncertain reception because of their appearance, or to remain as a mutually supportive group in the Persian lands conquered by Alexander. The debate is framed in the mouths of two orators. One states that public and private reactions back home will be adverse, and they know this because they themselves would find each other's appearance intolerable if they were not all in the same boat. They should stay in Persia, keeping their misfortune hidden from those who had known them earlier. The second speaker suggests that decent people do not think like this, and the group should certainly return to breathe the sweet air of their homeland and enjoy their freedom, their own gods and culture.

A few of the men wanted to return to Greece, but the great majority voted to ask for land and benefits in Persia. When their delegates met Alexander again, he had already decided that they would opt to go home, and he had made arrangements for transport and cash in hand. When the men explained what they really wanted, Alexander changed his plan, granting them land, livestock, clothing, food, and money.

The incident has undergone much skeptical review by classical scholars, as many curious myths and legends are attached to Alexander's life. The earliest extant manuscript record of the story dates from about 1,200 years later. It may have been rooted in contemporary records, but it could have been fabricated centuries later. However, no evidence actually disproves the story. The mutilations, the anticipated public reactions, and other details are consistent with other data from Persia in that period. It appears as the world's earliest record of a recognizable debate among a large group of people with significant disabilities, and also the first record of such a group advocating their case with a ruler and causing him to change his plan for their welfare.

—Kumur B. Selim

See also History of Disability: Ancient West.

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ANTHROPOLOGY

Cultural anthropology is an especially well-suited disciplinary perspective to use in considerations of impairment and disability. This is partly evident in the number of nonanthropologists who have applied anthropology's methods and core concept of culture in their research. The central concern of cultural anthropology has always been the understanding of difference: how various forms of difference are defined, constructed, and managed in different times and places. This preoccupation with difference and the discrimination that is often attached to devalued differences reveal why anthropology can be of vital importance to the study of disability.

Particular dimensions of this work have produced questions that are especially salient for impairment. Some examples illustrate the connections: In what ways are the negative cultural constructions of subgroups based on their differences contributing to and rationalizing their marginalization and oppression? Parallel issues faced by many indigenous peoples are elaborated in ethnographic research. How do questions of power, resistance, voice, representation, and self-determination get worked out for cultural subgroups? We look at how both these processes also hold the potential for positive group identity and emancipation. Anthropologists interrogate medicalized, individualizing responses to what are fundamentally sociopolitical or economic justice problems in a way that echoes concerns in disability studies. Beyond its conceptual concerns, anthropological research methods and critical reflection on them offer potentially fruitful avenues for research in this field. This is especially true for new areas that require an exploratory approach because not enough is known to undertake standard survey research.

Although for various reasons anthropologists have been slow to engage more deeply in disability studies, original and controversial research in the past decade suggests that the tide is turning. Anthropology offers salient insights and practical tools for sharpening core disability studies debates, partly because it has already been over isomorphic terrain in relation to issues faced by indigenous people and minority groups around power, voice, intra-movement fragmentation, insider-outsider (emic/etic) debates, and how to stake claims for recognition and accommodation with a dominant group that uses different measures of value. Anthropological experience with cross-cultural comparison and its conundrums will also be instructive.

Anthropology would grow from greater attention to advances in critical disability studies where the aforementioned issues combine with sensitive cultural norms and ethical/medical taboos to reveal the limits of some theories' usefulness. For excellent examinations of how anthropology and disability are linked, see especially Kasnitz and Shuttleworth (1999), Linton (1998), and Stiker (1992).

DEFINITION OF TERMS

This entry uses the Union of the Physically Impaired against Segregation (UPIAS) definition of *impairment* as a physical or cognitive lack or abnormality a person has and *disability* as a restriction or disadvantage accruing to the person due to physical and social environments not being designed to support that impairment. The term *developmental disability* will be used to encompass intellectual disability (mental retardation) as well as autistic spectrum disorder, cerebral palsy, and other conditions that can result in substantial restriction of cognitive function or the expression thereof.

Anthropology and *culture* have no single, agreed-on definitions. This reflects both their breadth of subjects and theories and the discipline's tradition of self-critique. Minimally, anthropology is the study of human cultures that comprise human beliefs and behaviors. Culture, then, is what we think and feel, how we make sense of the world, and what that can lead us to do (action) and produce (artifacts). Anthropologists do not *create* meaning, but rather use their analytical writing (ethnography) to evoke and render intelligible (to others) a way of life that is already meaningful to those living it, as Clifford Geertz put it. While the audience used to be those "outside" the culture under study, increasingly, ethnographies are written with inside audiences in mind, through new articulations and analyses of their experiences.

For instance, Pamela Cushing's (2003b) ethnographic research of L'Arche, a residential support organization for people with developmental disabilities, sought to elucidate how that subculture worked against stigma to promote mutuality in caregiving relations. Her research aimed to inform and influence state policy makers and other providers who are currently struggling with how to improve relations and social inclusion in the mainstream. Esther Ignani's research (2005) with youths with disabilities seeks to work against misinformed but common notions of what life with impairment is like, as they co-create autobiographical films. This is part of what Cushing calls reshaping the public's moral imagination regarding disability, and what anthropologists Rayna Rapp and Faye Ginsburg (2001) call rewriting disability narratives.

Although anthropologists study all aspects of culture, current research focuses more on everyday life than grand, ritual events. Second, its methodological core is the grounded, long-term research of participant observation, which includes extended periods of sharing and participating in everyday life with those you are studying as well as in-depth qualitative methods such as individual and group interviews, or narrative analysis. Combined, these make anthropology well suited to identify gaps between stated beliefs and actual lived behavior. Rather than judge such gaps from their own worldview, anthropologists use the gaps as a starting point to begin asking critical questions about the culture: What purposes or whose interests might such a gap serve? What tensions or uses of power does it reveal? This perspective could help to explore the gap between the positive hopes of disability rights and the daily forms of exclusion faced by many individuals and families living with developmental disability.

Culture is often defined through its traits. Culture is not inherited but learned both consciously and inadvertently, and shared among a group. Although shared differential access to cultural knowledge is inevitable, subgroups develop specialized cultural norms and knowledge, or, alternatively, status differences can restrict one's access. For example, within disability culture, subgroups such as wheelchair users or Deaf people have their own nuances, jokes, and language based on shared experience. An understanding of culture as dynamic (changing), heterogeneous (having different, even disparate elements), and syncretic (many influences) has replaced the previous view of culture as static (unchanging), homogeneous, and bounded (closed). Since many disability scholars use culture as a core concept, the definition is important: The term is often diluted or misused outside the discipline. The idea of a "disability culture," for example, has been widely debated with little reference to anthropological theory, as discussed below.

Another important development in cultural theory is the recognition of how power is at work in cultures and of a need for greater critical examination of those processes. Feminist and postmodern scholars have shown that since cultures have multiple subject positions within them, cultural knowledge is always partial, positioned, and embedded in such power relationships. This does not mean that all perspectives are invalid or solipsistic, but rather that multiple views need to be gathered and consulted to establish an empirical sense of the whole. In terms of disability studies, such theories indicate that better evocation of the worldviews of people with anomalous bodies and minds will contribute to widening the scope of human understanding.

Finally, anthropologists have also identified common pitfalls in how the concept of culture is applied that are relevant to disability. Wikan (1992) argued that the very notion of "a culture" lures people to overemphasize differences, especially exotic ones, that tend to separate us as humans, over the commonalities that could bring us together. Roeher Institute (1996) and Trent (1994) have shown how detrimental a fixation on (devalued) difference has been for people with impairments whose identity becomes conflated with the impairment.

Others argue that the culture concept tends toward generalizations that gloss or flatten intragroup differences. For instance, the idea of promoting a coherent front for the disability movement or culture is a form of strategic essentialism and can be effective for rhetorical and activist purposes. The pan-impairment solutions that get proposed, however, do not necessarily meet the particular needs of all members. This has arguably been the case for people with developmental disabilities within the broader disability movement. They remain burdened with significant stigmas; ongoing resistance to their inclusion in schools and workplaces and rising rates of selective abortion of fetuses with impairments are two cultural indicators of this attitude.

HISTORICAL CONTRIBUTIONS

Anthropologists studying impairment such as Stiker ([1982] 1999), Kasnitz and Shuttleworth (1999), and Rapp and Ginsburg (2001) have variously lamented that no adequate anthropology of disability had yet emerged. Just 15 years ago, Oliver (1990) noted that most anthropologists still considered disability (unlike gender or race) to be an unproblematic category, and like many writers, consigned nontypical or so-called deviant people to footnotes. Anthropologists' lack of engagement can be traced to manifold factors. Goffman's (1963) "courtesy stigma" (avoidance of deviance) could play some role in our field site choices, and perhaps disability was not as visible a "social issue" for the mainly preindustrialized peoples we have classically worked with. It is not true, however, that impairment was absent in past ethnography because disabled people did not survive in tribal societies (Linton 1998).

Two theoretical explanations for our absence are also plausible. For many years, the ethnographic optic was predominantly *across* cultural groups; an interest in *intra*cultural heterogeneity or theorizing exceptionality (such as impairment) is only of recent interest. Marxist and feminist approaches have since added much-needed correction to this interpretive bias. Furthermore, prior to the 1970s, ethnographies aimed for a "snapshot" of a coherent, homogeneous tribe or cultural group, which did not leave much room for inclusion of anomalous characters or unusual scenarios. Corrective research has emerged such as those that explicitly consider exceptional circumstances of families with a child with an impairment.

Interestingly, Oliver noted that the analyses of certain anthropologists who did venture into disability contained prescient insight akin to the future social model. Benedict (1934) made an impressively early attempt to argue for conceptualizing epilepsy and other abnormalities as cultural constructs. Farber (1968) wrote that disability is a "social imposition," not a personal limitation, and that the negative effects of labeling were equal to those due to actual "incompetence." Based on Mexican research, Gwaltney (1970) perceptively concluded that the meaning of blindness is variable and thus must be culturally contextualized. These insights hint at an idea of the *social* status of handicap historically and cross-culturally.

When Edgerton did his now famous longitudinal ethnographic study (1967) of deinstitutionalization of the "mentally handicapped," however, he chose to use Goffman's concepts of stigma and institutional effect, as well as labeling and symbolic interactionism. Edgerton's portrayal was evocative and was widely read across the social sciences, helping identify significant transition challenges. He described how people tried to pass (as normal) in society through coping tactics, relationships, and harmless ruses. Klotz (2004) argued that Edgerton's conceptual framework biased the course of ethnography toward concepts implying deficit or lack, and away from cultural construction or direct subject/worldview elaboration. Still, such vintage ethnographies offer useful perspectives on cultural norms of the period, and they drew much-needed attention to deinstitutionalization as a social concern.

CONTEMPORARY RESEARCH

Disability studies as a critical field of study based in human and social sciences (outside medical, rehabilitation, and education) has grown rapidly since the mid-1970s with the founding of the Society for Disability Studies (United States) in the early 1980s. While the use of anthropological theory and methods by other scholars has been an important part of that growth, engaged anthropologists remain few and, as Kasnitz and Shuttleworth (1999) noted, they often write for anthropological audiences without sufficient reference to disability studies developments, although this is changing.

Categories of Anthropological Research

Grouping the existing ethnographic research in impairment/disability helps to highlight the relevance of anthropology to impairment and disability studies, whether undertaken by anthropologists or not. There is no set typology for this formative area of research. The categories below reflect recent anthropological activity. See the final section of this entry for areas of strong potential. Cultural constructionism, cross-cultural comparison, and insider methods and perspectives are the three categories, and the risks of disability studies interdisciplinarity are also addressed.

The most effective of these works take disability seriously as an analytic category within the culture, rather than beginning from a traditional biological, individual perspective. While the latter is also useful, it can hide or distort other important cultural processes and beliefs at work. Groce's (1988) ethnography of Martha's Vineyard, an island off the New England coastline, is notable in this vein. She shows how the meaning of deafness, an impairment that was generally perceived in American culture to be a deficit and a "personal tragedy," was socioculturally contingent. Since hereditary patterns made deafness pervasive on the island, most locals learned to sign, thereby greatly reducing the stigma and "disabling effects" of the environment.

Another example of taking disability seriously as an analytic category comes from emerging attention to impairment in medical anthropology. Rapp and Ginsburg (2001) explore how parents' experience of having and raising a child with an impairment is interwoven with cultural expectations and taboos regarding perfection and health in individuals and families. Along with Gail Landsman (1998), they examine how the private narratives and experiences of American parents expecting or raising an anomalous baby interact with the mainly negative public narratives of disability. Their work builds from literature, such as Kenzaburo Oe's (1995) biography and novels about his family's transformation through the birth of their son.

Cultural Construction and History

A common approach to impairment/disability among anthropologists and others is to show how it is a socially and culturally constructed category, contingent on values and ideology as much as physical/mental conditions. Acknowledging this contingency helps to provide the analytical framework for understanding the powerful negative effects that labeling, segregating, and devaluing have had. Those effects are largely ascribed to the negative assumptions of the biomedical and functional models of impairment (although these should not be seen as separate from the moral fabric of the society that produces them). This critical cultural history approach examines the shifting meanings that disability has had over time in a culture.

It works from the postmodern assumptions that truth is partial, contingent, and interested. Four examples of this approach demonstrate its power and breadth.

Trent (1994) used archival research and document analysis of early- to mid-twentieth-century U.S. institutional records, correspondence, and government policy shifts. He teased out a set of cultural metanarratives that successively guided policy, welfare support, IQ testing, rehabilitation, and institutional life for "the mentally retarded." He shows how these conceptual changes had less to do with scientific advances than with broader sociocultural or economic changes. For example, he noted the impact on people with intellectual disabilities of changes in social organization due to industrialization, in notions of contagion due to rise of germ theory, and in systems of moral and social control that arose with eugenics. Trent outlined the public and professional shift from narratives of compassion and protection *of* "the handicapped" to that of suspicion and protecting society *from* them. Anthropologists have long examined how such metanarratives interweave cultures, effectively permeating public perspectives about a subgroup such as indigenous peoples.

Stiker ([1982] 1999) also situates impairment/disability in its cultural and historical context using cultural symbolism. He examined the emergence of state governance of the "invalid body" in France, as many war veterans acquired physical impairments. Stiker critiqued disability scholars for too smugly accepting the medical and social models as theoretical end points. Like Foucault's studies of madness and institutions, Stiker used enduring cultural problematics such as limits and boundaries (here, normal and abnormal) as his optic for exploring such social changes.

An anthropological perspective should, he argues, alter the reductive emphasis of considering disability simply in terms of oppression (rights, minority group politics) and economic systems (exclusion/poverty). That disabilities operate as powerful emotional triggers suggests deeper social conflicts than just material oppression in a particular social structure (Western, capitalist, medical). Disability discrimination also originates in our abiding collective cultural fantasies about perfect bodies, health, and minds and the converse fears of infirmity, deformity, and unreason.

Indeed Stiker suggested that the specificity and fundamental symbolic significance of disability can be clouded or drowned by those other emphases. For example, he applauded Murphy's use of cultural liminality as a heuristic with specific symbolic meanings for impairment related to modernist social order. Research into broader symbolic and cultural meanings could offer more thorough understanding of the bases for exclusion that would feed more creative ways of imagining impairment back into the social fabric.

Two anthropologists use this symbolic approach. Desjardins (2002) conducted research into the emic (insider) perspective of people with developmental disabilities on their experience of daily social life in relation to the mainstream, which he described as simulacra or parallel worlds. He uses his findings to undermine mainstream assumptions about what kind of inclusion people want and to explore what the symbolic meaning and function of the inaccurate assumptions were. He points to modern society's intolerance of real difference, but also to the potential richness of life on the margins. Michalko (2002) begins from personal experience of blindness and usefully generalized to cross-impairment issues with a range of theoretical perspectives. He insisted that disability is a difference that matters symbolically and practically and should not be elided with other differences.

Cross-Cultural Comparison

Anthropology's locus classicus has been preindustrial, non-Western societies and thematic cross-cultural comparisons using those findings. Some anthropologists, and other scholars using ethnography, are beginning to answer the call for greater ethnographic description and theorizing of anomalous bodies and minds in those settings. This work has helped substantiate further that impairment and disability as conceived in the West are culturally located notions, but improvement is still needed. The disability specialists Kasnitz and Shuttleworth (1999) and Linton (1998) argue that more cross-cultural studies are needed. Specifically, they call for studies designed for this purpose, not ones that mine old data for signs of (Western-defined) impairment, which makes for thin data and risks layering etic interpretations on local perceptions. Phenomenological studies are needed that do not begin from Western categories and that assess local understanding and management of perceived challenging, anomalous conditions.

Devlieger's (1995) ethnography of the African Songye people's worldview is a good model. His goal is to understand whether the concepts of impairment or disability hold any meaning in the Songye symbolic systems. He found that they have three categories of "abnormal" kids, none of which is equivalent to the U.S. term *disability*. He showed that Songye are more concerned with the existential and familial (the social meaning of anomalous children) than the technical (rehabilitation, cure, medicine). This leads them to think more about causes, especially social ones, and how to rebalance those social wrongs, rather than how to "fix" the child directly. This notion curiously echoes earlier Christian notions of disability as punishment, which may have been imported via missionaries. Furthermore, social consequences of impairment are variable.

Ingstad and Whyte's (1995) widely read collection of cross-cultural research introduced useful new perspectives, and the critiques of it are also instructive. Kasnitz and Shuttleworth (1999) noted inconsistent use of the terms disability and impairment across contributors, and various authors begin from an etic/outsider understanding of an impairment (e.g., blindness). Finally, these and other cross-cultural researchers often neglect to acknowledge, use, or challenge existing disability studies theory, hence omitting key disciplinary concerns. Still, this and other cross-cultural texts are necessary first steps.

Oliver (1990) noted that the paucity of existing material and its tendency toward a medical or individual model makes it difficult to develop either an empirical or theoretical account of disability cross-culturally. More research is needed both on specific impairments and on pan-impairment conceptions, and both need to draw on and evoke the emic point of view more extensively. While Devlieger cautioned that greater state involvement does not necessarily signal better quality of life, there is also an unhelpful tendency for some authors to romanticize the non-Western societies' approaches, assuming that the *lack* of an elaborate medical labeling system indicates de facto greater support or acceptance. For example, the lack of state or medical support for people with developmental disabilities in Ukraine reflects rejection and lack of political will or resources, not acceptance. Greater anthropological attention to these concerns should aid in creating a basis for cross-cultural comparison even without common terms. Oliver reviewed research that begins to name common factors that effect perception and treatment.

Insider's Perspective and Methods

Disability studies scholars continue to call for greater inclusion of the active voices of people with disabilities in research and less emphasis on the perspectives of nondisabled peoples' *response to* disability. Insider (emic) writing has expanded in the past two decades. These tend to be by or about people with physical impairments, often late-onset or acquired ones. They are mainly autobiographical and only occasionally analytical (e.g., Murphy 1990). People with developmental disabilities often need special supports or alternative media forms to tell their story. College and university access centers and disability studies programs are beginning to develop creative solutions for increasing disabled students' access to social science education.

The qualitative, intimate research methods of anthropologists and some sociologists have begun to yield more representative accounts. Qualitative research can be especially fruitful when exploring new areas or emic worldviews such as the views of people with intellectual impairment. Klotz (2004) discusses anthropologists who have used participant observation and naturalistic phenomenology for this purpose to good effect. This research emphasized the centrality of interactions and relationships to understanding what a person with profound intellectual impairments is experiencing, and the meaning of certain behaviors. Such research can expand anthropological paradigms and contribute to better social care policy.

The anthropologist Gelya Frank (2000) undertook long-term collaboration with a social sciences student who had complex physical impairments. Both wrote about the student's life story, one as an autobiography, and one as a reflexive ethnobiography that critically explored what could be learned about the student's cultural environment from events, themes, and structures in her life story and how she narrates them. Narrative theory continues to flourish in the field.

The anthropologist Murphy (1990) wrote a combination ethnography and autobiography, which "anthropologized" his personal experience of acquiring a degenerative disability. This widely read book attempts to situate processes such as stigma in specific cultural values and personal interactions. He also explored, with some disdain, the direct relationship between his physical and mental decline and the quality or willingness of others to interact with him. He theorized his experience that when a person with impairments cannot fully "recover normalcy," he or she is socially positioned in what anthropologists term a "liminal" or "in-between" state: not ill but not well, neither sidelined fully nor integrated, and perceived somehow as at fault for being a disturbance to modernist order.

Challenges for Interdisciplinarity

Murphy's (1990) insightful book was critically acclaimed and widely read by anthropologists and activists, but it has also been critiqued in ways that illustrate the challenges of doing research in an interdisciplinary field. It is difficult to keep abreast of developments in theory across all the fields whilst also maintaining depth in one's own discipline.

Murphy chose to write within anthropological and sociological frameworks rather than within the emergent disability studies sociocultural model. While some, such as Stiker, praised his innovative application of those frameworks, others critiqued his insensitivity to disability studies theory. For instance, Arthur Frank identified common themes in acquired disability narratives such as restitution (cure/getting well again), chaos (confusion), and quest (illness as route to transformation). Kasnitz and Shuttleworth contended that Murphy sustained a restitution narrative through much of the book emphasizing only negative aspects of his impairment: loss, depression, and exclusion. Furthermore, his story often conflates identity and impairment in contrast to the disability studies theorists' attempt to show that impairment is neither deterministic nor universalizing. Many anthropologists and other authors have similarly either ignored disability studies and even accused it of analytical omissions that it did not have, presumably due to inadequate knowledge of that literature.

Anthropologists must better situate their research both in anthropology and emergent disability studies theory to avoid a merely add-on treatment of disability. This theory is increasingly sophisticated and offers insights around difference, power, and exclusion, which will also refine anthropological theory. For instance, classic ethnographic categories such as kinship and reproduction are problematized and enriched by considerations of the exceptional family, while still avoiding exotification or overemphasis on role of difference. Disability studies theorists must also become more familiar with fundamental advances in relevant anthropological theorizing such as cultural analysis and change, difference, positionality, representation, voice, narrative, and interpretivism.

FUTURE RESEARCH DIRECTIONS

Anthropological theory and approaches are especially well suited for illuminating disability as a social, cultural, and symbolic process. Greater attention to questions raised by impairment-disability will also sharpen and inform that theory. What follows are a few suggestions for future research directions for anthropology and impairment-disability.

Symbolism and Cultural Analysis

Anthropological theories of voice, power, difference, and representation can illuminate underlying cultural tropes and values that impairment and disability trigger. Theorizing exceptionality, anomaly, and marginality may provide one fruitful avenue. More nuanced studies of disability symbolism in Western and other cultural stories, idioms, and events are needed. Further examination of the role of religion and spirituality as symbolic systems of meaning in relation to impairment fits well into this category.

Medical Anthropology

Medical anthropology involves reflexive analysis of the construction of knowledge of health, illness idioms, and social injustice. It can reintroduce disability studies to questions of embodiment, the role of medical technologies in people with disabilities' lives, and issues with health care systems. Anthropologists have recently turned greater attention toward the sensory, somatic, and biological aspects of life, after years of neglect. Sterilization, euthanasia, reproduction, caregiving, and abuse are all potential disability studies topics. One question is, how does neo-eugenics come to make cultural sense amid the inclusive discourses of disability rights? What are the roots of the countervailing discourses of perfection and mastery?

Disability Culture Debate

The scholarly and popular disability communities continue to debate whether or not there is a disability culture, its politics and cohesiveness, and boundaries (who is in or out of it). Anthropologically informed voices could help articulate the characteristics and evolution of the social movement and support it to consider its options, for example, to sound a caution about how strategic essentialism (pan-disability arguments) is used for rhetorical/activist purposes, since it can leave people out, render inadequately considered solutions, and ultimately fragment the group.

Policy: Social Inclusion

Social inclusion and exclusion policy provide a good starting point for bringing cultural and disability questions together (Cushing 2003a). The challenge is, what alternatives are we giving people with disabilities? Social inclusion is not either/or; it is an ongoing process involving many important cultural variables alongside the economics. Anthropology could provide subtle insight around the negative or fearful attitudes toward disability in our culture that act as barriers to greater social acceptance along with the physical integration. It can also illuminate the diverse, culturally contingent meanings of inclusion from an emic (disability) standpoint. Considerations of quality of life, belonging, and spirituality are all salient.

Methodology

Participant observation and creative forms of personal interviews hold the possibility of greater phenomenological understanding of insiders' everyday life experience of impairment-disability, and of generating more positive narratives of this experience as grist for the social mill. The long-term nature of fieldwork lends itself well to studies of impairment and the life course, adult-onset changes, and shifts in self-understanding. Participatory action research offers a route to include the voice and agency of more people with disabilities; however, such work must carefully balance activist aims with research standards of empiricism.

—Pamela Cushing

See also Autobiography; Citizenship and Civil Rights; Cultural Context of Disability; Deafness, on Martha's Vineyard; Developmental Disabilities; Disability in Contemporary Africa; Inclusion and Exclusion; Sociology.

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ANTIDISCRIMINATION LAW: JUDICIAL INTERPRETATIONS

The U.S. Congress took a comprehensive approach to disability discrimination in the Americans with Disabilities Act of 1990 (ADA), defining the covered class broadly, providing flexible, individualized requirements, and authorizing various remedies. Congress's approach reflected a civil rights approach to disability. Under this model, people with disabilities are recognized as a minority that traditionally has been unnecessarily excluded from full participation in society. This modern approach to disability contrasts with traditional models that saw disability as an automatic and necessary basis for exempting people from both the benefits and responsibilities of full community participation. The traditional model addressed disability as either a medical issue to be cured or a justification for charity and segregations. While Congress intentionally used the civil rights model in drafting the ADA, the courts, and most notably, the U.S. Supreme Court, often have continued to rely on the traditional models in interpreting the law. This has led to severe, and sometimes inconsistent, restrictions on disability law.

LIMITATIONS ON WHO IS PROTECTED

Mitigating Measures

The ADA defines a disability as a physical or mental impairment that substantially limits a major life activity. Congress took a broad view of disability when enacting the ADA. The U.S. Supreme Court, in its first case analyzing that definition, appeared to adhere to that definition. The Supreme Court in *Bragdon v. Abbott* took up the issue of when an impairment's limiting effect is substantial. The divided Court found that Ms. Abbott's asymptomatic HIV substantially limited the major life activity of reproduction. The Court concluded that the risk of transmitting the disease to a fetus or sexual partner constitutes a limitation on the ability to reproduce.

Thus, the *Bragdon* Court indicated that limitations external to the disabled individual may be taken into consideration. The Court also made clear that the impairment need not completely prevent the major life activity. In this case, the 8–25 percent risk of HIV transmission to a fetus was substantial enough.

The Court considered whether the "substantial" inquiry should take into consideration personal choices as well as objective limitations. Because of the divisions within the majority, the Court did not provide a clear answer. The Court noted that Ms. Abbott had testified that the risk of transmission controlled her decision not to have a child, thus implying that the decision might have turned out differently if she had made the decision for other reasons or if she had chosen to ignore the risk and have a child. However, the majority drew back from giving dispositive weight to the personal choice factor, stating that "in the end, the disability definition does not turn on personal choice."

However, in a subsequent series of cases interpreting the definition of disability, the U.S. Supreme Court has severely restricted the scope of the statute's protection. The Supreme Court imposed significant restrictions in *Sutton v. United Air Lines, Inc.* and its companion cases, *Albertson's Inc. v. Kirkingburg,* and *Murphy v. United Parcel Service, Inc.*

In *Sutton,* twin sisters had vision worse than 20/200 in both eyes, but corrective lenses gave them 20/20 vision. United rejected them for positions as pilots based on a company requirement that pilots must have uncorrected vision of at least 20/100. In *Albertson's,* Mr. Kirkingburg was a truck driver who was blind in one eye. When the company discovered that he did not meet a federal vision guideline, it fired him without exploring the possibility of a waiver of the federal guideline. In *Murphy,* the plaintiff was a mechanic with high blood pressure that was near normal when he took medication. His job required him to drive commercial vehicles, and he was fired because the employer believed his high blood pressure would not meet a federal requirement.

Together, this trilogy of cases raised the issue of whether mitigating measures should be taken into consideration when assessing whether a person's impairment is substantially limiting. Mitigating measures are measures, such as medication, equipment, or internal coping mechanisms, that reduce the effects of an impairment. The Supreme Court made clear that, when judging whether an individual is substantially limited for purposes of ADA protection, the individual's mitigating measures must be considered.

Thus, the Sutton sisters are not covered by the ADA because their eyeglasses improve their vision to 20/20. Mr. Murphy is not protected because, when medicated, his high blood pressure does not prevent him from functioning normally. Mr. Kirkingburg may not be protected, despite having vision in only one eye, because his brain has developed subconscious adjustments to compensate for reduced depth perception. The Court made clear that the side effects of medications and other mitigating measures should also be taken into account and could weigh in favor of finding a substantial limitation.

The Court relied on three parts of the statute to support its conclusion: (1) the fact that the statute is written in the present indicative verb tense ("limits"), thus "requiring that a person be presently—not potentially or hypothetically—substantially limited"; (2) the requirement of an individualized inquiry focusing on the actual effects on the particular individual, rather than general or speculative effects; and (3) the statute's findings stating that there were approximately 43 million people with disabilities in the United States and the Court's belief that covering everyone who wears glasses would far exceed that number. The Court's conclusion rejected the opposite analysis adopted by the U.S. Department of Justice and the Equal Employment Opportunity Commission and supported by the ADA's legislative history.

The Court's approach in the *Sutton* trilogy demonstrates a particular view of disability and discrimination protections. The Court views people with disabilities as fundamentally different from the general population, rather than as part of the spectrum of ability levels within society. The Court treats disability rights protections not as a check on unfairness, justified by a history of prejudice, but as a type of affirmative action or charity intended only for a small group of individuals whose disabilities set them apart from the Court's view of the general population.

The Court's analysis will prevent individuals with minor impairments from receiving accommodations, such as equipment or policy changes, in the workplace. It will allow a defendant to refuse to hire an individual solely because of his or her impairment, such as diabetes, but escape liability by arguing that the impairment does not arise to the level of a disability because the individual takes medication. It creates a gap in which individuals are considered (quite possibly unfairly) too impaired to work but not impaired enough to be protected from discrimination.

As a result of the analysis in the *Sutton* trilogy, courts are frequently called on to analyze whether a plaintiff's impairment significantly restricts him or her from engaging in a major life activity. Because the plaintiff bears the burden of proof on this issue, impairments that respond to medication, such as diabetes, depression, and epilepsy, are difficult to establish as disabilities, often being ruled out on summary judgment without reaching the merits of the case. However, mitigated impairments still may be "regarded as" disabilities, and entitled to coverage under another prong of the ADA definition of disability.

Major Life Activity

To be covered under the ADA, a person's impairment must substantially limit one or more major life activities. Major life activities include "functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working." The Supreme Court in *Bragdon v. Abbott* provided that major life activities are not restricted to those that have "a public, economic, or daily character." Thus, purely personal activities, such as reproduction, can be major life activities. However, the activity must be of "comparative importance." In *Toyota Motor Mfg., Kentucky, Inc. v. Williams,* the Supreme Court emphasized the need to assess work-related and non-work-related activities in determining whether a limitation is substantial.

In *Toyota,* the plaintiff, Ms. Williams, had carpal tunnel syndrome, which prevented her from lifting more than 20 pounds, working with her arms raised, and doing repetitive wrist or elbow movements. She worked doing paint inspection and assembly inspection at a Toyota factory. Toyota added body auditing and surface repair to Williams's job. To do these tasks, Williams had to hold her arms at shoulder height for several hours at a time. Because her carpal tunnel syndrome bothered her, she requested to be reassigned to do only paint inspection and assembly inspection. Toyota refused. Williams was, therefore, placed under a no-work restriction and fired.

In that case, the Court addressed the boundaries of the major life activity of performing manual tasks. A unanimous Court found that major life activities are those "activities that are of central importance to most people's daily life." The Court went on to decide that performing manual tasks could be a major life activity only if the tasks included were centrally important to most people's daily lives. The Court recognized that "the manual tasks unique to any particular job are not necessarily important parts of most people's lives." Instead, "household chores, bathing, and brushing one's teeth are among the types of manual tasks of central importance to people's daily lives."

The *Toyota* Court, therefore, required a weighing of the objectively important manual tasks Ms. Williams could and could not do. No special weight or emphasis is to be placed on whether the impairment actually affects the job from which the plaintiff is being excluded. While the *Toyota* decision is arguably limited to the major activity of performing manual tasks, some courts that have addressed the issue have applied the requirement of "central importance to most people's daily lives" to other types of major life activities as well.

Direct Threat to Self

The U.S. Supreme Court has narrowed the protection of the ADA by excluding from coverage anyone whose disability would be aggravated by the job or activity in which they seek to participate. Thus, in

Chevron v. Echazabal, Mr. Echazabal was denied employment by Chevron because Chevron believed the job would exacerbate his hepatitis. Although the statute only allows employers to exclude disabled employees who pose a direct threat to the health or safety of others, the Court ruled that Title I, as interpreted by the Equal Employment Opportunity Commission, allows employers to exclude qualified people with disabilities from the workplace because they pose a direct threat of harm solely to themselves. Therefore, people whose disabilities do not prevent them from doing the job and do not pose any risk to other employees or customers may be excluded from jobs because the job might aggravate their disabilities. Disability advocates oppose this approach as allowing paternalistic attitudes of employers to override their own choices.

LIMITATIONS ON RIGHTS CONFERRED

The Supreme Court has not only narrowly interpreted the size of the class of individuals protected by the ADA, it also has interpreted the scope of the rights conferred by the act narrowly. In general, Title I does not require an employer to violate legitimate seniority provisions to accommodate an employee with a disability. The Supreme Court, in *U.S. Airways v. Barnett,* held such an accommodation to be presumed unreasonable where the seniority policy or collective bargaining agreement contains bona fide seniority provisions. The Court held that reassignment to another job in direct violation of a company seniority system is unreasonable as a matter of law, absent a special showing by plaintiff to the contrary.

A showing that reassignment would violate the rules of a seniority system therefore typically warrants summary judgment for the employer, "unless there is more." According to the Court, the plaintiff bears the burden of showing that special circumstances demonstrate the assignment is reasonable. Once the plaintiff has made this showing, the employer then must show evidence of case-specific circumstances that demonstrate undue hardship.

In *Hernandez v. Hughes Missile Systems Co.,* the plaintiff worked as a technician for Hughes. During his employment, he was addicted to drugs and alcohol, and he eventually tested positive for cocaine. The plaintiff was given the option to resign in lieu of termination, which he chose to do. Two years later, the plaintiff applied to be rehired with Hughes, attaching a letter from his counselor to his application. His counselor indicated that Hernandez had been attending Alcoholics Anonymous and staying sober. Hughes declined to rehire the plaintiff based on an unwritten policy of not rehiring former employees whose employment had ended due to termination or resignation in lieu of termination.

The Ninth Circuit Court of Appeals had found this facially neutral policy could be discriminatory if Hughes regarded the plaintiff as being disabled—by virtue of being a previous drug and alcohol user—at the time it failed to rehire him. The appeals court applied a disparate impact analysis to the plaintiff's claim, finding that the facially neutral no-rehire policy violated the ADA because it excluded former drug addicts based on their disabilities. The Supreme Court used this case as an opportunity to focus on a distinction between disparate treatment and disparate impact theories of disability discrimination, a distinction that had not played a large role in previous disability rights case law. A disparate impact claim challenges a facially neutral rule that has an undue effect on a protected population. A disparate treatment claim challenges a rule that treats people with disabilities differently from nondisabled people. The Supreme Court found that Hernandez's argument that Hughes's policy was discriminatory toward former drug addicts was a claim of "disparate impact," rather than a claim of disparate treatment. However, because Mr. Hernandez had not specified such a claim in his complaint, he was precluded from relying on disparate impact as a basis for liability. This approach requires courts and claimants to be specific about the bases for ADA claims, at the risk of losing them.

LIMITATIONS ON ENTITIES COVERED BY THE LAW

In *Board of Trustees of the University of Alabama v. Garrett,* the Supreme Court held that an individual state is immune, pursuant to the Eleventh Amendment to the U.S. Constitution, to suits for money damages under the employment provisions of the ADA. The

Court's reasoning in *Garrett* can be summarized as follows: To abrogate the states' Eleventh Amendment sovereign immunity pursuant to Section 5 of the Fourteenth Amendment, Congress needed to find sufficient proof of a pattern of unconstitutional discrimination against people with disabilities in the area of state employment. The unconstitutionality of this state behavior must be judged by a rational basis standard, because people with disabilities do not receive heightened scrutiny under the Equal Protection Clause. The Court held that Congress failed to meet the requisite standard of proof and that the means it employed to remedy ADA violations were not a congruent and proportional remedy to the harms it did find.

In *Tennessee v. Lane*, the Court faced the issue of whether states are immune from suits for money damages under Title II of the ADA. The plaintiff in *Lane* sued the state of Tennessee for failure to make a state courthouse accessible. The Court held that because access to courts is a "fundamental" constitutional right under the Due Process Clause, Congress validly abrogated states' sovereign immunity insofar as Title II applies to this category of claims. The Court's decision was a narrow one, and left unclear whether states can be sued for damages for ADA violations of other fundamental rights or in cases that do not involve fundamental rights.

There has been a separate question regarding the application of ADA Title III to foreign-flagged cruise ships that enter U.S. waters. The courts of appeals have split on the issue. In *Stevens v. Premier Cruises, Inc.*, the Eleventh Circuit Court of Appeals held that Title III applies to those aspects of cruise ships that qualify as public accommodations in themselves (e.g., lodging, restaurants, shops, and spas), at least while the ships are in domestic waters. The Eleventh Circuit found that foreign-flagged ships were not, in themselves, extraterritorial when they were in U.S. waters. The Fifth Circuit Court of Appeals disagreed, and in *Spector v. Norwegian Cruise Line Ltd.* applied a presumption against extraterritoriality absent a clear expression of intent by Congress. The Fifth Circuit believed that Title III enforcement in U.S. waters would necessarily result in extraterritoriality, because the architectural changes would be permanent and would be carried into foreign waters by the ships. The Fifth Circuit relied on *EEOC v. Arabian American Oil Co.*, in which the Supreme Court held that Title VII of the Civil Rights Act does not apply to American employees of American companies abroad. The Supreme Court granted *certiorari* to review the question, and a decision is expected in mid-2005.

—Eve Hill, Charles D. Siegal, Michael Waterstone, and Peter Blanck

See also Americans with Disabilities Act of 1990 (United States).

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ANTIPSYCHIATRY MOVEMENT

The antipsychiatry movement is lacking a clear definition, and the name itself was not totally accepted by its supporters. Nonetheless, one could say that it is characterized by its diversity, both theoretical and geographic. The effort to offer a synthetic, global image risks reducing this important dimension. Developed in Great Britain, it spread to several European countries, including Italy, and also had proponents in the United States. The movement was built up around forceful personalities from the psychiatric profession, who elaborated an important critique both of the ideas at the heart both of theories of the mind and of associated practices. Its exponents have drawn on contributions from outside the profession, in particular from philosophy, and social criticism, the latter deriving in part from the context of the political and social confrontations of the 1960s. Their philosophical inspiration is based as much on existentialism as on phenomenology, Marxism, and certain libertarian currents.

The physicians D. Cooper, R. Laing, F. Basaglia, and J. Foudraine have by and large challenged the validity, even the necessity, of existing institutions for treatment of psychiatric disorders. They fault these institutions for their violence against patients, for example, through the use of electroshock treatments. They also blame them for being the more-or-less voluntary instruments of social repression, in which the sick person is the exemplary victim. Psychiatrists of the antipsychiatry movement react against the excesses of the old hereditary determinism and the nosography that had become a finality rather than a stage in the understanding of the patient's suffering. The various exponents of the movement have not limited their criticism to the notions and concepts at the heart of psychiatric reasoning; they have been equally active in the sphere of praxis. Kingsley Hall in Great Britain, Trieste with the Italian Basaglia, and the Bonneuil Center in France represent some of the efforts to create real alternatives to the psychiatric hospital and have quickly become sites of pilgrimage for caregivers and intellectuals, who have placed a great deal of hope in the realization of these alternatives.

But the critical spirit of antipsychiatry practitioners and the hope that it raised have not been widely diffused. The antipsychiatry movement has remained a collection of individuals rather than a true school of treatment. Its probable legacy is, then, difficult to assess. On the one hand, the radical nature of its critique has engendered lively resistance. Without necessarily associating antipsychiatry with the left-leaning political and intellectual movements of the 1960s and 1970s, it must be stated that the psychiatric community has, on the whole, not been favorably disposed toward antipsychiatry. It has interpreted the antipsychiatry project as a denial of mental illness, which is a considerable exaggeration. On the other hand, antipsychiatry has renewed the critique of a medical discipline that, by the admission of its own representatives, cannot meet its own costs. Nonetheless, such criticisms have necessarily been generated from a common base: the utility and necessity of a science of the human psyche that produces facts and norms. The most fruitful lesson of antipsychiatry is doubtless to have reminded us that psychiatric knowledge is a tributary in the link between the production of medical facts and social norms. From this perspective, the Italian law on mental health inspired by Basaglia and passed in 1978 bears witness to the way in which a society can renew its relationship with exclusion and alterity. This is what antipsychiatry, however awkwardly but sincerely, wished to point out.

—Jean-Christophe Coffin

See also Mental Illness; Psychiatry.

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ANTISOCIAL PERSONALITY DISORDER

Antisocial personality disorder (APD) is characterized by a pervasive pattern of disregard for the feelings of others often accompanied by violation of the rights of others through negligence or overt actions. This disorder is believed to occur in 3 percent of adult males and 1 percent of women. In the past, this disorder was often called "psychopathic" or "sociopathic," though these terms are misleading as in the past they have been identified too closely with serial killers and other extreme and violent forms of this disorder. While it has a lifelong course, many patients with this disorder "burn out" in later life and become less problematic.

These behaviors usually begin in childhood and are often marked by early problems with the law. The most common childhood diagnosis is conduct disorder. People with APD usually lack empathy and often do not have the capacity to engage in close relationships. They may experience odd beliefs and behaviors as well as distorted and paranoid thinking. Such individuals have great difficulty conforming to social norms and rules, making it very difficult for them to maintain employment and function within a family. Although individuals with APD are most commonly seen as a problem to society, they are also disabled. Many individuals with APD engage in high-risk, novelty-seeking behavior often associated with substance use. Because of these behaviors, they are much more likely to die prematurely or have morbidity associated with disease, vehicular accidents, and homicide or suicide attempts.

—Joseph A. Flaherty

See also Psychiatric Disorders.

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ANXIETY DISORDERS

Anxiety is an innate emotion and an adaptive mechanism that signals a potentially harmful internal or external change and enables us to avoid harm. When anxiety occurs for seemingly no reason, or in an exaggerated manner, to relatively innocuous stimuli and disrupts a person's life, an anxiety disorder (AD) is diagnosed. ADs are the most common psychiatric disorders in the world. Despite effective treatments, most ADs are not diagnosed or treated adequately. ADs are often chronic and disabling conditions associated with enormous emotional and monetary costs. Surprisingly, very little research has been done on the quality of life, functional impairment, and disability associated with ADs.

DISABILITY ASSOCIATED WITH ANXIETY DISORDERS

People with ADs experience significant emotional distress due to anxiety symptoms associated with an abnormally increased expectation of harm and overestimation of danger. This leads to a pattern of progressive avoidance of situations that may trigger symptoms, which, over time, envelops all aspects of life. They have an increased risk of developing depression, substance abuse, suicidal thoughts, and an excessive use of medical services. Anxiety also complicates the manifestation and treatment of other illnesses such as schizophrenia, depression, and heart disease. Severe ADs can be as disabling as other disorders associated with increased disability such as heart disease and depression. The seriousness and public health relevance of ADs is highlighted by a U.S. study that estimated the annual cost (for 1990) associated with ADs, to be $42 billion, accounting for almost a third of costs due to all mental disorders. More than 50 percent of those costs resulted from repeated use of nonpsychiatric health services.

Specific Anxiety Disorders

Panic Disorder

Panic disorder (PD) is characterized by sudden, sometimes spontaneous attacks of terrifying anxiety accompanied by mental and bodily symptoms such as the experience of terror, heart palpitations, and sweating. Fear of the attacks themselves generates a pattern of avoidance that can severely constrict the person's life. During attacks, fear that the symptoms may signal a heart attack, stroke, or other medical problem leads to repeated emergency room visits and expensive workups. People with PD report poor emotional and physical health and significant impairment of family life, and they have increased work absenteeism and decreased productivity. They are more likely to be financially dependent, attempt suicide, and have extremely high rates of using medical care compared to people without PD. PD patients are equally or more impaired on ratings of mental health and role functioning as people with depression or diabetes. They have higher rates of other ADs and depression, the presence of which increases the severity of the disability.

Social Anxiety Disorder and Specific Phobias

Social anxiety disorder (SAD) typically develops in adolescence, is more common in women, and usually runs a chronic course. SAD and phobias involve an exaggerated, irrational fear of usually nonthreatening objects or situations. Symptoms of anticipatory anxiety, distress when in the presence of the feared object or situation, and active avoidance of triggering situations are characteristic. SAD is often accompanied by depression and a higher risk of alcohol abuse. Persons with SAD are more likely to rate themselves as low functioning, to be impaired in their social relationships, and have a specifically increased risk of dropping out of school and college. They are more likely to have lower incomes, greater rates of unemployment, and financial dependency compared to those without SAD. Persons with SAD report significant subjective distress comparable to other ADs (such as PD). Even subthreshold SAD symptoms have been shown to be associated with significant disability, which increases with concurrent depression.

Generalized Anxiety Disorder

People with generalized anxiety disorder (GAD) have persistent worry and anxiety symptoms for at least a six-month period. GAD affects women more than men. Prevalence rates are higher in midlife, and it tends to run a chronic course. GAD is often accompanied by other disorders such as depression, PD, SAD, and substance abuse. Indices of disability in GAD such as impairment in social and role functioning and reduced work productivity have been reported to be comparable in severity with those for major depressive disorder. GAD is more prevalent in primary care patients compared to the general population and possibly the most common AD in this group. GAD patients in primary care have worse emotional and physical health perceptions than those with other ADs, increased unexplained physical symptoms, and high rates of use of medical care. People with GAD have also been shown to have significantly more impairment in social and role function compared to medical disorders such as diabetes and congestive heart failure, despite less physical impairment. The presence of depression (which is common), and other conditions, increases the burden of disability as well as economic costs (due to absenteeism, increased health care use, and hospitalizations).

Posttraumatic Stress Disorder

Persons exposed to a life-threatening trauma (sexual abuse, combat, natural disasters) may, as a sequel, have troubling symptoms including recurrent intrusive thoughts and dreams of the trauma, abnormally increased alertness and anxiety, and emotional numbing, as well as avoidance of situations that remind them of their trauma. Posttraumatic stress disorder (PTSD) is highly prevalent, tends to run a chronic course, and is often associated with other anxiety disorders, depression, and substance abuse. Patients have significant problems with anger and trust, leading to difficulty in interpersonal relationships. Follow-up studies of PTSD in war veterans reveal significantly diminished subjective well-being as well as increased physical limitations, unemployment, and increased work absenteeism and early medical retirement in firefighters. Veterans with war-related PTSD have high rates of health complaints, medical conditions, and health care use. Similar impairments of subjective distress, poor physical and emotional health, and impaired social and role functioning are also experienced by nonveteran PTSD patients (e.g., rape victims). PTSD often co-occurs with chronic pain and other medical conditions (such as HIV) and is associated with intensified pain, greater disability, and worse medical outcomes. PTSD is associated with higher rates of suicide attempts compared to other ADs and the general population.

Obsessive-Compulsive Disorder

Obsessive-compulsive disorder (OCD) is characterized by the presence of repetitive, highly intrusive, anxiety-provoking thoughts and images known as obsessions, leading to mental and motor compulsions (repetitive ritualized thoughts or acts) to reduce the anxiety. People with OCD often spend several hours a day engaged in compulsions, to the exclusion of normal life activities. OCD usually manifests in children or young adults, tends to run a chronic waxing-and-waning course, and is associated with significant disability in many life areas. Many OCD patients report low self-esteem, tend to seek help very late, have an increased chance of being unmarried, and have high rates of major depression during their lifetime. People with severe OCD have seriously impaired independent living skills and social functioning, and they tend to be financially dependent, similar to people with schizophrenia. OCD is one of the most disabling (10th) of all medical illnesses in the world according to a World Health Organization study. Family members of the patient are often caught up in the compulsions, which reduce quality of life for the entire family and is a significant obstacle to treatment success.

ASSESSMENT, ADVOCACY, AND LEGISLATION

ADs are clearly and severely disabling, but surprisingly, assessment of functional disability in persons with anxiety and depression in primary care and specialty clinics is still not routine practice. Specifically targeting functional gains rather than just symptom reduction with treatments could greatly improve functional outcomes. Routine use of simple validated rating scales can objectively document functional impairment, aid in evaluating the true efficacy of treatments, and assist patients in their application for disability benefits or appropriate workplace accommodations. This is extremely relevant to persons with ADs, who often experience shame, ridicule, and stigmatization. The Americans with Disabilities Act (ADA) prohibits discrimination against an individual with a mental or physical disability in employment and other life areas and is of great potential value in efforts to improve functional capacities and reduce stigma of those with ADs. However, actual application of this legislation to patients with ADs is far from optimal. Though participation in family support groups has not been systematically studied, clinical observations suggest that such groups could provide useful information and support to people with ADs and their families.

THE EFFECTS OF TREATMENT

Several options for treating people with ADs exist, including cognitive-behavioral therapy and medications. Obstacles to treatment include frequent failure of the health system to detect disorders and the shame, fear, and stigma that often accompany diagnoses. Even when treated, many patients are left with residual symptoms and disability. However, there is also clear evidence that both effective psychotherapeutic and medical treatment can improve personal and occupational functioning, raise quality of life, and reduce unnecessary medical use costs in most ADs.

—Brian Martis

See also Behavior Therapy; Obsessive-Compulsive Disorder; Panic Disorder; Posttraumatic Stress Disorder; Psychiatric Disorders.

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APHASIA

Aphasia is an acquired disorder of linguistic processing that disturbs translating thoughts into language. Aphasia does not arise from loss of memory for words as associated with dementia, or loss of organs of speech production as occurs after laryngectomy or muscles weakened by motor neuron diseases (e.g., ALS). All patients with aphasia suffer from the inability to precisely name objects on confrontation. Aphasia disturbs the syntax of language, the rules of organizing language, lexicon, and the meaning of the sounds.

Aphasia can be caused by stroke, head trauma, and primary or secondary brain tumors that destroy or disconnect portions of the speech-related centers of persons that are located in the left hemisphere of almost 90 percent of all humans. Two-thirds of left-handed persons have speech facility localized to their left cerebral hemisphere.

Nonfluent aphasia causes decreased rate of word production. Broca's aphasia causes mispronunciation, decreased fluency, loss of grammatical structure, and inability to repeat verbatim phrases that contain conjunctive, or conditional, words. These patients retain understanding and appropriate speech content and are angered by inability to communicate. The lesions of Broca's aphasia involves Brodmann's areas 44, 45, and 46, but also areas 8, 9, 10. (See an illustration of Brodmann's areas online at http://spot.colorado.edu/~dubin/talks/brodmann/brodmann.html.) Transcortical nonfluent aphasia is diagnosed when patients can repeat, but have impaired ability to name and to speak fluently. The lesion for this disorder lies in the frontal lobe of the speech-dominant hemisphere anterior to the locus for Broca's aphasia.

The fluent aphasias include Wernicke's and transcortical fluent aphasia. Persons speaking fluently but displaying faulty repetition and loss of meaningful content, who are unable to understand written or spoken words and unaware of meaningless utterances, are diagnosed with Wernicke's aphasia. Damage to posterior portions of left auditory association cortex (Brodman's area 22) and Brodman's areas 37, 39, and 40 produces Wernicke's aphasia. Persons repeating accurately but speaking or reading out loud with paraphrastic words, due to erroneous substitution of a letter or a concept, are diagnosed with transcortical fluent (sensory) aphasia.

Conduction aphasia (CA) is distinguished from other aphasias by inability to repeat accurately, intrusion of paraphrastic words, and normal fluency and understanding. CA is caused by damage to area 40, the supramarginal gyrus and the left auditory cortices (areas 41 and 42).

Global aphasia patients manifest nearly complete loss of ability to comprehend language and formulate speech, with right hemiparesis. Damage to the terminal branches of the left middle cerebral artery produces this disorder, or multifocal infarctions from emboli can damage Wernicke's and Broca's areas, sparing intervening basal ganglia and internal capsule. Speech output is greatly reduced due to damage to the head of the caudate nucleus and subjacent internal capsule. Loss of speech function cannot be attributed solely to an isolated area of the brain, but rather disconnection of working units within the brain.

Recovery from global aphasia depends on permanence of hemiparesis. If there is damage to Broca's and Wernicke's areas and sparing of the intervening tissue, recovery from global aphasia can occur. Treatment directed at the physiological defect will hasten recovery. Melodic intonation therapy ameliorates patients with loss of word production; visual communication therapy improves global and Wernicke aphasia.

—Edward J. Fine

See also Apraxia; Paul Broca; Speech and Language Pathology; Traumatic Brain Injury.

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APRAXIA

Apraxia has been defined as a disorder of voluntary actions that can neither be referred to as elementary motor disorders, such as paresis or tremor, nor general cognitive problems, such as dementia or aphasia. Symptoms can be observed in a variety of settings, from traumatic brain injuries to cerebral infections to congenital disorders. Notions about apraxia have been important in our developing understanding of the workings of the human brain.

The concept of apraxia arose from the debate over cerebral localization of function in the late nineteenth century. In particular, it was linked to another condition, aphasia, a complete or incomplete inability to comprehend or use language (often because of brain injury, infection, or stroke). A central issue of this debate was whether language is an isolated function of the human mind, the neural substrate of which can be localized within the brain. Opponents of this compartmentalization of the human mind into localizable functions emphasized that aphasia is regularly accompanied by disturbances of nonverbal intellectual capacities. The German psychiatrist Carl Maria Finkelnburg observed that communicative gestures of aphasic patients are frequently clumsy and incomprehensible. In a very influential paper published in 1870, he posited that they suffer from a general "asymbolia" preventing the use and comprehension of any communicative signs. Ten years later, the linguist Heymann Steinthal used the term *apraxia* to denote the faulty use of everyday life objects, such as a fork and knife or a penholder, by patients with aphasia. He considered their errors an "augmentation" of aphasia.

Modern theories of apraxia have been shaped in the early twentieth century by the German psychiatrist Hugo Karl Liepmann. By systematic group studies, he confirmed the frequent occurrence of disturbed communicative gestures and aberrant use of tools and objects in patients with left-hemisphere brain damage and aphasia. To this confirmation, he added the new observation that these patients commit errors also when imitating gestures, an observation central to his conception of apraxia. He reasoned that in imitation the model of the intended movement is unequivocally provided by the demonstration and that errors thus testify to insufficient motor execution. He concluded that apraxia is a disorder of motor control that frequently accompanies aphasia but is itself a distinct and localizable symptom of circumscribed brain damage rather than indicating the augmentation of aphasia to general mental deterioration. For explaining the frequent co-occurrence of aphasia and apraxia after left-hemisphere brain damage, Liepmann speculated that the left hemisphere has a dominance for motor control beyond and perhaps above its dominance for speech.

The dependence of apraxia on left-hemisphere damage has since then been largely, although not completely, confirmed. Whereas the production of communicative gestures on command seems to be very tightly bound to left-hemisphere integrity, imitation of gestures and the use of tools and objects may be sensitive to right-hemisphere brain damage too depending on the exact nature of the task used to assess them. Liepmann's proposal that apraxia is a disorder of motor control fares less well in the light of contemporary research. His idea that faulty imitation implies deficient motor execution of a correctly conceived gesture was challenged by studies showing that patients who cannot imitate gestures have similar difficulties when asked to replicate them on a manikin or to select them from an array of pictures, and by reports of single patients in whom severely defective imitation of gestures contrasted with flawless execution of communicative gestures on command.

After more than 100 years of research, the existence of apraxia in many patients with left-hemisphere brain damage is firmly established, but its nature and its relationship to aphasia and to hemisphere dominance remain subject to debate and inquiry.

—Georg Goldenberg

See also Aphasia; Speech and Language Pathology; Traumatic Brain Injury.

Further Readings

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ARATA

See Australian Rehabilitation and Assistive Technology Association (ARATA)

ARCHAEOLOGY

The consideration of disability in archaeology is a recent development. It has emerged in response to challenges to the discipline, particularly to those critiques that question archaeology's relevance in the contemporary world. Archaeological reactions to these concerns have included the development of both public archaeologies and community-based archaeologies. These ways of doing archaeology represent some archaeologists' attempts to frame archaeology outside its traditional niche as a private, professional, and academic pursuit. This is accomplished through collaborative projects formulated through the cooperation of archaeologists and communities from outside the discipline. Through these community-based methods, archaeologists hope to increase diverse communities' engagement with the past.

Public and community-based strategies ultimately allow archaeologists to forge connections with audiences and participants traditionally alienated from professional and academic circles. One such group of audiences and participants includes persons with disabilities. To create relationships with new audiences and participants, including persons with disabilities, archaeologists must address research questions related to the experiences and interests of these individuals. This has been enacted in two distinct ways.

First, archaeologists strive to understand disability in past human populations by placing disability at the center of their research questions. In so doing, they attempt to develop knowledge that is relevant to individuals concerned with experiences of disability across both time and place. To interpret disability in the context of past peoples, archaeologists make interpretations based on the consideration of various types of data. These data include, but are not limited to, the remains of structures, material objects, and human remains.

Archaeologists have traditionally based their interpretations of disability on medical models. Owing to the influence of larger sociopolitical movements, such as the disability movement, social models are becoming more common in archaeological interpretations related to disability. This trend builds on the use of social models to interpret and understand how humans have both constructed and experienced ideologies of gender, sexuality, age, and race across time and place.

Second, archaeologists have begun to recognize how ideas about ability, disability, and the body are connected with the practice of archaeology. This has occurred as a result of sociopolitical movements that have raised awareness about disability across communities and experiences. Media institutions present archaeology as a very physical pursuit. Moreover, these institutions portray archaeologists as nondisabled individuals. For instance, images of archaeologists with disabilities rarely grace the covers of glossy science magazines or show up on prime-time television specials. As a result of observations such as these, archaeologists have begun to develop research that looks at the ways in which ideas about ability and disability affect the accessibility of archaeology and archaeological programming. Some current research addresses these issues by focusing on the involvement or lack of involvement of people with disabilities in archaeology. In addition, following work that explores the theoretical issues connected to these relationships, more and more archaeologists are attempting to create practical, grounded solutions by archaeological programming that is accessible to a diverse range of embodiments and experiences.

—Meredith A. Fraser

See also History of Disability: Pleistocene Period.

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ARISTOTLE (384–322 BCE)

Greek philosopher and scientist

Student of Plato, tutor to Alexander the Great, Aristotle is one of the most influential ancient figures in Western thought. A scientist and philosopher, Aristotle was interested in categorizing and systematizing all phenomena. Aristotle is important to disability studies for several reasons. His writings rest on careful observation; some observations are strikingly modern; others, such as his speculations in *Generation of Animals* that a female is technically a deformed male or that children sometimes inherit from their parents such characteristics as scars and brands, seem quaint at best. Aristotle considers the ideal state and proposes several highly regulated components of human organization in the *Politics*. These regulations, within a detailed caste system, include his recommendation for the elimination of deformed infants. "As to exposing or rearing the children born, let there be a law that no deformed child shall be reared" (1335b). Ironically, according to later biographers, Aristotle's own physical characteristics were far from perfect. In addition to being bald and having thin legs, he lisped. Paul Cartledge (2000:199–200) provided a succinct overview of Aristotle's life in *The Greeks: Crucible of Civilization*.

—M. Lynn Rose

See also Euthanasia.

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ARNOLD, IVAN KARLOVICH (1805–1891)

Russian school administrator

Ivan Karlovich Arnold, who was deaf, was the founder of the first Moscow school for the deaf (1860). The school was later named after him—Arnoldo-Tretyakov School. He was educated in the St. Petersburg School for the Deaf and then in Berlin, Germany. He graduated from the Art Academy in Dresden, Germany. Arnold was the director of the Moscow School for the Deaf from 1860 to 1866.

—Anna Komarova and Victor Palenny

See also Deaf, History of the.

ART THERAPY

Art therapies allow individuals to express themselves through creative means. Often the process of making art is the core of the process of art therapy: Through the work, individuals can experience themselves as empowered, valued, able to achieve, and able to deal with a task. Art can articulate deep feelings and can bring unconscious issues to the fore. Group art therapy approaches can also foster sociality and find forms of being with others not usually sanctioned by everyday life.

Dance, music, drama, drawing, photography, sculpture, creative writing—most art practices have specialized art therapy approaches associated with them. One significant difference between "mainstream" art practices and art therapy is the status of the final product: Concepts such as mastery, control, and commercial value are either not important or much less important than self-expression. Also, public consumption is not necessarily an aim of art therapy. Public display can have therapeutic effects on individuals, in particular, people who have seen themselves as being devalued, invalid, for a long time, but the processes and products of art therapy are also private and often remain so.

Against both mainstream practice and art therapy approaches stands community or participatory art practice. Here, training is also often unimportant, and process is often stressed over product as a value in its own right. Different from art therapy, though, community and participatory practices often stress the community as the focus of the work practices. Doing something together and finding ways of expressing a shared vision become important concepts in this art practice, and public display is often seen as effective in community transformations.

Within disability culture, art therapies have a dual standing. On the one hand, art therapy approaches can be useful in allowing people to work through the social stigma or personal problems associated with impairment and disability issues. Art therapy is also often the first place where institutionalized people encounter the alternative expressive means of art, enabling them to find new perspectives on their life experiences.

On the other hand, the potential emphasis of art therapies on the individual as the locus of intervention can be seen to hinder political processes. For many disability activists, the "problem" of disability is not the individual and his or her acceptance or adjustment, but the wider social world and its exclusionary practices. The "medical" framing of art therapy, and the professional status of art therapists, many of whom are licensed or part of professional bodies that control training, can here be seen as extensions of the oppressive regime of normalization. For this reason, many disability activists resist the wider connotations of "therapy" and instead investigate other forms of art making, both inside and outside the mainstream.

—*Petra Kuppers*

See also Dance; Drama and Performance; Music; Poetry.

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ARTHRITIS AND CARTILAGE DISEASES AND INJURIES

Musculoskeletal diseases are the most prevalent causes of chronic medical disability, due to painful and/or restricted mobility of any joints, weakness, and potentially, associated predisposition to visceral impairments. Of the diseases that have been separated from "rheumatism," this entry briefly describes osteoarthritis (OA), gout, rheumatoid arthritis (RA), ankylosing spondylitis, and juvenile polyarthritis.

OA is by far the most common arthropathy. Its actual prevalence in relation to disability has been difficult to establish because surveys have usually based the diagnosis on radiographic findings and, except in advanced cases, the correlation between the radiographic findings and symptoms of pain and/or restricted motion is poor. OA primarily is a disease of articular cartilage, but not necessarily a consequence of aging. It is not a sufficiently specific diagnosis since cartilage may deteriorate for a variety of reasons. The disease may be an isolated result of injury to the affected joint or adjacent bone, or be due to asymmetric weight bearing, as results from unequal leg length. It can be attributed to a heritable predisposition affecting only the finger joints, or be the end result of cartilage damage from RA or gout. It may be multi-articular and resemble RA. Joint infection, mainly due to tuberculosis or gonorrhea, once was an important cause, but this has become rare since the advent of effective antibiotic therapy.

Treatment of OA has continued to depend mainly on analgesics with some anti-inflammatory potency. These numerous nonsteroidal anti-inflammatory drugs (NSAIDs) have largely replaced aspirin. The principal potentially serious side effect from the older "COX-1" medications is gastrointestinal bleeding, and from the "COX-2" medications, cardiovascular injuries.

Advanced disease in individual joints is treated orthopedically. Joint replacements were first performed in the hips and now in many joints. These procedures are performed more frequently in cases of OA than RA. All require postoperative physical therapy to maximize range of motion and/or improve the strength of adjacent muscles.

Gout, which had frequently been a synonym for rheumatism in the mid-nineteenth century, was the first to be differentiated by the new science of biochemistry. While it remained uncertain how an excess of uric acid in the blood causes gout, this substance became accepted as etiologically critical. As the diagnosis became dependent on the detection of uric acid, gout became recognized less frequently, and again increased as the sensitivity of uric acid determinations improved, achieving its present level in the 1960s. Gout also was the only musculoskeletal disease for which a fairly specific and effective medication became available in the nineteenth century. While colchicine can abort acute joint inflammation, it has no effect on the production or elimination of uric acid. Thus, the development of chronic disability due to the accumulation of tophi (uric acid nodules) was not diminished. Subcutaneous tophi may be disfiguring, but usually are not disabling. However, accumulation of urate in joints causes destruction of articular cartilage as well as bone, resulting in loss of motion, contractures, cutaneous ulcers from which urate extrudes, and chronic pain. These manifestations were first ameliorated by the discovery of drugs that stimulate increased elimination of uric acid by the kidneys (probenecid in 1952 first), and a drug that inhibits the synthesis of uric acid (allopurinol in 1963).

Numerous terms were coined for both rheumatoid arthritis (RA) and osteoarthritis (OA), and, indeed, RA was called OA at one time. *Rheumatoid arthritis* was proposed in 1859 because it did not imply "any necessary relation between it and either gout or rheumatism [i.e., rheumatic fever]" (Garrod 1859:542). The first objective differentiation was made radiologically, based on excess bone formation adjacent to joints (hypertrophy) in OA and loss of bone (atrophy) in RA. This soon was followed by description of a fundamental pathologic difference: OA begins with deterioration of articular cartilage, and RA begins with inflammation of the synovial tissue that lines joints and only secondarily affects the cartilage.

The discovery of *rheumatoid factor* in the blood of patients with RA in the 1950s was hoped to overcome diagnostic uncertainties. However, it has proven to develop in no more than three-fourths of cases of RA and often only develops after clinical findings have made the diagnosis likely; furthermore, positive tests are not limited to RA. Overdependence on this test has led to many misdiagnoses. It, however, has prognostic value. The presence of rheumatoid factor tends to be associated with the eventual development of extra-articular manifestations and a more aggressive course of RA than is typical of cases that remain rheumatoid factor-negative.

The simplest of numerous sets of criteria to classify the severity of RA and response to treatment is the Steinbrocker Functional Classification:

I. Unrestricted in all activities
II. Normal activities can be performed, but with discomfort and/or some limitation of joint motions
III. Activities are limited mainly to self-care
IV. Incapacitated with little or no self-care capability

Salicylates, and soon thereafter synthetic analgesic drugs, became available about 1880, aspirin in 1898. Aspirin became accepted as the drug of choice for rheumatic fever, but pessimism prevailed for any drug therapy for RA. Physical therapy, mainly hydrotherapy and massage, was recommended with guarded hopes until the 1930s, when aspirin in larger doses became the choice for analgesia and gold salt injections to retard disease progression. Because of their potent anti-inflammatory effect, corticosteroid drugs, beginning with cortisone in 1950, were for some years believed to be the solution to the treatment of RA. However, the recognition of serious side effects with chronic use dashed this hope after a decade. These drugs are still employed in small doses in combination with other agents. The breakthrough for advanced disease began in the 1950s with orthopedic surgery: osteotomies (realignment of a joint) and insertion of prosthetic joints. In the 1980s, immunologically based therapy that endeavors to interrupt the inflammatory process before joints are seriously damaged began and is now the forefront of research.

Two-thirds of patients with RA are women, and nine-tenths of patients with pain and stiffness usually progressing from the pelvis up the vertebral column are men. Nevertheless, whether the latter is a variant of RA, rheumatoid spondylitis, or a separate disease, ankylosing spondylitis, was not resolved until the 1970s. This resulted from the discovery of a class of antigens inherited from both parents (HLA) and that specific immunologic types of these could be distinguished. The presence of some of these types appeared to predispose to the development of or resistance to certain diseases. The presence of HLA-B27 was found to be present about 12 times as frequently in cases of ankylosing spondylitis than in the general Caucasian population, but no more frequent in cases of RA. The same technique demonstrated that most cases of polyarthritis in children are not RA.

The primary therapy of ankylosing spondylitis, contrary to other arthropathies, from the 1920s to 1950s was roentgen irradiation. For unknown reasons, this had a significant analgesic effect on the inflammation of the spinal column, but not on peripheral joints. It was discontinued not because a more effective drug had been found, but because of evidence that it may induce myelogenous leukemia. Courses of physical therapy are more important in this disease than in other arthropathies. There still is no therapy to prevent adjacent vertebrae from fusing, and there is a strong tendency for anteflexion to develop. Therefore, the goal of the physiatrist is for erect posture to be maintained. A severely flexed back, even with unaffected extremity joints, can be totally disabling.

Juvenile polyarthritides occur less than 5 percent as frequently as RA. The eponym of Still's disease resulted from a description in 1897, which distinguished it from the then common disease of rheumatic fever. It remains uncertain how many diseases are included within childhood arthritis. The syndrome described by Still is the most acute, with fever and potentially multiorgan involvement, but the least common. Cases with few affected joints (*pauci-articular*) are the most frequent and most likely to undergo cessation of symptoms but most prone to ocular inflammation and permanent impairment of vision. In the third category (*oligo-articular*), many joints are affected without visceral involvement. These cases most closely resemble adult RA, but they differ in their HLA type. No doubt, a few children do develop adult RA or ankylosing spondylitis and some adults develop juvenile chronic polyarthritis. Skeletal disability depends greatly on the age of onset. The earlier the disease begins the more growth centers are likely to be affected. This may result, for example, in arrested growth of the jaw or, most often, small stature. The principal modes of treatment have until recently been physical and aspirin or NSAID because of apprehension of untoward effects from the more potent immunosuppressive agents.

—Thomas G. Benedek

See also Orthopedics; Pain; Physical Therapy.

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ASPERGER SYNDROME

HISTORY

Asperger syndrome is an eponymous neurodevelopmental disorder on the autistic spectrum, named after the Viennese pediatrician Hans Asperger (1906–1980). In 1944, he described a group of children with difficulties in affective contact, a lack of "practical intelligence," academic failure, motor clumsiness, and less frequently, obsessions or stereotypies, using the term *autistic psychopathy* (*Die Autistischen Psychopathen im Kindesalter*). The publication was largely ignored by contemporaries, appearing first in translation in 1991. In 74 of Asperger's case records, 68 percent fulfilled current criteria for Asperger syndrome while 25 percent fulfilled criteria for autism. Asperger's original descriptions were similar to those of childhood autism published in English by Leo Kanner in 1943.

EARLY LITERATURE

A number of early case descriptions have been provided for individuals who may have had Asperger syndrome, most notably in the Scottish case of Hugh Blair of Borgue. Many famous individuals may have been affected. These include L. S. Lowry, Ludwig Wittgenstein, Sir Keith Joseph, Eric Satie, Albert Einstein, and Isaac Newton.

DIAGNOSTIC CRITERIA

Asperger syndrome first appears as a clinical disorder in both the World Health Organization's International Classification of Disease (ICD-10) in 1993 and in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) in 1994.

On both the ICD and *DSM* systems, the core features of Asperger syndrome are as follows:

Impairment in social interaction

Restricted, repetitive behavior and interests

No "clinically significant" delay in language

No "clinically significant" cognitive impairment;

Does not meet criteria for other problems such as schizophrenia

Current nomenclature in the area of autism, including Asperger syndrome, is in a state of flux. Much of the published literature has used varied criteria not matching those in the current diagnostic systems. Less restrictive criteria have often been used, sometimes including those with communication problems, learning difficulties, and comorbid schizophrenia.

Physical Correlates

There are no consistently reported physical features. There are reports of excessive joint flexibility, dermatological abnormalities, and muscular dystrophy. Metabolic abnormalities, particularly of prefrontal cortical function, and of mitochondrial dysfunction are reported. No data have been collected indicating the extent of such associations.

Differential Diagnosis

DSM or ICD criteria do not clearly distinguish between Asperger syndrome and "high functioning autism." The distinction is supposedly on exclusion of clinically significant communication problems, learning delay, or schizophrenia. Autism can be diagnosed in individuals without such problems. Any difference would, therefore, need to be on the basis of factors additional to the current diagnostic criteria. Some reviews and research studies conclude there is no basis on which to differentiate.

Neuropsychological Differentiation

The neuropsychological profile in Asperger syndrome may discriminate the condition from other autistic spectrum disorders on the basis of a nonverbal learning disability (NVLD) profile. Similar differences have been reported in several studies analyzing Asperger cases. Others, however, have failed to replicate the findings across reported groups or consistently within the reported population. A subgroup of individuals with a diagnosis of Asperger syndrome shows an NVLD profile; a further subgroup does not.

—Kenneth J. Aitken

See also Autism.

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▣ ASSISTIVE TECHNOLOGY

The Technology-Related Assistance for Individuals with Disabilities Act of 1988 defined *assistive* *technology* (AT) as “any item, piece of equipment or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain or improve the functional capabilities of individuals with disabilities.” Conceptually, this definition encompasses not only the device but also the applied nature of how the device is used and who uses the device. Fundamental to this definition is the concept that assistive technologies enhance the ability of a person with a disability to participate in major life activities, actions, and tasks that would be difficult or impossible to perform without technologies that are used as a consequence of the individual’s impairment-related limitations. This principle of enhanced ability includes an increased level of independent action, a reduction of time spent in activities of daily living, more choices of activities, and greater satisfaction in participating in activities. In short, the technology included under the rubric of assistive technology has to assist the user to participate in activities.

The other essential inclusion criterion for defining AT is setting the rules for who is or is not included as disabled. Who is considered disabled varies by the type and severity of impairment (mild arthritis to near total paralysis), functional capacity (reduced vision or hearing to deaf or blind), or type of activity (work tasks or personal care). Well over 50 definitions of disability are in use in the United State alone. Most of these definitions are based on the idea that the inability to do an activity is caused by the person’s physical or cognitive impairment. Recent models and classifications of disability portray disability as the outcome of interactions of people and their environments. The expression of disability changes with nature of the environment. AT devices are a part of the environment that can reduce the expression of disability. AT is used to improve building accessibility, augment communication, afford computer access, allow environmental control over electronic devices, modify homes for access, assist with personal care activities and family activities, enhance mobility, stabilize seating, and modify workplaces and schools. The impact AT has on individuals’ ability to interact effectively and independently in their environment has been established, and millions of people with disabilities rely on numerous AT devices daily.

The International Classification of Functioning, Disability, and Health (ICF) uses *disability* as a term that covers problems in organ structures and functioning, activity limitations, and restriction in participation. Improvement in any of these three components reduces disability and improves function. This new ICF classification framework allows for AT to be applied to reducing an individual’s impairments, improving tasks performance in activities, and promoting full participation in major life activities. This framework is important because devices that improve structure and their functions (e.g., prosthetic legs, cochlear implants, implanted electronic control of bladder); devices that improve activity performance (e.g., voice entry, stair-climbing wheelchairs, communication boards); and environmental modifications (e.g., automatic door openers, level entrances, accessible bathroom) that reduce or eliminate restriction to participation can all fit the definition of AT.

AT SERVICES

A model for assessing the component interactions of the service delivery system has been developed to provide a framework for understanding how AT and the services often needed for acquiring AT can change performance of people with disabilities. This model, the human activity assistive technology model (HAAT), postulates four components: human, activity, assistive technology, and context. All components must be considered when selecting an AT device.

For simple, inexpensive AT, consumers require little if any help in acquiring devices. However, when the AT device is complex, costly, or paid for by a third party, the process of obtaining the device can require the help of individuals trained in providing AT services. The services needed may include evaluations for the types of AT that are needed to enhance physical, sensory, and cognitive functions; improve performance in activities; and increase participation in major life activities. The evaluation may involve an interdisciplinary team of people who have training in engineering, therapy, medicine, and device use. The introduction of AT into the life of a person with a disability requires an analysis of the existing capacities of the consumer, the settings where the AT will be used, the features included in the AT device, and the goals of the consumer and his or her family, employer, and educator.

After the AT device is selected that best fits the consumer's situation, the device is purchased. If the device is inexpensive or the consumer has the necessary funds, the acquisition is relatively straightforward. However, if other organizations provide the funds for the AT purchase (third-party payers), then the consumer may find the process difficult, lengthy, and frustrating. For example, when the AT is paid for by health insurance, the rules for what may be purchased and the forms required for reimbursement are very complex. This part of AT services requires that competent, experienced individuals assist the AT consumer in providing the information required by the reimbursement entity. For AT deemed to be medically necessary, a physician must sign and send in a letter that describes the individual's diagnosis, prognosis, and the functions that will be improved or maintained by the requested device. If the first request for reimbursement is denied, then a lengthy process of appeals ensues.

Once a device is acquired, services may be needed to fit, customize, maintain, or repair the AT device. These services are provided at durable medical equipment companies, rehabilitation facilities, or volunteer organizations. An additional important but often neglected service is the training or technical assistance provided to the consumer and his or her family in the use of the AT. For example, communication boards that allow individuals with no or poorly understood speech to make their needs and views known take a significant amount of time to learn. To offer this full array of services, people need to be trained in the wide variety of skills required to match the individual's needs and capabilities with the features of the AT.

AT CLASSIFICATION AND CHARACTERIZATION

Well over 20,000 AT devices are listed in computer databases (http://www.abledata.com/) and in sales catalogs. A device can be located using any of several strategies including product name, company, or key word, which helps when searching for a device. In the United States, the following categories are used to provide a structure for organizing AT: architectural elements, sensory elements, computers, controls, independent living, mobility, orthotics/prosthetics, recreation/leisure/sports, and modified furniture/furnishings. Each general category has a numeric code, as do the subdivisions of the categories. In Europe, AT devices used by individuals with disabilities are classified by the 2002 ISO 9999 "Technical aids for persons with disabilities—Classification and terminology." The classification uses a three-tiered hierarchical organization with the highest level describing a broad set of functions such as devices for housekeeping. The second level, subclass, includes a great degree of specificity in the use of the device (e.g., AT for meal preparation). The specific devices are classified at the third, or division, level, which could include devices such as special knives and cutting boards. These classifications allow for rapid information retrieval, tracking product inventories, and matching devices to impairment, activities, and participation.

AT devices that help people do activities can be characterized in many ways. Some devices are technologically complex, involving sophisticated materials and requiring precise operations and are referred to as *high tech*. Examples include prosthetic limbs that have joints that can move in several planes, powered mobility devices that balance on two wheels, communication devices that are programmed to output speech, and computer screen readers for graphic displays. Simple, inexpensive, and easy-to-obtain devices are commonly referred to as *low tech*. Finger extenders, large-handled eating utensils, canes, and large-print reading materials are examples of low-tech devices.

Another distinguishing characteristic is *hard technologies* and *soft technologies*. Hard technologies are tangible components that can be purchased and assembled into AT systems. This includes everything from simple mouth sticks to computers and software. Soft technologies are much harder to obtain because they are the human areas of decision making, strategy development, training, and concept formation. They may be available in one of three forms: (1) people (e.g., a teacher or therapist, effective strategies), (2) written (e.g., an instruction manual), and (3) computer (e.g., help screens). Hard technologies cannot be successful without the corresponding soft technologies, which are difficult to acquire because they are depend so much on human knowledge that is obtained slowly through formal training, experience, and textbooks.

Another distinction is between commercially available devices—those that are mass produced for the general population or for individuals with disabilities—and those that are custom made for an individual person. Often commercial products are designed according to the principles of universal design so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

Some AT devices are used in many different applications across a wide range of applications (general purpose) and others are intended for a specific application (special purpose). The first type includes (1) positioning systems for body support, (2) control interfaces (e.g., keyboards, switches, and joysticks), and (3) computers. Specific applications include devices for communication, manual and powered wheelchairs, feeding devices, hearing aids, and mobility aids for persons with visual impairments. Due to the unique needs of people with disabilities in each of these areas, the assistive devices must be specifically designed to meet those needs.

An assistive device may function as an appliance or a tool. The distinction is based on whether skill is required to operate the device. If there is skill required, the device is referred to as a tool and soft technologies become important. If no skill is required, then the device functions as an appliance. Examples of appliances are eyeglasses, splints, a wheelchair seating system designed for support, and a keyguard for a computer keyboard. Since a powered wheelchair requires skill to maneuver it and success depends on the skill of the user, the wheelchair is classified as a tool. Other examples are augmentative communication devices, electronic aids to daily living (EADLs), and reading devices for individuals who are blind.

AT USERS

In 1990, more than 13.1 million Americans, about 5 percent of the population, were using AT devices to accommodate physical impairments, and 7.1 million persons, nearly 3 percent of the population, were living in homes specially adapted to accommodate impairments. The majority of persons who use AT are elderly. They primarily use low-tech devices for maintaining their capacity to do their personal care (e.g., grab bars in the bathroom, special kitchen utensils, brighter lighting, canes, and walkers). Children and young adults use a significant proportion of the devices, such as foot braces, artificial arms or hands, adapted typewriters or computers, and leg braces. By 2000, approximately 10 percent of the U.S. population (25 million people) used AT devices and/or modifications to their home, work, or school that allow them to participate in major life activities.

Several studies have reported that the most frequently used AT is mobility devices, 60 to 70 percent of all devices reported. Hearing devices, personal care devices, information technologies, and anatomical devices were reported by less than 10 percent of the people in these U.S. national surveys. The sources for payment of these devices included personal pay, health insurance, Medicare, Medicaid, vocational rehabilitation, employers, Department of Veterans Affairs, charitable organizations, and several others. The consumer most often pays for mobility devices (canes, crutches, walkers, specialized recreational wheelchairs), hearing devices, and home modifications. To offset those who pay for their own AT, deductions from earned income are allowed for most medically necessary devices, businesses that make their buildings accessible, and some modifications to vehicles. Many charitable organizations raise funds that are used to provide AT for children whose families cannot afford to pay for the devices the child needs.

High-tech devices for mobility (electric powered wheelchairs), voice recognition systems, and prosthetic limbs were most often paid for by third-party payers (e.g., private insurance, Medicare, Department of Veterans Affairs, schools, and vocational rehabilitation). Medicare and Medicaid (Centers for Medicare and Medicaid, CMS) use a list (*Coverage Issues Manual*) of devices (termed *durable medical equipment*) to guide the purchase of about $7.7 billion of medically necessarily equipment. However, third-party payers such as private insurance companies, Medicare, Medicaid, and the vocational rehabilitation system have no consistent or compatible payment formulas across geographic regions, by types of impairment or disability, or by eligibility criteria.

BENEFITS OF AT USE

With the introduction of AT, some people with disabilities can do activities without the help of family members or paid assistants, participate in parenting, improve their work productivity, avoid being institutionalized, and join in active recreational activities. Although many people with disabilities report that the use of AT greatly improves their quality of life, measurement of the change in their choice, satisfaction, self-esteem, adaptability, safety, and competence have been little studied. Several new assessments are beginning to be used to assess how individuals feel about their devices, how they use their devices, and the quality of their participation in major life activities.

The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) is a measure of satisfaction with device features and service provision. The QUEST includes a broad range of variables reflecting that user satisfaction is a multidimensional phenomenon involving three types of variables: those involving the environment, pertinent features of the person's personality, and the characteristics of the AT itself. The QUEST allows the user to determine the relative importance of the satisfaction variable. The Psychosocial Impact of Assistive Devices Scale (PIADS) is a self-report measure that provides a measure of the psychological response to using AT devices. Three components of the PIADS are adaptability, competence, and self-esteem. The PIADS has been applied to measurement of outcomes with a variety of AT devices from eyeglass and contact lens wearers to users of EADLs. The PIADS and QUEST are reliable and valid measures of the consumer perspective in conjunction with assessments of functional status.

AT USE AND DISUSE

Most of the literature on AT is focused around the issues of design; consumer preferences; use, disuse, and abandonment; and costs and policy. Phillips and Zhao (1993) surveyed more than 200 users of AT devices and identified four factors that were significantly related to the abandonment of AT devices: (1) failure of providers to take consumer opinions into account, (2) easy device procurement, (3) poor device performance, and (4) changes in consumer needs or priorities. Consumers may abandon devices when their opinion is not considered. An essential component of the assistive device delivery system is an effective process that ensures that the needs and goals of the individual are accurately identified. Easy device procurement refers to the situation in which a consumer obtains a device from a supplier without an evaluation by a professional provider. This most often occurs with simple devices such as crutches, canes, or reachers. Poor device performance may be the result of inaccurate or inappropriate expectations on the part of the user, a mismatch between consumer skills and device characteristics, or actual device failure.

AT LEGISLATION

In addition to defining AT and AT services, U.S. federal legislation influences many aspects of AT from basic research to mandating provision to providing funds for purchase. The Rehabilitation Act of 1973 (P.L. 93–112), as amended, requires that programs receiving federal funds to provide reasonable accommodations (Section 504), make electronic equipment accessible to people with disabilities (Section 508), and include AT in vocational rehabilitation plans. The Individuals with Disabilities Education Act (IDEA) of 1990 (P.L. 101–476) and 1997 (P.L. 105–17) states that a child's need for AT must be determined on a case-by-case basis, made part of the individualized education program (IEP), and paid for by the public school system. The Technology-Related Assistance for Individuals with Disabilities Act of 1988 (Technology Act) and the Assistive Technology Act of 1998 (AT Act) provide funds for state programs to support increased AT services, advocacy for AT, information on AT, and alternative financing for AT. The Americans with Disabilities Act of 1990 (ADA) (P.L. 101–336) prohibits discrimination against people with disabilities in employment, public institutions, commercial facilities, transportation, and telecommunications. The impact of the ADA on AT and AT service provision has been enormous because nearly all buildings have had to make accessible entrances, bathrooms, program areas, and parking spaces. In addition, the provision of interpreters for the deaf, Braille, and large-print materials for the blind are required for effective communication. The Telecommunications Act of 1996 (P.L. 104–104) requires the telecommunication industry to make equipment that will support transmission of information in forms accessible to people with disabilities including broadband and television program captioning.

FUTURE DIRECTIONS

Advancements in AT will occur in the technology itself, the services associated with the technology, and in the government policies and programs relative to AT. There will more widespread use of universal design, with less special-purpose AT required. People who have disabilities must continue to have access to the Internet to participate in the knowledge-based economy. This is a challenge since the Internet is becoming more and more dependent on multimedia representations involving complex graphics, animation, and audible sources of information; people who have disabilities have greater challenges in the retrieval of information. This creates barriers for those who are blind or deaf. Complicated websites that may include flashing pictures, complicated charts, and large amounts of audio and video data will be difficult for people who have learning disabilities and dyslexia to use.

AT needs to take advantage of advances in handheld, portable, and satellite-based communication and computing technologies to allow greater capability for persons with disabilities. Control interfaces that directly sense signals from the brain or nerves need to be further developed to allow greater control of devices by people with severe physical disabilities. Intelligent interfaces are required to adapt to the needs of persons with disabilities to allow greater participation in work, recreation, and self-care. Devices that can transmit messages from the brain to activate target muscles (e.g., finger, arms, feet, legs) without having to pass through the spinal cord need to move from basic research laboratories to clinical trials. Devices based on direct stimulation of the brain for those with visual and hearing loss need further development. Technology advances will also occur in materials (lighter, stronger, and more durable) used to make devices such as wheelchairs and the cases for portable electronic devices.

In the area of service delivery, community centers are needed where people with impairments can try different types of AT without first having to purchase a device. To avoid device abandonment, consumers of AT devices need a greater say in what is recommended for and provided to them and greater control over the resources to purchase AT.

In the area of government policy and programs, longitudinal studies are needed to assess the effects of AT interventions on the lives of consumers. Tax reforms are needed to reduce the cost of purchase for the individual and to encourage investment in new AT. Justification for government programs and health insurance purchase of AT needs to expand beyond medical necessity and in-home use to include activities that are important for community participation by people with impairments, including employment, recreation, education, volunteer services, and many others.

—David B. Gray and Albert M. Cook

See also Accessible Internet; Americans with Disabilities Act of 1990 (United States); Communication; Computer Technology; Educational Assistive Technology; Individuals with Disabilities Education Act of 1990 (United States); Information Technology; Mobility Aids; Rehabilitation Act of 1973 (United States).

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ASSOCIATION FOR THE ADVANCEMENT OF ASSISTIVE TECHNOLOGY IN EUROPE (AAATE)

The Association for the Advancement of Assistive Technology in Europe (AAATE) is an interdisciplinary association devoted to increasing awareness, promoting research and development, and facilitating the exchange of information. AAATE is composed of more than 250 members from 19 countries. It was founded in 1995.

AAATE activities include a biannual conference, special interest groups, the scientific journal *Technology and Disability*, seminars, and workshops. Current special interest group topic areas include Robotics and Education.

AAATE interacts with sister organizations the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation Assistive Technology Association (ARATA) to advance assistive technology use worldwide. On August 26, 2000, the leaders of the four organizations signed the Tokushima Agreement to promote exchange of information and collaboration.

—Glenn Hedman

See also Assistive Technology; Australian Rehabilitation Assistive Technology Association (ARATA); Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) (United States); Rehabilitation Engineering Society of Japan (RESJA) (Japan).

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Association for the Advancement of Assistive Technology in Europe, http://139.91.151.134

ASTHMA

Asthma is an ancient condition and a modern chronic disease. Wheezing, struggling for breath, awakening every night with a cough that will not stop—these signs of an acute asthma attack, accompanied by a feeling of suffocation, form the central experience of asthma. Descriptions of wheezing, heavy breath, and desperate suffocation can be found in the earliest medical texts. The term had its origin in the ancient Greek, ασθμα, which described gasping or breathlessness, and first appeared in the *Iliad* of Homer to describe a hero out of breath after battle.

Before 1800, *asthma* was generally used as a generic term. Depending on the context and the author, it could describe the symptom of shortness of breath in anyone from any cause. By the 1820s, asthma was a disease we would recognize as much like our own ideas about the disease, a chronic illness characterized by wheezing and shortness of breath with its origins in pathological changes in the lungs. Other disorders that caused shortness of breath, most notably heart and kidney disease, no longer carried the label “asthma.” Indeed, after early autopsies of “asthmatics” in the 1810s showed that most had heart disease, emphysema, or tuberculosis, asthma became defined as a chronic lung disease with no specific pathological findings at autopsy. Despite changes in diagnosis and treatment, asthma remained an entity without clear boundaries. The symptoms of asthma—coughing, shortness of breath, the flush of exertion, pain in the chest from the use of accessory breathing muscles—are shared by many respiratory disorders, infectious and noninfectious, chronic and acute. In the nineteenth century, a cough or wheeze could be the first sign of a cold, asthma, bronchitis, tuberculosis, or a dozen other diseases. As stethoscopes, x-rays, and other tools and techniques became available, asthma was increasingly viewed as a distinct disease.

Because there has not been a single test, gene, lesion, sensitivity, antibody, or other biological or chemical marker of asthma, the disease has been defined by its symptoms. Several physicians in the eighteenth and nineteenth centuries who wrote about asthma also suffered from it. These doctors worked to convince their colleagues that asthma had a physical mechanism and was not simply a reflection of nervousness or emotional imbalance. Their dual status as experts and sufferers gave them credibility to challenge their colleagues’ more stigmatizing perspective.

Because of changes in diagnosis, treatment, theory, and practice, every generation has its particular “asthma.” The patient who suffered from asthma in 1850 would have been advised to visit Saratoga Springs or consider a trip to the Swiss mountains or the Mediterranean coast. In 1900, the same patient might have been offered adrenaline, cocaine, or one of a variety of patent remedies to inhale or smoke. In 1950, the same person’s asthma might have been treated with steroids or an intensive analysis by an émigré disciple of Freud to work through suppressed emotions or a smothering maternal relationship. By 2000, the standard treatments for asthma were inhaled medications, symptom-relieving β-2-agonist inhalers such as albuterol and preventive treatments such as inhaled corticosteroids and inhaled sodium cromoglycate. Some patients also pursued allergy treatments including antihistamines and allergen immunotherapy—receiving weekly or monthly injections of purified pollens, venoms, and other allergens to modify their bodies’ reactions to these substances.

The early 1900s saw improvements in available drugs for asthma, with the debut of adrenaline in 1900, theophylline in 1922, and ephedrine in 1924, all drugs with stimulant properties used to treat the acute asthmatic crisis. Cortisone, available in 1949, was established as a treatment for asthma within the first years of its use. Definitions of asthma have changed repeatedly as new treatments altered the way the disease was understood. In the era of stimulant therapy, bronchial spasm, hyperresponsiveness, or “twitchy airways” defined the disease. In an era of steroid treatment, the emphasis shifted to inflammation. Current treatments combine aspects of allergen avoidance in sensitive individuals with bronchodilating inhalers for both acute symptoms (chemically related to adrenaline) and anti-inflammatory inhalers to reduce the chronic reactivity of the lungs that can lead to chronic shortness of breath and severe attacks.

Since the 1960s, asthma prevalence, hospitalizations, and mortality have been rising in most of the industrialized world. In the United States from 1982 to 1994, asthma prevalence rates increased 61 percent, rising from 3.1 percent of the U.S. population to 5.4 percent, and by 2002 the national average asthma prevalence was over 10 percent. In some urban areas in the United States, up to 30 percent of children are reported to be asthmatic. These changes appear to be happening at both ends of the severity spectrum, with severe asthma and mortality worsening at the same time that there is expansion of the diagnosis toward milder cases of wheezing and shortness of breath with exercise or in the setting of upper respiratory infections that a generation ago would likely not have been diagnosed at all.

From 1970 to 1995, asthma hospitalization rates almost tripled in the United States. Asthma hospitalization rates among children under age 15 rose faster than in any other age group with 5.8 hospitalizations for asthma per 10,000 members of the U.S. population under age 15 in 1970 and 36.7 hospitalizations per 10,000 in 1995, a six-fold increase. By the mid-1990s, hospitalization rates for asthma in the United States began to level off, attributed more to the efforts of insurance companies to limit hospital stays than to decreases in population morbidity.

There has been a persistent linkage in the epidemiological literature around the world between asthma and measures of increasing Westernization, urbanization, and industrialization. The narrative of asthma as a "disease of civilization" is almost irresistible, inspiring images of the dirty, diseased city and the healthy countryside.

The epidemiology of asthma in the United States points to greater prevalence and severity of asthma (measured as rates of mortality and hospitalization) in inner-city areas with large poor and minority populations. Living in inner-city areas appears to confer special risk, but it is unclear whether the most important features of inner-city asthma severity and mortality are driven by poverty, environmental conditions (including allergens and atmospheric pollutants), housing conditions, health habits, access to health care, or other factors.

Asthma deaths, though terrifying, are rare, occurring in a tiny fraction of severe asthmatics, amounting to approximately 5,000 deaths per year for the past 10 years in the United States, out of an estimated population of 14 to 28 million asthmatics. These severe asthmatics typically have multiple risk factors for death, often including severe disease, poverty, and poor access to health care. In the United States from 1979 to 1998, asthma mortality rates doubled from approximately 1 per 100,000 to 2 per 100,000. While this increase was concerning, it took place against a background decline since the 1950s, when asthma mortality peaked at 4.4 per 100,000. In fact, the most obvious feature of the trends in asthma mortality in the United States is that in some years there are sharp discontinuities—increases, decreases, or inflections in the curve. These reflect changes in the coding of deaths under the International Classification of Diseases (World Health Organization 1992). Changes in classification have frequently shifted deaths between the categories of asthma, chronic bronchitis, and more recently chronic obstructive pulmonary disease (COPD). And while the sum of mortality from all of these disorders continues to climb, in part because of the continued impact of tobacco on population health, the significance of rising then falling asthma mortality in the past 25 years is not completely clear.

Is asthma truly rising in prevalence, or do more people now label their shortness of breath as asthma and seek treatment for the condition? It is possible that on the mild end of the asthma spectrum the prevalence rates can be partially explained as an increase in patients considering themselves sick and more physicians willingly prescribing the safer new generation of asthma drugs? The long-distance runner who is asthmatic according to specific criteria of bronchial hyperreactivity, and therefore seeks treatment, is quite a different asthmatic than the frail wheezing child of the past. This element of choice for the individual, visible in asthma, is seen throughout health and illness. People choose when to seek help, how, and what advice to accept or reject. What some label noncompliance others see as autonomy. Asthma is a disease without a cure, a diagnosis that an individual carries forever, and one that despite improved treatments can still force a change of occupation, residence, and lifestyle like so many other disabilities.

—Carla Keirns

See also Acute and Chronic Conditions.

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ASYLUMS

See Brigham, Amariah; Dix, Dorothea; Fernald, Walter; Fuller, Margaret

`ATA IBN ABI RABAH (645–733)

Nubian teacher

`Ata ibn Abi Rabah was a highly respected legal adviser and teacher at Mecca (Makkah) during the first century of Islam. He may have specialized in the rites of pilgrimage, a practice incumbent on all Muslims. Of Nubian descent, he was described as "black in colour, blind of an eye, flat-nosed, having the use of only one arm, lame of a leg, and woolly-haired; when advanced in life he lost the use of his sight" (*Ibn Khallikan's Biographical Dictionary* 1842–1871). These features would have been socially disadvantageous in Arabia, yet they were outweighed by the fact that his knowledge of law, and of the traditions of the prophet Muhammad, came directly from several of the companions of Muhammad.

—*Kumur B. Selim*

See also Abu 'l-`Ala al-Ma`arri; Abu 'l Aswad ad-Duwali; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

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ATTITUDES

Attitudes are evaluations that help decide how an individual will respond to the individual, group, object, or idea that is evaluated. When applied to persons with disabilities, attitude theories have concerned the content of attitudes, applicability of attitude content across cultures, formation of attitudes, and attitude change. In recent years, attitudes have become an important component of a social definition of disability. A key aspect of the social definition is that an individual's disability may be as much or more a function of negative attitudes and misconceptions of others in society than it is a function of the individual's particular limitations or conditions. Attitudes can create or remove barriers to full life for persons with disabilities. For example, attitudes can play a crucial role in facilitating or hindering implementation of legislation to counteract prejudice against people with disabilities. Understanding attitudes toward people with disabilities and learning how they can be changed may be a key factor in improving the lives of people with disabilities.

L. L. Thurstone (1946) defined an *attitude* as "the intensity of positive and negative affect for or against a psychological object" (p. 39). As the role of thought processes came under growing scrutiny by psychologists, definitions of attitudes shifted from being centered on responses to being seen as mechanisms influencing behavior, and increasingly included components of thought processes and behavioral intentions in addition to emotional responses. The shift from affective response to behavioral formation is reflected in the evolution of measures of attitudes toward persons with disabilities. Attitude measures developed in the 1960s and 1970s tapped general evaluations, beliefs, and intentions, with items containing general statements of beliefs about persons with disabilities, such as "Disabled people are often unfriendly" and items measuring affective responses, such as "The way disabled people act is irritating." By the 1980s, measures of attitudes included behavioral intentions, such as willingness to socialize with persons with disabilities. By the 1990s, attitudes began to be conceptualized according to their relevance to community inclusion efforts and implementation of the Americans with Disabilities Act.

Another aspect of the definition of attitudes is what is meant by the concept of evaluation. Once limited in scope to general positive or negative feelings about an object, evaluations involved in attitudes are now seen as having multiple dimensions. Charles Osgood suggested that all attitudes may be reduced to positions on three dimensions. An object may be evaluated as to whether it is good or bad (moral dimension), strong or weak (potency dimension) and active or passive (activity dimension). A similar categorization has been used in classifying historical and societal attitudes toward persons with disabilities. This viewpoint suggests that in times and societies when persons with disabilities were regarded as good, strong, and active, they were deified, that is, believed to have special divine gifts. For example, the great astronomer Tycho Brahe (1546–1601) had a man with mental retardation as a close companion. Brahe wrote down the words spoken by the man, and then endeavored to put them together in order to form divine prophecies. However, in times when persons with disabilities were regarded as bad, strong, and active, social norms and policies would favor their destruction, as was the case during the height of the eugenics movement at the beginning of the twentieth century.

STRUCTURE OF ATTITUDES

Recent measures of attitudes toward persons with disabilities usually assess different types or facets of attitudes. For instance, the Community Living Attitudes Scale, a contemporary measure of attitudes toward inclusion of persons with intellectual disabilities, assesses contradictory and specific aspects of more general questions regarding community inclusion and participation. The Empowerment subscale asks about the extent to which persons with intellectual disabilities should make their own decisions even in the face of opposition by family members and professionals. In contrast, the Sheltering subscale assesses attitudes toward the protection of persons with intellectual disabilities from harm. Likewise, the Similarity subscale measures the extent to which respondents believe people with disabilities are similar to other people, while the Exclusion subscale assesses attitudes toward separating people with disabilities from the rest of society.

The shift from general evaluations to multiple facets of specific attitudes has occurred as philosophies of service and support for persons with disabilities have moved toward community inclusion. Increased inclusion efforts have revealed numerous specific instances when attitudes create barriers. For example, a person may hold the general belief that persons with disabilities should have job opportunities, but be reluctant to hire a person with a disability for a specific job. Because general positive evaluations may mask more negative specific attitudes, measures of attitudes have moved toward assessing behavioral intentions on specific issues. This movement is reflected in recent measures of attitudes toward mental retardation and eugenics, attitudes toward specific educational practices for children with disabilities, attitudes towards inclusion in education, disability rights, and the Americans with Disabilities Act.

A final issue in the structure of attitudes is the extent to which the attitude structures found in U.S. studies generalize to other populations. Much of the disability attitude research has been conducted in the United States, and some has been done in other nations. Recent research suggests that dimensions of community inclusion attitudes generalize to samples in Japan, Korea, Israel, and Australia. However, these other nations emphasize these dimensions to different degrees than do samples in the United States. For example, a study of Israeli staff serving people with intellectual disabilities found that they emphasize protecting persons with disabilities from harm to a greater extent than they emphasize individual rights and self-determination, whereas the reverse was true of staff in the United States. It has also been suggested that in cultures characterized more by collectivism than individualism, measures assessing the effects of an individual's disability on families and communities may need to be developed to assess attitudes more accurately and completely.

ATTITUDE CHANGE

Another important aspect of attitude research is studying attitude change. Social psychologists have conducted substantial research into methods for changing attitudes, much of which applies well to attitudes toward persons with disabilities. The oldest theory of attitude change is the idea that attitudes change when the rewards for maintaining them change, an idea based in early learning theories. According to this theory, attitude formation is dependent on the incentives that are offered. Cognitive consistency theories, on the other hand, suggest that people strive to maintain consistency in their attitudes, and between their attitudes and their actions. Inconsistency is a painful state, which motivates a person to change either attitudes or behavior. Other theories of attitude change focus on the individual's conformity to others' attitudes or pressure to change from peer groups.

Another theory of attitude change draws both on cognitive consistency theories and on social psychological experiments demonstrating that hostility between groups can be reduced if common interests can be found and emphasized. If people come to see persons with disabilities as like themselves and not as different, the desire for consistency in their attitudes will motivate change in other disability-related attitudes. Thus, the more persons with disabilities are constructively included in normal community life, the more negative attitudes toward them should decline. In fact, several literature reviews have found prior positive contact with people with disabilities to be related to positive attitudes. Positive contact can also be an effective method of improving attitudes, especially when combined with information about people with disabilities. Recent research has shown that including disability-related course work, rationales for inclusion, and rotations or practicum experiences in the training of teachers, social workers, and health care providers can strengthen attitudes about the similarity of persons with disabilities to others, which may then lead to other attitude improvements.

An area of particular concern for attitude change interventionists is the persistence of a preferential hierarchy based on disability type. Several researchers have found that people with intellectual or psychiatric disabilities are viewed more negatively than people with physical disabilities.

Attitudes toward persons with disabilities play a key role in the inclusion of children with disabilities in education and the employment of persons with disabilities. Educational inclusion has become common, yet not universal, practice in North America, Europe, and other continents. Attitude research has contributed to the success of educational inclusion efforts. Researchers have explored the attitudes of students with and without disabilities, teachers, and administrators and pointed out the necessity of providing appropriate supports for educational inclusion to succeed. Research on attitudes toward employment of persons with disabilities has found that global attitudes toward the employment of persons with disabilities tended to be positive. However, more specific behavioral intentions of employers were conflicted or negative when the costs of accommodation, training, supervisory demand, absenteeism, and other factors were considered.

More needs to be understood about attitudes toward persons with disabilities in the workplace and other contexts, and how such attitudes can be changed. Attitudes toward persons with disabilities are likely to be related to quality of services and acceptance in community life. As a marginalized group, persons with disabilities often face discrimination and exclusion. Public attitudes influence public policy and its implementation. Knowledge of attitudes of service providers and community members can identify areas in which persons with disabilities are most likely to encounter resistance, as well as highlight concerns which need to be addressed in education and advocacy.

—David B. Henry

See also Employment; Inclusion and Exclusion; Stigma.

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AUDIO DESCRIPTION

Audio description renders visual images into spoken word for people who are blind or visually impaired. It is the process of narrating visual aspects of theater, museum exhibits, films, television programs, parades, and other public venues in such a way that a partially sighted or blind recipient may access the presentation more comprehensively. It provides descriptions of key visual elements such as actions, scene changes, text captions, wardrobe, sets, scenery, facial expressions, colors, textures, and composition.

Gregory Frazier is credited with developing the concept of audio description in the 1970s. In 1981, Margaret Rockwell Pfanstiehl, visually impaired, and her husband, Cody Pfanstiehl, were the first to provide audio description to theater audiences at the Arena Stage Theater in Washington, D.C. In addition, they founded Audio Description Services, which promoted theater descriptions throughout the United States.

In the mid 1980s, WGBH in Boston became the first public television station to provide audio description. Using the secondary audio program (SAP), viewers can hear the regular sound track as well as a prerecorded audio description. The United Kingdom's Broadcasting Act of 1996 requires a minimum proportion of audio-described programming. Japan, Spain, and other countries voluntarily provide some audio-described television programming, and the United States provides up to 10 hours of audio-described programming per week.

Theater performances are narrated live, while playbill information can be prerecorded. A trained audio describer speaks into a microphone, which is transmitted directly to visually impaired patrons through an earpiece. In this way, the description is heard individually and does not disturb other patrons. Description of Hollywood films at cinemas, available on a limited basis, is provided with similar equipment, while video/DVD films use the SAP capability of the video player. Similarly, prerecorded material can be provided via personal headsets to patrons of museums, art galleries, nature walks, and other exhibits.

It is important for audio descriptions to be precise and concise to fit the short spaces between dialogues, and to be objective and specific to allow the audience members to draw their own conclusions. Audio descriptions should maintain the artistic integrity of the work without qualification or interpretation. For example, instead of stating, "She looks upset," the describer should translate her facial expression or action, such as "She is crying with her face in her hands."

Television audio description is currently under debate in the United States. In 2000, the Federal Communications Commission (FCC) passed regulations requiring 50 hours of described programming per quarter by each major broadcasting company. These regulations were overturned in 2002. While many U.S. blindness groups fought strongly to get these regulations in place, the National Federation of the Blind (NFB) and the Motion Picture Association of America (MPAA) led its opposition. The NFB advocated that an easier and more straightforward version be mandated, which includes on-screen text, especially for broadcast alerts, weather reports, and advertisements. The MPAA claimed First Amendment violations because of significant changes in the creative work required for audio description.

—Terri Thrower

See also Assistive Technology; Blindness and Visual Impairment; Television.

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AUDISM

The term *audism* was coined in 1975 by Tom Humphries to name the discrimination against persons who are Deaf. According to Humphries, *audism* would appear in a dictionary as the following:

> **audism** (o diz m) *n.* The notion that one is superior based on one's ability to hear or behave in the manner of one who hears.

The primary manifestations of audism, Humphries (1975) noted, is "in the form of people who continually judge deaf people's intelligence and success on the basis of their ability in the language of the hearing culture." It also appears when deaf people themselves "actively participate in the oppression of other deaf people by demanding of them the same set of standards, behavior, and values that they demand of hearing people" (n.p.).

As Humphries defines it, *audism* is a set of beliefs held by individuals (either hearing or deaf) that stem from the common assumption of the superiority of hearing over deafness. People who hold and practice these beliefs could be labeled "audists." At this level of analysis, Humphries's definition of audism would be roughly analogous to the notion of "individual racism" in which an individual holds beliefs and exhibits racist behaviors, ranging from assumptions about the intelligence of speakers of ebonics to racist jokes to the most obvious act of hate crimes. Thus, the initial discourse of audism came in the form of identifying "individual audism" as it manifests in the beliefs of individuals, whether hearing or deaf themselves.

It was not until the 1990s that the term *audism* appeared in several publications, beginning with Harlan Lane's 1992 *Mask of Benevolence,* where Lane defined *audism* as "the corporate institution for dealing with deaf people . . . [it] is the hearing way of dominating, restructuring, and exercising authority over the deaf community" (p. 43). Lane draws on the work of French philosopher Michel Foucault and others to interrogate the organizations that attempt to care for the Deaf but actually perpetuate the conditions of disability. Since the beginnings of deaf education and the science of audiology, Lane demonstrates, educational and medical institutions have assumed authority over deaf persons, claiming to act in their best interests while not allowing them to have a say in the matters that concern them the most. From the crude and tortuous methods of French doctor Jean Marc Gaspard Itard to the surgical procedure of cochlear implants, and from the strict oralism of Johann Conrad Amman to the current trend of mainstreaming, Deaf people have been physically and pedagogically coerced into adopting hearing norms, whether they wanted to or not.

Lane's analysis has added this important historical and systemic perspective to the notion of audism. This systemic perspective coincides with definitions of structural or systematic racism. Borrowing from David Wellman, Beverly Daniel Tatum (1997) defined racism as "a system of advantage based on race." "This definition of racism is useful," Tatum wrote, "because it allows us to see that racism, like other forms of oppression, is not only a personal ideology based on racial prejudice, but a system involving cultural messages and institutional policies and practices as well as the beliefs and actions of individuals" (p. 7). The implications of this definition are far reaching, for it brings the notion of "privilege" to the fore, which allows us to grasp the benefits allotted to white individuals within a white system of advantage. Such advantages range from the ease with which many white people get housing to the availability of "skin color" Band-Aids (McIntosh 1988). Hearing privilege may come in the form of unfettered access to information, for which they cannot be faulted; however, settings that are designed to cater to deaf persons (i.e., schools) famously create barriers to communication by denying deaf persons access to a sign language and a visually rich learning environment. Therefore, there is a whole system that still favors hearing persons in environments designed for deaf people. Thus, we may succinctly use this definition to articulate the definition of *institutional audism* as a system of advantage based on hearing ability (Bauman 2004).

In this vein, Humphries's and Lane's contributions to the concept of audism have helped to make previously hidden structures of thought and beliefs visible. Institutional oppression is inherently difficult to detect, for it often masks itself as practices that follow common sense. The production of common sense—that is, the hegemony of hearing-as-norm—has roots that extend to fundamental metaphysical questions of human identity.

Thus, the discourse on audism has extended from the individual and institutional sites to include the metaphysical site. Thus, *metaphysical audism* refers to the orientation that links human identity and being with language defined as speech (Bauman 2004:242). Historically, humans have been identified as the speaking animal; those who cannot speak are seen as akin to humans in body but animals in mind. In this orientation, we see ourselves as becoming human *through* speech. Brenda Brueggemann (1999) summed up this condition of audism in the form of a syllogism: "Language is human; speech is language; therefore deaf people are inhuman and deafness is a problem" (p. 11).

It is within this orientation (language is human/speech is language) that deaf people have frequently been described as animals, especially by those who have taught them. One of the earliest practitioners of audism, Johann Conrad Amman (1873) wrote in 1700 about deaf persons: "How dull they are in general. How little do they differ from animals" (p. 2). A century and a half later, an American oralist, Lewis Dudley, wrote that the deaf students are "human in shape, but only half-human in attributes" (quoted in Baynton 1996:52). The metaphorics of deaf-as-animal became especially widespread in the aftermath of Darwin's theory of evolution. For many educators of the deaf in the late nineteenth and early twentieth centuries, Doug Baynton explained, "To be human was to speak. To sign was a step downward in the scale of being" (p. 55). Yet it was not only the oralists who constructed their deaf pupils as animals. The famous successor of the Abbé de l'Épée in France, Abbé Roch-Ambrose Sicard (1984), asserted even more vehemently that the deaf were even lower than animals prior to education. He referred to the uneducated deaf pupil as "a perfect nonentity, a living automaton . . . the deaf person lacks even that unfailing instinct directing animals destined only to have that as their guide" (p. 84).

If "deaf people are inhuman," then the logical consequence is that deafness becomes a problem of immense proportions. If poor deaf creatures are to be included in the human family, they must be made to be more fully human, that is, a speaking animal. At this point, the metaphysics of audism gives way to the systemic level where institutions of education, medicine, and law work to make the deaf creature a more normal, fully speaking human being.

Since the revelation of the grammatical nature of sign languages, and the recent work in neurolinguistics, we know that all humans (whether hearing or deaf) are born with the equal capacity to receive and produce a manual as well as a spoken language. Indeed, if this is true of humans born today, then we must assume that we have always had the potential to be the signing as well as the speaking animal. This insight now enables us to assert that Western traditions have been operating with an incomplete definition of language and hence of human identity. A theory of audism, then, may work toward the deconstruction of this presumed natural status of speech in the Western metaphysical heritage so that speech may be seen not as *the only,* but as *one of* the modalities of human language. In this vein, a critique of the Western audist orientation dovetails with a critique of *phonocentrism,* a project set under way in Jacques Derrida's *Of Grammatology* (1974). Thus, the discourse of audism has implications, not only for those most directly affected by it but also for those who have critiqued, for one reason or another, the predominance of speech and phonetic writing as the sole means of human language modalities.

Now that these three levels of audism—individual, institutional, metaphysical—have become defined and published, a more thorough dictionary definition may be offered:

audism (o diz m) *n.*

1. The notion that one is superior based on one's ability to hear or behave in the manner of one who hears.
2. A system of advantage based on hearing ability.
3. A phonocentric orientation that links human identity with speech.

Now that the term is rapidly becoming more common in the Deaf community, it may function much like a lens that brings into focus what was previously obscured behind trappings of institutionalized procedure and protocol. Foregrounding these aspects of the oppression of deaf and hard-of-hearing persons allows resistance to be articulated as struggle for human rights and dignity for a linguistic minority to have access to a fully human language that best fits their visual learning needs. Thus, the discourse around audism allows its users to perceive the overarching drive to normalize Deaf persons into hearing persons as a severe instance of discrimination and oppression at the hands of a ruling majority.

—H-Dirksen L. Bauman

See also Alexander Graham Bell; Deaf Culture; Sign Language; Speech and Language Pathology.

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AUGMENTATIVE COMMUNICATION

Augmentative communication comprises methods of communicating without speech. It includes the use of communication aids such as alphabet boards and electronic communication devices that speak as well as unaided communication methods such as sign language and gestures. People who are unable to speak or speak clearly rely on augmentative and alternative communication (AAC) methods to exchange information, express needs, maintain relationships, and participate in the activities of their community. People typically use multiple AAC methods and may use different methods with different people. For example, a child with dysarthric speech may be understood by his parents; however, for classroom participation and phone conversations he may need to augment his communication with an electronic communication device.

AAC methods are typically differentiated as aided or unaided. Unaided communication methods include vocalizations and speech attempts as well as gestures and body movements. It includes those communication methods used and understood by most people, such as facial expressions, looking (eye gaze), pointing, and other common gestures as well as methods and individualized signals that may only be understood by familiar people. For example, a child may raise her arm to talk about someone who is tall and look toward a kitchen to talk about food, hunger, or the person who cooks. In addition, people with limited ability to move may use subtle finger movements or eye blinks as codes for answering "yes" or "no" questions.

Sign language is also considered an unaided communication method. There are many different sign languages, specific to different cultures, such as American Sign Language and British Sign Language. Elements of sign language may be used by people who are unable to physically produce all the hand shapes and coordinated two-handed movements typical of sign languages. Individuals with limited speech and multiple impairments may be taught to use individual signs or adapted signs from a sign language. For example, a child with cerebral palsy may learn to use sign positions to quickly communicate needs or wants, such as touching a fist to his forehead to indicate "father" and touching his mouth to indicate "eat."

Aided communication methods include use of electronic and nonelectronic communication aids. Nonelectronic aids include writing tools, as well as boards and books with letters, words, pictures, and/or other symbols. There are many types of communication symbols; however, Blissymbolics, a language composed of more than 2,000 graphic symbols, is currently used in 33 countries. Also, Boardmaker, a graphics database for making communication aids, contains more than 3,000 picture communication symbols translated into 24 languages. People may communicate by eye-pointing or directly touching symbols with their fingers or other body parts. If someone cannot point, a communication partner may point to symbols until the person indicates which symbols he or she wants.

The category of electronic communication aids includes more than 100 dedicated communication devices, as well as computer-based communication systems and AAC software. The selection of devices is based on individual needs and capabilities of the person in his or her environment. For example, people who can spell typically choose devices that have synthesized speech to speak messages that are typed. Most devices allow people to sequence words/symbols to create messages or recall pre-stored phrases. People who cannot operate devices by touching symbols or letters may use alternate access methods such as scanning, joystick, and mouse emulation.

—Patricia A. Politano

See also Assistive Technology; Autobiography; Communication; Computer Technology; Sign Language; Speech and Language Pathology.

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AUGUSTINE, SAINT
(354–430 CE)

Roman philosopher and Christian reformer

One of the four fathers of the Catholic Church, Saint Augustine of Hippo was born in Tagaste (Algeria) and died in Hippos (Annaba), his life spanning the formal collapse of Antiquity and the rise of the Middle Ages, with the fall of Rome (410). In between, he wrote approximately 5 million words, which substantially reshaped the early Church and the nature of its subsequent development; in particular he helped to reform the newly Christianized Rome and to unify the concepts of salvation and faith. His principal works include the *Confessions* (ca. 397–400), *On Christian Doctrine* (ca. 397), and *The City of God* (413–426).

At least two Augustinian aspects relate to disabilities: his life and works. The man himself endured a mysterious, painful chest condition in his 32nd year, impairing his teaching and cutting short his meteoric rise in Roman academics. His convalescence, however, allowed his baptism by (Saint) Ambrose and his eventual elevation to the bishopric of Hippo. As he entered old age, Augustine was plagued by recurrences of this condition and by many debilities of aging. Both experiences notably affected his faith and his writings.

In his works we find numerous connections with disability, two of which are mentioned here. Critically, Augustine formulated the core of the evolving ecclesiastical precept of Christian charity with its far-flung impact on disability. In addition, Augustine's neoplatonic dualism offers tantalizing insights into the Christian supremacy of the soul and yet the author's profound dependence on experiences of the body to interpret the soul. Much work remains to be done to integrate Augustinian precepts with modern disability theory.

—Walton O. Schalick III

See also Charity.

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AUSTIN, MARY HUNTER

(1868–1934)

American author

Raised in Illinois by a disabled Civil War veteran and a mother who was a nurse and temperance activist, Austin's youth involved an early awareness of the familial impact of disability. After college, Mary Hunter moved to California, where she soon married Stafford Wallace Austin and gave birth to their only child, Ruth Austin (1892–1918). Ruth's developmental disability (possibly autism) soon became apparent; Mary Austin struggled to provide or arrange adequate care for her daughter, and in 1904 placed the girl in a private hospital in Santa Clara, where she would remain until her death. Mary Austin's disappointment, guilt, and sadness about her daughter inspired her to work for marriage reforms and sex education. In her Western short stories, disabled characters appear often, and themes of "nature versus nurture" are common. Austin's 1932 autobiography, *Earth Horizon,* was frank about the isolation Mary experienced as a young mother, the blame she placed on her husband, and the pressure she felt in her career: "Caring for a hopelessly invalid child is an expensive business. I had to write to make money," she explained, in a 1927 essay.

—Penny L. Richards

See also Family.

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AUSTRALIA

See Disability in Contemporary Australia; Disability Studies: Australia

AUSTRALIAN REHABILITATION ASSISTIVE TECHNOLOGY ASSOCIATION (ARATA)

The Australian Rehabilitation Assistive Technology Association (ARATA) provides a forum for exchange of information between professionals and consumers involved in assistive technology. ARATA achieves this through conferences, regional chapters, and a quarterly newsletter.

Special interest groups (SIGs) also give ARATA members a means of sharing ideas on specific areas of assistive technology. SIGs exist in augmentative and alternative communication, manufacturers and suppliers of communication/computer assistive technology, computer users and environmental control systems, service delivery and government policy, wheeled mobility and seating, and human perspectives of technology.

ARATA interacts with sister organizations—the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), the Association for the Advancement of Assistive Technology in Europe (AAATE), and the Rehabilitation Engineering Society of Japan (RESJA)—to advance assistive technology use worldwide. On August 26, 2000, the leaders of the four organizations signed the Tokushima Agreement to promote exchange of information and collaboration.

—Glenn Hedman

See also Assistive Technology; Association for the Advancement of Assistive Technology in Europe (AAATE) (Europe); Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) (United States); Rehabilitation Engineering Society of Japan (RESJA) (Japan).

Websites

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▣ AUTISM

Autism is one of the most controversial and provocative disability topics. From diagnostic methods to questions of origin, autism maintains an ambiguous existence. Autism evades classification; depending on perspective and discipline, autism appears under many classificatory rubrics. Autism is often defined as a neurological condition, psychiatric/psychosocial profile, pervasive developmental disorder, comprehensive communication disorder, or disintegrative sensory pathology. Researchers in medicine, hard sciences, social sciences, and the humanities, as well as parents, teachers, and professionals, actively contest the meaning, cause, and implications of autism. In any case, neither theory nor statistics exhausts the full scope of autism. Furthermore, any accurate account of autism necessitates the voices, thoughts, and experiences of autistic individuals.

AUTISM SPECTRUM

Autism constitutes a continuum of impairment. Hence, contemporary autism specialists articulate a spectrum of autism variations. The autism spectrum ranges from highly verbal, high-functioning individuals with superior intelligence, to nonverbal persons with low IQs. These impairments may or may not be disabling depending on their location along the autism continuum and environmental barriers. About 10 percent of people with autism have some form of savant skills—special limited gifts such as skill in memorizing lists or calculating calendar dates, drawing ability, or musical skills. Many people with autism have unusual sensory perceptions.

HISTORICAL CONTEXT

Leo Kanner, a child psychiatrist at Johns Hopkins University, first recognized autism as a syndrome in 1943. Kanner described a social impairment characterized by some of the following traits: aloofness; lack of social reciprocity; absence of eye contact; an inability to effectively communicate; repetitious, stereotyped behavior such as rocking, hand flapping, or preoccupation with seemingly arbitrary facts like types of vacuum cleaners; and strong resistance to changes in environment or routines.

Part of the controversy surrounding autism derives from Bruno Bettelheim's archaic theories. After being interned in German concentration camps at Dachau and Buchenwald from 1938 to 1939, Bettelheim immigrated to the United States. As the head of the Orthogenic School at the University of Chicago, he employed a controversial theory of autism, which blamed mothers' emotional indifference. Bettelheim claimed these so-called refrigerator mothers were to blame for their child's autism. Many autistic children institutionalized in his school were isolated and abused under the auspices of therapy. Ultimately, the research community discredited and renounced Bettelheim's theory of autism. In 1990, Bettelheim committed suicide.

MODERN DIAGNOSTICS

The fourth *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) of the American Psychiatric Association constitutes the dominant diagnostic tool. The Autism Diagnostic Interview-Revised (ADI-R) operationalizes the American Psychiatric Association's *DSM-IV* criteria for diagnosing autism. Both the ADI-R and *DSM-IV* consider effects in three main areas: communication, social development, and restricted, repetitive behaviors. Furthermore, the *DSM-IV* corroborates diagnostic practices used by the World Health Organization's International Classification of Functioning, Disability, and Health (ICF). According to the *DSM-IV*, autism is a type of pervasive developmental disorder. It interferes with a person's ability to communicate with and relate to others. Autism is a lifelong condition. Autism affects how a person perceives and processes sensory information. Signs of autism almost always develop before a child is three years old, although the condition is frequently undiagnosed until later. Typically, parents first become concerned when they notice their toddler does not respond or interact like other children of the same age. Toddlers with autism do not usually babble or talk normally, and they may seem to have hearing problems. Early diagnosis and treatment helps young children with autism develop to their full potential. However, standard treatment guidelines to achieve this goal have not yet been established by the pediatric community.

Autism is often difficult to diagnose. Unlike fragile X or Down syndrome, autism cannot be located in any chromosomal structure. Most research suggests that people with autism have irregular brain structures. More study is needed to determine the cause of these irregularities, but current research indicates they are inherited. While there is some evidence that suggests neurological or physiological differences in the brains of autistic people, medical authorities still rely on behavioral characteristics to assert an autism diagnosis. Parents who have had one child with autism are more likely than other couples to have a second child with autism. There is no way yet identified to prevent autism, but experts agree that early educational intervention, often in conjunction with medicine or therapy, increases an autistic individual's chances for social success and a high quality of life.

—Heather Stone

See also Asperger Syndrome.

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AUTOBIOGRAPHY

Insofar as it is regarded as a departure from a norm, disability, especially visible disability, seems to demand or provoke autobiographical narrative: What happened to you? In fact, a collection of autobiographical narratives edited by Lois Keith has been published under that title. Yet, until very recently, autobiographical narrative of disability has been rare. Instead, third-person narrative has dominated the representation of disability—in various literary genres, such as drama and fiction; in mass media; and in tacit cultural scripts. Disability has loomed large in myth, legend, and drama from the classical Greeks onward and in the novel from its more recent origins. Historically, then, disability has been represented primarily by nondisabled writers and almost exclusively in fictive or imaginative genres.

Such representation, moreover, has typically been hostile or, at best, patronizing toward people with disabilities. Disability has largely been represented as a trope for a moral or spiritual condition (usually, but not always with a negative valence), rather than as a lived condition of interest and value in itself. The most prejudicial "explanations" for disability have been divine disfavor or moral flaw in the individual (which are variants of a single trope). Many conventional rhetorics of disability—for example, those of triumph or spiritual compensation—tend to devalue it, portraying it as a problem for an individual to overcome through force of will or for God to offset through force of grace.

Before 1900, autobiographical representation of disability was sporadic. In the latter half of the nineteenth century, a small number of American women produced narratives of institutionalization in mental asylums. And from the mid-nineteenth to the mid-twentieth centuries, tuberculosis patients produced numerous written (but not always published) accounts of illness and invalidism. In the second half of the twentieth century, personal narrative of disability grew significantly. For his classic study *Stigma: Notes on the Management of Spoiled Identity* (1962), Erving Goffman surveyed the extant autobiographical literature; his bibliography is thus a good resource for early narratives, most of which concern physical or sensory impairments and appeared before World War II. (One of these, Katharine Butler Hathaway's *The Little Locksmith,* was recently rediscovered and reprinted.) The return of disabled veterans after the war gave a new visibility to disability autobiographies such as Harold Russell's *Victory in My Hands;* while exceptional, insofar as circumstances associated disability with patriotic duty, sacrifice, and heroic masculinity, these narratives may constitute a market breakthrough.

The next waves of narratives had to do with disability caused by disease rather than war. The spread of polio (and its middle-class demographics) gave rise to a significant number of narratives; polio was thus perhaps the first disabling condition to generate a significant number of autobiographical narratives over a short period of time. Decades later, HIV/AIDS, an epidemic with very different demographics and politics, also generated a considerable literature. In the early years of that epidemic, however, when AIDS was tantamount to a death sentence, it was typically represented biographically, by surviving partners or relatives; only after the development of drugs that made it possible to live with AIDS as a chronic illness did autobiographical accounts proliferate. The autobiographical literatures of polio and AIDS (and breast cancer) suggest, then, that one important factor in the development of disability autobiography has been medical advances that have enabled individuals to survive serious illnesses. This is true of the growing autobiographical literature of paraplegia and quadriplegia as well; only in an era when people can live indefinitely with significant paralysis can these conditions generate much in the way of autobiographical literature.

A different phenomenon was the sudden proliferation in the 1990s of narratives devoted to a large range of conditions, some relatively obscure, some of recent cultural (read medical) creation, hence hitherto absent from autobiographical literature. Such conditions include (in alphabetical order) amnesia (Robinson), amyotrophic lateral sclerosis or Lou Gehrig's disease (Robillard), Asperger syndrome (Willey), asthma (Brookes, DeSalvo), cystic fibrosis (Rothenberg), deformity of the legs (Fries), depression (Styron), diabetes (Roney), disfigurement (Grealy), epilepsy (McLean, Robinson), locked-in syndrome (Bauby), multiple sclerosis (Mairs), obsessive-compulsive disorder (Wilensky), stroke (McCrum and Robinson), stuttering (Jezer), Tourette syndrome (Handler and Wilensky). More remarkable, conditions that might seem to preclude verbal self-representation have recently been given autobiographical treatment: autism (Grandin, Williams), Down syndrome (Kingsley and Levitz), and early-stage Alzheimer's disease (DeBaggio, McGowin). Conditions that preclude writing in conventional (i.e., manual) modalities have been represented by way of collaborative mediation. For example, Ruth Sienkiewicz-Mercer, who has cerebral palsy so severe that she cannot walk or talk, wrote *I Raise My Eyes to Say Yes* with the assistance of Steven B. Kaplan and through the mediation of customized word boards.

Autobiography is a particularly valuable and liberatory medium for the representation of disability because by definition it involves *self*-representation; the growing number of disability autobiographies is encouraging insofar as it suggests that the marketplace is opening up to the voices of disabled people. Autobiography is increasingly living up to its potential as the most democratic, most catholic (i.e., inclusive), and most accessible of literary genres. Indeed, this phenomenon seems to parallel the increasing inclusion of disabled people in public life in the United States in the wake of the Americans with Disabilities Act (1990). As legislation mandates their inclusion in public institutions, and as such individuals are revalued in the body politic, people with disabilities have felt encouraged to represent themselves—in the political as well as mimetic sense—in autobiography. They become more visible, more audible, more assertive. The relation between civil rights legislation and autobiographical discourse is a recursive one: Each at once reflects and advances the other.

Numbers are not everything, however, and self-representation is not necessarily advocacy. Even contemporary disability autobiography sometimes recycles and thus perpetuates prejudicial rhetorics. One such rhetoric is that of spiritual compensation; in this schema, the disabled individual finds compensation in the spiritual realm for a physical or sensory impairment. The formula can be found in contemporary narratives such as Reynolds Price's *A Whole New Life,* which has to do with paralysis caused by spinal tumor in midlife, and Ruth Cameron Webb's *A Journey into Personhood,* which has to do with cerebral palsy. Webb, a Ph.D. and counselor to people with disabilities, resolves her sense that God "gave" her cerebral palsy only through a transfiguring visitation in which a voice tells her to give up her anger and accept God's love. Though it is clear to the reader that Webb has suffered primarily from discrimination, she seeks solace not in political action or disabled identity but in a sense of divine sanction. In her view, disability is her problem—a challenge given her by God for inscrutable reasons—not a social or political issue.

A more common script in disability narrative, including autobiography, is that of triumph over adversity. This emplotment of disability, like other culturally preferred scenarios, is consistent with the medical paradigm, which locates disability entirely within a "defective" or "abnormal" body. Disability is presented primarily as a "problem" that individuals must overcome by way of individual will and determination rather than political action. This formula, however, is susceptible to a progressive variant: that of triumph over *discrimination.* It matters, then, whether adversity is defined as *impairment* and located in the body or as *disability* and located at the interface between individual and culture.

A subgenre that embraces the latter approach is the increasingly popular "coming out" narrative. Narrators in this vein are typically people with congenital or early-acquired disabilities; in adulthood, they undergo a change, not in their condition, but in their relation to it, such that they self-identify as disabled. They are newly assertive and proud of that identity. Their narratives may either retrace the emergence of a disabled identity, in the manner of Stephen Kuusisto's *Planet of the Blind* (in which his acquisition of a guide dog marks him as blind in a new way), or explore it more self-reflexively and in an essayistic manner, such as Georgina Kleege's *Sight Unseen,* which begins, "Writing this book made me blind." (In the case of Irving Zola, his coming out was a product of his residence, as a researcher, in a community of disabled people in the Netherlands.)

When the focus is on overcoming discrimination—that is, oppression—we move toward a rhetoric of emancipation, as is the case in the aforementioned narrative by Sienkiewicz-Mercer. In her case, collaborative self-inscription—the use of word boards to narrate her life—is integral to the project of releasing herself from the custody of state hospitals in which she was placed as a girl; personal narrative is thus crucial to her physical and psychological emancipation. While she does not achieve physical independence, Sienkiewicz-Mercer moves to a position of greater power and mobility. The narrative is not a story of overcoming her cerebral palsy. It is thus not what Arthur Frank calls a "narrative of restitution"—a narrative in which a physician would play a transformative role. Nor is it even primarily a narrative of rehabilitation. Though she does learn to use various assistive technology devices to communicate, Sienkiewicz-Mercer never manages to walk or talk; she will always require care. The comic resolution of her narrative is not a function of removing or correcting her impairment, but of getting the world to accommodate her irreparable impairments, of removing the physical, social, and cultural obstacles to her integration into mainstream society.

Indeed, *I Raise My Eyes to Say Yes* has interesting affinities with slave narratives. The narrative is reminiscent of a slave narrative both in the sense that, on the level of plot, it traces a movement from virtual imprisonment to relative freedom, and in the sense that her emancipation is a function of a broader movement to deinstitutionalize disabled people. Like many, if not all, slave narratives, it defies the ascription of mental deficiency to the body of the Other and exposes the confinement of those bodies as a contingent social phenomenon rather than a "natural" one. It has particular affinities, then, with those slave narratives elicited by sympathetic abolitionists, for Sienkiewicz-Mercer's account is in effect promoted and sponsored by individuals seeking to liberate people with disabilities and even to abolish their "institutionalization." And in this regard, it represents a distinctly new, implicitly political, self-narrative of disability. Even more important, then, than the quantitative uptick in the autobiographical literature of disability, then, is a qualitative change: Disabled authors are increasingly departing from or challenging conventional formulas, tropes, and rhetorics.

Another significant aspect of *I Raise My Eyes to Say Yes* is that it represents, by implication, many lives that generally go unrepresented, uninscribed because of disability. In that sense, it suggests not the limitations of people with disabilities but those of autobiography as an accessible medium of self-representation. The book communicates both the liberation of access to language and the limitations of it. That is, it suggests that autobiography as traditionally conceived, with its inherent valorization of individualism and autonomy, presents its own barriers to people with disabilities.

It may also be considered a form of *autoethnography*, as Mary Louise Pratt (1992:7) defined the term: "instances in which colonized subjects undertake to represent themselves in ways that *engage with* the colonizer's own terms. If . . . ethnographic texts are a means by which Europeans represent to themselves their (usually subjugated) others, autoethnographic texts are those the others construct in response to or in dialogue with those metropolitan representations." (It is autoethnography, too, in that it is an inmate's view of the asylum.) As this narrative suggests, then, contemporary disability autobiography may display a postcolonial impulse—the impulse to define oneself in resistance to the dehumanizing categories of the medical and health service institutions. Both as individual and institutional history, *I Raise My Eyes* supplements, challenges, and indicts official discourse, which assumes that standardized testing can adequately indicate the inner life of the subject in question.

To characterize it as standing in for other unwritten, perhaps unwritable, accounts is to suggest its affinity with a more current first-person genre: *testimonio.* John Beverley (1992:103) has distinguished testimonio from autobiography as follows: "*Testimonio* represents an affirmation of the individual subject, even of individual growth and transformation, but in connection with a group or class situation marked by marginalization, oppression, and struggle. If it loses this connection, it ceases to be *testimonio* and becomes autobiography, that is, an account of, and also a means of access to, middle- or upper-class status, a sort of documentary *bildungsroman.*" In *I Raise My Eyes,* we have a disability memoir that moves toward, though it may not fully occupy, the position with regard to the disability rights movement that testimonio occupies with regard to the movement for the rights of indigenous peoples. *I Raise My Eyes to Say Yes* is testimonio to the (considerable) extent to which its narrator speaks not as a unique individual but for a class of marginalized individuals, in ways already suggested.

One of the arguments made against *narrating* disability would seem to apply to all forms of life writing, including autobiography: that presenting disability in narrative form serves to reinforce the individual paradigm of disability. First-person discourse cannot be exempted summarily from this critique. Indeed, much autobiographical literature individualizes (and sometimes medicalizes or pathologizes) disability. Thus, although autobiography may offer a degree of access that other literary genres do not, and although it may offer a degree of control over representation that other media may not, cultural constraints continue to limit the counterhegemonic potential of disability memoir. Culture filters and manipulates even seemingly "self-generated" texts in various ways, protecting its interest in marginalizing and ignoring disabled lives.

At the same time, there are signs of promise in some recent texts—narratives from hidden corners, some of which may connect with each other in ways that challenge and undermine the limited medical paradigm of disability. Such narratives not only attest to but advance the work of the disability rights movement; in their consciousness of their own condition as culturally constructed and as shared by others, their authors move beyond the familiar formulas of disability memoir and point the way to broader critiques of the construction of disability today.

—G. Thomas Couser

See also Augmentative Communication; Blindness and Visual Impairment; Katharine Butler Hathaway; Novel, The; Harold Russell.

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AVERSIVE THERAPIES

In the education and human services fields associated with developmental disabilities, *aversives* are programmatically designed and systematically induced punishments sanctioned by professionals and directed at people with disabilities to directly control their actions and hypothetically shape their behaviors toward what are determined to be appropriate ends. Over the past two decades, numerous disability-related organizations and panels have called for an end to the use of aversives because they are abusive, dehumanizing, and psychologically and physically dangerous (see, e.g., Autism National Committee 1999; National Council on Disability 1995; TASH 2004; International Association for the Right to Effective Treatment 2003).

The National Council on Disability (1995), a federal agency making recommendations to the president and Congress on disability issues, noted:

> Prisoners [in the United States] are afforded protection under the law from [harsh and abusive] treatment. . . . Students with severe behavioral disabilities are not criminals, and yet present law allows them to be subjected to procedures which cannot be used on the most hardened criminals, or, in some cases, even on animals.
>
> Public funds intended to provide positive educational experiences and results for children should not be expended to have these children subjected to unproven, experimental, dangerous, or violent program procedures which—by design—result in pain, physical injuries, psychological damage, hunger, social deprivation, or other such negative experiences. In any other context, the use of these procedures would be considered child (or dependent) abuse or neglect. They should not be viewed as "treatment" just because a student has a disability. Through its support of these procedures used on children with disabilities, the United States could be cited for human rights violations against people with disabilities under its own Country Reports on Human Rights published annually by the Department of State.

While the proclamation of the National Council on Disability has been available for more than a decade, use of aversives on people with significant disabilities continues to be widespread. As documented by the disability-advocacy organization TASH (formerly the Association for Persons with Severe Disabilities), current, common aversive practices used to control behavior include electric shock applied to the body (e.g., arm, leg, or hand) for the purpose of discouraging the specific behavior it follows by causing pain; extremely loud white noise or other auditory stimuli not uncommonly delivered through a mask-like device; forced exercise; shaving cream to the mouth; lemon juice, vinegar, or jalapeño pepper to the mouth; water spray to the face; placement in a tub of cold water or cold showers; placement in a small room, closet, or box; slapping or pinching with hand or implement; pulling the hair; ammonia capsule to the nose; blindfolding or other forms of visual blocking; placement in a dark isolated box or other methods of prolonged physical isolation; ice to the cheeks or chin; teeth brushed or face washed with caustic solutions; prolonged restraint through manual or mechanical techniques (e.g., face-down four- or five-point restraint using mechanical tie-downs or several staff applying physical pressure); and withholding of multiple meals/denial of adequate nutrition.

HISTORY OF AVERSIVES

Harsh treatment and daily punishment have been a consistent part of the disability experience in Western cultures for centuries. Wrote Aristotle in his *Politics* (1997), "As to the exposure and rearing of children, let there be a law that no deformed child shall live" (p. 543). Such overt hostilities, often guised as benevolence, continued unabated into the eugenics era in the United States during the first half of the twentieth century. In 1942, the American Psychiatric Association developed a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles:* "Those hopeless ones who should never have been born–nature's mistakes" (p. 14).

Though euthanasia was never widespread in the United States, the use of systematic aversives gained scientific legitimacy with the early-twentieth-century emergence of the field of psychology and its predominant paradigm of behaviorism. Edward Thorndike (1914), an early psychological behaviorist, claimed that *learning,* as opposed to reasoning, rationalism, motivation, goal seeking, and higher-level emotions, was the singular explanation for all human behavior. Learning, according to Thorndike, was the trial-and-error process of forming bonds between physical events (i.e., environmental stimuli and an individual's immediate response) and mental events (described merely as things perceived by the senses). Education was the process of stamping in what were deemed to be correct perceptions and responses to stimuli through pleasurable consequences and stamping out incorrect perceptions and responses through the use of aversives.

At the same time that Thorndike's learning theory came to dominate American behaviorism, state legislatures across the United States were passing compulsory education laws. These resulted in increasingly larger, far more rigid schools and the emergence of the first special education classrooms. The use of aversives, central to the fledgling science of learning, quickly became acceptable practice in these classes made up of struggling students segregated from the mainstream but forced by law to remain in school.

Thorndike's behaviorism focused on the individual's response to recognized stimuli, but what about individuals considered to have more severe intellectual disabilities, who, it was believed, could not meaningfully perceive or respond to stimuli? Compulsory education laws specifically excluded individuals with significant disabilities, but parents of children categorized as severely disabled were beginning in the mid-twentieth century to organize educational opportunities for their children. As professionals began to take over these new schools, they began to implement versions of the learning theory developed by psychologist B. F. Skinner in laboratories using pigeons, rats, and mice.

Beginning in the 1940s, Skinner (1974) identified classes of behavior called operants that individuals emit, but whose initial stimuli are unknowable in any absolute sense. Instead, professional focus is firmly placed on stimuli that follow the behavior. Reinforcers are stimuli that increase the probability of the operants reoccurring. Aversives are punishing consequences said to decrease the probability of the behavior's reoccurrence.

In 1949, researchers at Indiana University were the first to tie Skinnerian psychology to people with significant disabilities. In the introduction to the study appearing in the *American Journal of Psychology,* Fuller (1949) first described rather mixed results of stimulus-response (i.e., Thorndikian and classical) conditioning using people with disabilities as subjects. He noted, for instance, that while one experiment showed "subnormal children formed conditional responses to shock faster than normal children," another experiment failed in its "attempt to condition a salivary response to an 18-yr.-old idiot, probably due in part to [subject's] refusal to have a saliometer attached" (p. 587).

In contrast, the Indiana University experiment was an operant conditioning (i.e., Skinnerian) effort using an 18-year-old "vegetative idiot" (p. 588). The researchers deemed desirable the subject's movement of his right arm. To increase this operant, they withheld his food for 15 hours, then waited for the behavior to be emitted. When the subject's arm moved, they injected sweetened milk into his mouth. The experiment was hailed as a success as the subject increased his right arm movements considerably. Fuller (1949) concluded:

> According to the attending physicians, Subject had not learned anything in the 18 years of his life—yet, by using the operant conditioning technique, an addition was made to his behavior which, at his level, could be termed appreciable. . . . For years many psychologists have experimented exclusively with infrahuman subjects. Perhaps by beginning at the bottom of the human scale the transfer from rat to man can be effected. (p. 590)

The Fuller (1949) experiment served as the genesis for the mass implementation of operant conditioning in programs for individuals with significant disabilities and initiated the scientific justification for the use of aversives on this population. Sobsey and Dreimanis (1993) noted:

> To apply the laboratory science of behaviorism to special education, it was necessary to model the special education classroom after the laboratory rather than the regular classroom. The highly controlled conditions that were considered to be necessary for teaching students with special needs were alien to and incompatible with the regular classrooms. The results have been catastrophic for students with disabilities. (p. 6)

Most recently, accumulated research demonstrates that a wide range of instructional methods are available that not only are more effective than use of aversives and behavior modification in general but also do not inflict pain on, humiliate, dehumanize, or overly control or manipulate individuals with disabilities. Alternative approaches that are proven to be effective attempt to identify the individual's purposes in behaving as he or she does and offer support and education to replace dangerous or disruptive behaviors with alternative behaviors that are positive and will achieve the individual's needs.

The international disability advocacy organization, TASH (2004), has publicly called for an end to all use of aversives:

> Be it resolved, that TASH, an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field, affirms the right of all persons with disabilities to freedom from overly restrictive procedures and from aversive or coercive procedures of any kind. TASH is unequivocally opposed to the inappropriate use of restraint and to the use of overly restrictive and aversive procedures under any circumstance and calls for the cessation of the use of all such procedures.

—Christopher Kleiwer

See also Euthanasia.

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▣ AYRES, A. JEAN (1920-1988)

American occupational therapist and scholar

A. Jean Ayres, an occupational therapist and a clinical psychologist, pioneered development of therapy for children who have subtle neurological impairments. Her work with children with cerebral palsy and learning disabilities led to the development of the sensory integration theory. This theory attempts to explain how certain learning or behavioral problems can be based in difficulties of processing sensations, such as touch, movement, sight, and sound. Children with sensory integration problems exhibit insecurity or fear of movement and consequently can have difficulty with ordinary activities such as playing with toys and doing self-care.

During her 35-year career, Ayres wrote several books and published multiple scholarly articles addressing her theory and techniques for clinical application. In 1976, she founded the Ayres Clinic where she evaluated and treated children using the approach she developed. Sensory integration therapy stresses detailed evaluation and understanding of each child's unique sensory style and challenges as a basis for providing the child appropriate opportunities to learn how to process and use sensory information to enhance skill in performance.

Today, sensory integration theory continues to evolve and is one of the most extensively researched and developed models of practice in occupational therapy. The approach has evolved away from a more exclusive focus on remediation of the underlying sensory processing impairment to emphasize environmental adaptation, self-understanding, and personal management of sensory challenges.

—Eynat Shevil

See also Occupational Therapy.

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B

BABY BOLLINGER (1915–1915)

American victim of infanticide

"Baby Bollinger" (first name: Allen) was born to Anna and Allen Bollinger at the German-American Hospital in Chicago, Illinois. The seven-pound Baby Bollinger was diagnosed with multiple physical anomalies and became the first victim in a string of public infanticides of disabled babies committed by the head of staff at the hospital, Dr. Harry Haiselden. The doctor declared Baby Bollinger a "monster," a "pitiful bundle of semi-life." Anna Bollinger was encouraged to allow her baby to die by withholding life-saving surgery. "I want my baby. But the doctor has told me . . . I want him to live—but I couldn't bear to think of how he would suffer . . . how he would so often curse the day he was born. So I agreed with the doctor." On the day of Baby Bollinger's death, a Chicago newspaper printed the following description of him: "A pink bit of humanity lay upon the white cloth. Its blue eyes were wide open. Its hair was brown and silky, it dug at its face with little fists. It cried lustily as it drew up chubby legs and kicked out. It seemed quite vigorously informed with life."

—Sharon Lamp

See also Eugenics; Infanticide.

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BANK-MIKKELSEN, NIELS ERIK (1919–1990)

Danish reformer

Niels Erik Bank-Mikkelsen, an early champion of normalization, was born in Denmark in 1919 and received a degree in law in 1944 from the University of Copenhagen. During World War II, he joined the Danish resistance movement, was captured, and interned in a Nazi concentration camp. He developed the concept of normalization in response to his perception that institutionalized people with disabilities were treated only slightly better than concentration camp inmates. Following the war, he entered the Danish Ministry of Social Affairs. In 1950, he moved to the Danish Service for the Mentally Retarded, becoming departmental head in 1959.

He introduced the concept of normalization in a piece of Danish legislation called the 1959 Mental Retardation Act. He described normalization as a means to ensure people with this diagnosis the right to the same community-based existence as their peers without disabilities, including clothing, housing, education, work, and leisure. Normalization was seen as a way to ensure that this population received the same legal and human rights given to other citizens. In 1968, Bank-Mikkelsen received the Kennedy Foundation

Award in recognition of his work. In 1971, he became the Director of the Department of Care and Rehabilitation of the Handicapped, Danish National Board of Social Welfare, and was instrumental to the 1980 formation of Denmark's Central Committee on the Handicapped.

—Pamela Block

See also Bengt Nirje; Normalization.

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BARBELLION, W. N. P.

(1889–1919)

English naturalist and author

The fledgling scientist and writer W. N. P. Barbellion, born Bruce Frederick Cummings, kept a journal from the age of 13 almost to his death. Earlier parts show the lad's abilities as a naturalist, a largely self-taught thinker, and voracious reader. When he learned in 1915 that the ailments long plaguing him arose from "disseminated sclerosis" (multiple sclerosis), the journal recorded a race against time to achieve some large ambitions before his body collapsed. He was by then married, had had scientific papers published, and held a minor post at the British Museum of Natural History. Barbellion (1984) continued "tinkering about in the Museum," though he found it "excoriating to be thus wasting the last few precious days of my life in such mummery merely to get bread to eat" (pp. 282–283), against a background of the Great War across Europe. A bowdlerized edition of his journal, published in 1919, impressed most of the critics with its freshness and lively acumen. Barbellion died knowing that he had made his mark in the world of human self-knowledge. Ironically, despite republication in the late twentieth century, his work remains practically unknown and unused by the disability movement.

—Kumur B. Selim

See also Autobiography; Multiple Sclerosis.

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BARKER, ROGER GARLOCK

(1903–1990)

American scholar and author

Just after World War II, Roger Barker, while on the faculty in psychology at Stanford University, was asked by the Social Science Research Council to conduct a comprehensive review of the psychological literature on physical disability to help meet the needs of returning war veterans with injuries. Not content with an annotated bibliography of the literature, Barker, in collaboration with Beatrice A. Wright, Lee Meyerson, and Mollie Gonick, published an extensive theoretical and research monograph dealing with the social psychology of physique, disability, and illness. The monograph was revised in 1953.

In this work, Barker applied Kurt Lewin's field theoretical concepts of new and overlapping psychological situations to problems of physique, physical disability, and illness. He coined the term *somatopsychological relation* to refer to the question of how variations in physique affect the psychological situation of a person by influencing the effectiveness of the person's body as a tool for actions or by serving as a stimulus to the person or others. This pioneering monograph helped to establish the psychology of physical disability and rehabilitation as a research and professional discipline and to the launching of the division on Rehabilitation Psychology of the American Psychological Association.

—Phil Schoggen

See also Kurt Lewin; Psychology.

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BASHSHAR IBN BURD (714/715–783/784)

Arab poet and critic

The renowned blind poet Bashshar ibn Burd spent much of his life at Baghdad. He was probably born blind, though some writers argue that he lost his sight later. Efforts have been made to elucidate the question from his verses. Of the poetry of Al-A'sha and Bashshar, the celebrated critic Al-Jahiz wrote that these two blind men succeeded in catching truths that sighted people failed to discern, and Bashshar in particular excelled in doing so. Bashshar's self-reflexive wit gave rise to anecdotes, as when he broke wind in company and dismissed it as "merely a noise. Don't believe anything unless you see it!" Sometimes the joke turned against Bashshar. He publicly teased another savant, Said the Philologer, for academic fraud, by asking him the meaning of the word *jaranful* among the Bedouin. Said, who had himself invented this bogus word, was briefly silent, then came back, "The *jaranful* is one who has commerce with blind men's wives," causing hilarity among those present.

—Kumur B. Selim

See also Abu 'l-`Ala al-Ma`arri; Abu 'l Aswad ad-Duwali; `Ata ibn Abi Rabah; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

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BEECHER, HENRY KNOWLES (1904–1976)

American anesthesiologist and researcher

Henry Knowles Beecher was an outspoken advocate of ethical standards in human subjects research and a pioneer in the study of pain, analgesia, and the placebo effect. He was also influential in the growth of anesthesiology as an independent medical specialty. Born in Kansas in 1904, Beecher earned his medical degree from Harvard Medical School in 1932. After early surgical training, Beecher was appointed Chief of Anesthesia at the Massachusetts General Hospital, despite having no formal education in anesthesia. In 1941, Beecher was named the Dorr Professor of Research in Anaesthesia at Harvard University, the first endowed chair of anesthesia in the world. Beecher's career was interrupted by service in World War II, when he observed pain responses of battle-wounded soldiers to be quantitatively different from those of surgical patients. Later, Beecher compared morphine and placebo to investigate psychological context in the physiology of pain control. This work has led to Beecher's appellation, "father of the prospective, double-blind, placebo-controlled clinical trial."

Beecher will be remembered most for his stance on human experimentation. He argued for informed consent by research subjects, and he condemned research that did not demonstrate potential benefit to patients as ethically unjustifiable. His landmark 1966 article in the *New England Journal of Medicine* chronicled 22 published studies with ethical infractions and consequently stimulated U.S. researchers to obtain informed consent prior to experiments.

In 1970, Beecher retired and received the Distinguished Service Award from the American Society of Anesthesiologists. Beecher died in 1976.

—Hugh M. Smith

See also Consent to Treatment; Ethics; Pain.

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BEERS, CLIFFORD WHITTINGHAM (1876–1943)

American advocate

Clifford Whittingham Beers developed the concept of mental hygiene, the precursor of our term *mental health* and the basis of much of prevention emphasis.

A Yale graduate who shared his struggles with mental illness openly in his autobiography, *A Mind That Found Itself* (1908), Beers garnered the support of mental health professionals and the public alike in an effort to advance the fledgling sciences of psychiatry and psychology. As founder of the Connecticut Society for Mental Hygiene (1908) and the National Committee for Mental Hygiene (1909), these groups picked up the term *mental hygiene* coined by Adolf Meyer, and developed an educational and reform movement for care of the mentally ill.

Beers's emphasis on prevention and his own example of recovery from a severe illness in his early adult life could be likened to the abolitionist efforts against slavery. As an articulate insider of Yale intelligentsia and some of the best-known private and public asylums of his day, Beers crafted a vision of recovery that engaged others and caught the attention of mental health professionals. His autobiography provided a balanced, substantive view into mental illness, allowing others to view compassionately and realistically the struggle of the human mind to come back from this loss. As a businessman and a communicator, he played a major role in formulating mental health policy by establishing a database on mental institutions, counting the number of individuals served by these institutions, and the psychiatrists serving there. Among the legacies of Beers's courage is the National Mental Health Association, formed in 1950. This organization's mission is to continue Beers's goals of "spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health."

—Patrick H. Tolan
and Karen Taylor-Crawford

See also Advocacy; Autobiography; Mental Illness.

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BEGGING

People with disabilities have begged throughout history and across the world. They have asked for money and other kinds of charity. Peddling, the selling of typically inexpensive items, can be similar to begging. Begging is done by individuals and in more organized ways. Societies have supported and opposed begging by those with disabilities. Begging by those with disabilities reflects their subordinate position in society.

People with disabilities have begged for thousands of years. In ancient Egyptian and Hebrew societies, blind people often begged. The Bible records that Jesus encountered blind people who begged. While individuals born with disabilities in ancient Greece were often killed, those who became disabled later in life were spared. Some who were spared turned to begging, often near well-traveled places such as temples. During the Middle Ages, begging by those with disabilities was widespread. Many works of art have associated disability with begging.

Begging continues today, though it may be more prevalent in developing countries. Most people with disabilities live in developing countries, where opportunities for them to earn a living without begging are often few. Begging becomes a means for survival. It may be the most common employment worldwide for those with disabilities.

Similar to begging is peddling. For example, some deaf people sell cards printed with the manual alphabet and other small items at airports and other public places. They may ask the recipients to "spend" whatever they wish. The unskilled playing of a musical instrument by a blind person in order to receive donations from passers-by is comparable to begging.

Begging by those with disabilities has been an individual and an organized enterprise. Adults have enlisted disabled children to beg. They have even maimed children in order for them to beg more successfully. During the Middle Ages as competition among beggars occurred, guilds and brotherhoods were established, including ones for blind beggars. Pensions have been provided to beggars, as they were to elderly, blind beggars in Italy in the fourteenth century. Some deaf peddlers, at times illegal immigrants who do not know well the language of their host country and have little education, have been organized into peddling rings under the control of deaf or hearing bosses.

Communities have supported begging by those with disabilities. Disabled people have often been viewed as the deserving poor. They deserved the charity of those more fortunate. Religions such as Christianity, Hinduism, and Islam teach their followers to show charity toward those in need, including those with disabilities. In the ancient world, blind people were assigned the role of beggar. Statutes in France from the mid-fourteenth century governed the begging by blind residents for the benefit of their entire community. During the Middle Ages, the church at times supported begging by those who were blind by allowing them to beg near their entrances or on church grounds. Laws restricting begging by nondisabled people sometimes made exceptions for those with disabilities, as did statutes in more than a dozen states in America in the early part of the twentieth century that made exceptions for blind people who begged.

Societies have also discouraged or prohibited begging by those with disabilities. Begging became so widespread during some eras that disabled beggars were viewed with contempt, as dangerous rascals, with suspicion and hate. Laws were enacted to limit begging.

As societies industrialized, begging may have become less accepted. Industrialization emphasized paid work as the way to contribute to society. Work increasingly became a measure of a person's worth. Begging was not paid work that contributed to society. Furthermore, with the development of the Enlightenment, the view spread that people with disabilities could be, should be, educated in order to be productive members of society. Begging was contrary to this understanding of those with disabilities.

Begging expresses a complex relation between people with and without disabilities. It relies on the sympathy, pity, perhaps relief, and maybe fear of the nondisabled donor. It enacts interpersonally the larger social relation of inequality between those with and without disabilities. Yet when people with disabilities beg, they also assert themselves. They make themselves visible instead of hidden and ask, even demand, to be compensated for the inferior position the nondisabled world puts them in. Begging may help reproduce the subordinate position of those with disabilities, but it is also a rational response to limited opportunities. Until societies enable all members to sustain themselves through paid work or other means, some people with disabilities will beg.

—Paul Higgins

See also Charity; Poverty.

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BEHAVIOR THERAPY

Behavior therapy refers to a broad range of theories (hypotheses about factors that contribute to the prediction and control of behavior) and a set of treatments that derive from these theories designed to change behavior that is disruptive to patients' lives and functioning. In 1919, John Watson published *Psychology from the Standpoint of a Behaviorist,* and in his preface he states:

> The present volume does some violence to the traditional classification of psychological topics and to their conventional treatment. For example, the reader will find no discussion of consciousness and no reference to such terms as sensation, perception, attention, will, image, and the like. These terms are in good repute, but I have found that I can get along without them. (p. viii)

Watson proposed that the aims of psychology were the prediction and control of behavior. It is reputed that a major newspaper of the day ran an article with the headline "Psychology Loses Its Mind." Other early contributors to the theory and practice of behavior therapy were Ivan Pavlov (respondent conditioning), B. F. Skinner (operant conditioning), Joseph Wolpe (desensitization), Albert Bandura (social learning theory), and Aaron Beck's and Albert Ellis's independent development of cognitive behavior therapy. What characterized these diverse thinkers and their paradigms was an adherence to the scientific method for establishing principles of learning and functioning that formed the basis of their theories and therapeutic methods.

There are three major disabling conditions from a psychiatric perspective: developmental disability, autism, and schizophrenia. Behavior therapy has developed effective treatment strategies for each of these conditions primarily using the operant paradigm, or contingency management, going back more than 40 years.

Before the 1960s, developmentally disabled people were largely warehoused in residential and hospital settings with very little hope for any other life. With the advent of behavior modification programs focusing on verbal behavior, social skills, and independent living skills, most of this population can live more normal lives working in lower-level jobs or sheltered workshops and living in independent or semi-independent (supervised) settings.

Similarly, Ivar Lovas's pioneering work, starting back in the 1960s, with autistic children using intensive operant conditioning procedures on acquisition of verbal behavior, communication skills, social skills, self-care, and independent living skills has increased substantially the proportion of this population able to live more normal lives (some entirely normal) outside of institutional settings.

Schizophrenia is another area in which major contributions have been made by behavior therapy since the 1960s. Gordon Paul's seminal research showed clear superiority for a token economy treatment program over milieu and standard state mental hospital care. Patients were more functional in terms of symptom reduction, social/communication skills, and independent living skills, as indicated by higher discharge rates and lower relapse rates (ability to function and maintain themselves in the community). Even more impressive is the fact that these results were achieved without the use of medication. More recently, cognitive therapy and behavioral systems therapy are being used effectively with patients and their families to further enhance the patient's ability to live in the community.

In addition to the above three conditions, the crippling effects of severe depression and anxiety can result in disability. Disorders such as major depressive disorder, bipolar disorder, panic disorder with agoraphobia, posttraumatic stress disorder, obsessive-compulsive disorder, as well as other anxiety disorders, have been the focus of a great deal of research resulting in the development of effective treatment protocols. For more than 30 years, Beck and his colleagues have been developing cognitive therapy as a treatment of choice for depression. During the same time frame, Peter Lewinsohn and, more recently, Neil Jacobsen with his behavioral activation therapy, have effectively approached depression from an operant perspective. Exposure and response prevention (ERP), which was pioneered by Edna Foa with obsessive-compulsive disorder, and later by David Barlow with panic disorder with and without agoraphobia, has become the treatment of choice for anxiety disorders, producing significant improvement rates of between 70 and 80 percent.

Other potentially disabling conditions such as attention deficit disorder with or without hyperactivity (ADD and ADHD), substance abuse, and borderline personality disorder have also been the focus of attention from behavioral researchers and clinicians. ADD and ADHD have been treated for many years with incentive programs focusing on academic performance and prosocial behavior, as well as parent training programs. More recently, Joel Lubar pioneered the development of neurofeedback therapy, a form of conditioning therapy focusing on brain wave patterns as a promising treatment for, in particular, ADD. Sophisticated behavioral approaches to substance abuse using a wide variety of behavioral techniques to target the multifaceted problems of this population (e.g., functional analysis of drinking behavior, self-management strategies, social skills, self-soothing and emotional regulation skills training, cognitive therapy, couples' therapy, and relapse prevention strategies) have been developed. Marcia Linehan's dialectical behavior therapy (DBT) and Jeffrey Young's schema therapy are the only psychosocial treatments for borderline personality disorder that have demonstrated efficacy.

Over the past 80 years, major contributions to the treatment of diverse disabling conditions have come from the operant, respondent, social learning, and cognitive paradigms. And over those same years, as might be expected, controversies have arisen. An early controversy involved the symptom substitution hypothesis;

that is, behavior therapy targets superficial symptoms rather than deeply rooted causes, and thus new symptoms will emerge. Another controversy involved the coercive nature of behavior modification programs in hospital and prison settings. The movie *A Clockwork Orange* raised a controversy about the use of aversive conditioning. In actuality, however, the goal was to create a stable disability of sorts (inhibited libido and erectile dysfunction), but if Alec's demonic smile at the movie's end is any indication, the goal was not achieved. Many technologies can be abused (e.g., cars result in a high number of injuries, disabilities, and deaths, as do guns, industrial waste, nuclear energy, and even food). The key here is in ensuring the knowledgeable, compassionate, and ethical use of an effective technology through well-conceived and comprehensive research, training, and monitoring of practice.

—Michael B. Evans

See also Agoraphobia; Anxiety Disorders; Autism; Developmental Disabilities; Obsessive-Compulsive Disorder; Panic Disorder; Posttraumatic Stress Disorder; Psychiatric Disorders; Schizophrenia

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BEHAVIORAL DISORDERS

Behavioral disorders can be defined as the state in which youths under age 18 behave persistently and repetitively in ways that violate the basic rights of others or major age-appropriate cultural, or ethnic norms. The person is more sick than wicked. When behavioral disorders occur after the age of 18, they are considered to be personality disorders.

There are four criteria to diagnose behavioral disorders. To make the diagnosis, at least three should be present during the past 12 months, and at least one should be present for six months:

1. *Physical aggression:* This includes physically cruel behavior toward people and animals, initiating physical fights, using dangerous weapons such as a knife or a gun against others, robbing, or forcing someone into sexual activity.

2. *Deliberate destruction of others' property,* with or without fire setting, to cause serious damage.

3. *Deceitfulness or theft:* This includes breaking into another's home, building, or vehicle; lying; and stealing (including shoplifting).

4. *Serious violations of rules:* This includes often staying out at night despite parental prohibitions (before the age of 13); running away from home overnight at least twice; frequent truancy from school before the age of 13. In many Eastern countries, however, truancy at any age is considered as a behavioral disorder—an example of how differences in traditions lead to different diagnostic criteria.

To fit the diagnosis, these behaviors must also significantly affect performance (academic, social, vocational, or personal skills); hence behavioral disorders are considered to be disabilities. Patients who suffer from behavioral disabilities also are unable to learn or work, and these disabilities are not due to intellectual, sensory, or health factors. These patients also lack the ability to build or maintain satisfactory interpersonal relationships.

Because the diagnostic criteria of behavioral disorder vary widely, its manifestations at different stages differ, and because of differences in the adopted methodology, it is impossible to determine precisely its prevalence. However, it is considered to be a common problem in children and adolescents. In the United States, the condition is more prevalent among boys (6–10 percent) than among girls (2–9 percent). The prevalence is more in urban and suburban than rural settings, and even greater in overcrowded cities.

Behavioral disorders can be present with, or derive from, biopsychiatric disease (mood disorders, psychosis, attention-deficit hyperactivity disorder), organic impairment, and mental retardation. Although some of these children and adolescents have family history of behavioral disorders (which might indicate a genetic role), in most cases family, socio-economic, and environmental factors contribute heavily to the genesis of behavioral disorders. Conduct disorders can be complicated by drug abuse, alcoholism, AIDS, dropping out of school, and criminal behavior.

Only a fraction of children with this disorder are treated. Family and school intervention, psychotherapy, cognitive-behavioral therapy, and medications (psychostimulants, antidepressants, antipsychotic, anticonvulsants) have been successful.

The most important preventive measure is the establishment of a strong and cohesive family, with a clear policy of child-rearing practices, stressing the importance of religious and social factors.

—Marwan M. Al-Sharbati

See also Crime and Delinquency; Parenting and Disability.

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BELL, ALEXANDER GRAHAM

(1847–1922)

American (Scottish-born) inventor and scientist

Alexander Graham Bell, inventor of the telephone, was one of the foremost proponents of a nineteenth-century oralist movement in Deaf education. Bell used his international fame to promote a philosophy that American deaf children should be taught to speak and taught only through articulation and speech-reading, with no use of sign language. The oralist ideology was very much a product of its times, riding the late-nineteenth-century wave of nativism and social Darwinism to promote a view that Deaf people should be linguistically and socially assimilated into a monolingual, auditory, speaking society.

Bell was one of a number of scientists interested in questions of heredity who would go on to found the American eugenics movement. Among his publications was the 1883 *Memoir on the Formation of a Deaf Variety of the Human Race* in which he claimed the intermarriage of Deaf people would invariably lead to a Deaf subset of humanity. This claim proved false, but would recur periodically among scientists and the general public over the next decades.

Bell was born to a Scottish elocutionist and his deaf wife in Edinburgh on March 3, 1847. His marriage to one of his first deaf pupils, Mabel Hubbard, was by all accounts a happy one, lasting 45 years. Both his mother and his wife did not use sign language. Bell died on August 2, 1922, in Nova Scotia, Canada.

—Joseph J. Murray

See also Audism; Deaf Culture; Eugenics; Sign Language; Speech and Language Pathology.

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BELL'S PALSY

Bell's palsy was named in honor of, but not by, the Scottish surgeon-anatomist (1774–1842) who discovered in 1821 the difference between the fifth cranial nerve that gives the face sensation (trigeminal nerve) and the seventh cranial nerve that gives the face expression (facial nerve).

Bell's palsy refers to a specific type of sudden, unexpected onset of facial paralysis on one side of the face and is the most common cause of facial paralysis in all age groups. It is a diagnosis of exclusion (idiopathic), meaning that all other causes of facial paralysis have been sought and excluded. This distinction is important because there are definable other causes of sudden facial paralysis that should be detected and treated differently; some of these may be quite dangerous, such as cancer, nonmalignant tumors, infections, and trauma.

Recently, herpes simplex virus, type 1, the common cause of fever blisters, has been implicated as a cause of some cases of Bell's palsy. Because of this, antiviral medications have begun to be used in conjunction with orally administered corticosteroids, such as prednisone, a commonly used treatment for Bell's palsy. However, there is little scientific evidence to prove these treatments are helpful.

The physical impairment from Bell's palsy falls in two time domains, immediate and late. Immediate impairment is the dysfunction of the facial nerve (seventh cranial nerve), resulting in complete paralysis or partial paralysis (also known as paresis). The resulting disability from this impairment is the inability to close the eyelids, thus failing to lubricate and protect the eye; the inability to express emotions or produce voluntary movements, such as smiling, on that side; and difficulty eating with the mouth fully closed. Because all cases of Bell's palsy recover to some degree, but not necessarily to normal, late impairments are common. Late impairments are permanent paresis, synkinesis, and contracture. Synkinesis is the concurrent movement of a portion of the face in a region other than the one voluntarily or emotionally moved, for example, winking when trying to smile. Contracture is the increased resting tone of the side of the face, which leaves the patient with an eye more closed than normal and a mouth with a permanent smirk. Disabilities from these late impairments are the inability to express oneself completely, especially smiling and softening of the eyes in the smiling process, and the inadvertent transmission of incorrect nonverbal facial messages, such as winking while eating or permanently smirking. Excessive tearing while eating, known as "crocodile" tears, may occur and impair or distort communication, such as tearing in one eye during a romantic dinner.

Facial expressions in human communications are important in both the receptive and the expressive modes. Because Bell's palsy is more common during the teenage and early adult years, times of important social development, the disabilities may be especially socially traumatic. Similarly, infants learn to detect facially expressed emotions and develop accordingly. Facial disfigurement may be distressing to the receptive infant and to the expressive sibling, parent, or grandparent who may look quite different with Bell's palsy.

—*J. Gail Neely*

See also Neurological Impairments and Nervous Disorders; Paralysis.

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▣ BIESALSKI, KONRAD (1868–1930)

German pediatrician and reformer

Konrad Biesalski was a pediatrician, orthopedic specialist, and the founder of the rehabilitation policy for the physically disabled ("cripples' care") in Germany. He was born in Osterode/Prussia and studied medicine in Halle and Berlin. In 1894, he passed his Boards, after which he got his Ph.D. in medicine and became an assistant doctor in Berlin and Würzburg. Biesalski initiated the first census of physically disabled youths, or "cripples" as they were officially known, in 1906. Through cure, education, and employment of the affected persons, he wanted to prevent the economical harm caused by the social needs of the physically disabled. His motto was "Vom Almosenempfänger zum Steuerzahler" ("From alms recipient to taxpayer"). In addition, in 1906 Biesalski opened a small institution in Berlin. After he had founded the *Zeitschrift für Krüppelfürsorge* (*Journal for the Care of Cripples*) in 1908, the Deutsche Vereinigung für Krüppelfürsorge (German Organization for the Care of Cripples) was created on April 14, 1909, as an umbrella organization for the care of the physically disabled.

In 1911, with the *Leitfaden der Krüppelfürsorge* (*Manual for the Care of Cripples*), Biesalski published a standard work for this new field of social policy. On May 27, 1914, he opened the Oskar-Helene-Heim für Heilung und Erziehung gebrechlicher Kinder (Oskar-Helene-Home for the Cure and Education of Frail Children) in Berlin, which soon became internationally known as a model facility. With the Kriegskrüppelfürsorge (care of war cripples) initiated by him during World War I, Biesalski laid the foundation for establishing specialized medical treatment for the first time, along with special institutions, and the prospect of social and professional rehabilitation. The Preußische Krüppelfürsorgegesetz (Prussian Cripples' Care Law) of 1920 enacted, for the first time, a right to medical care, and scholarly and occupational education for the physically disabled. In 1928, the Museum der Deutschen Krüppelfürsorge (German Cripples' Care Museum) opened in the Oskar-Helene-Home. Biesalski died two years later on January 28, 1930, of a cardiac infarction.

—Petra Fuchs

See also Advocacy Movements: Germany; *Cripple*.

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▣ BINET, ALFRED (1857–1911)

French psychologist

Universally known as the developer of the *quotient d'intelligence*, Alfred Binet was most of all an innovative psychologist. Initially, he undertook legal studies, receiving a law degree in 1878, but he also expressed interest in natural science. In 1883, he began work in Jean-Martin Charcot's laboratory at Salpêtrière Hospital in Paris. The birth of his two daughters provided him the opportunity to study child psychology, more particularly analysis of individual differences in connection with genetic inheritance and education. In 1892, he had his first contact with Theodore Simon, who solicited his counsel for the education of the abnormal children for whom he was in charge.

His question about abnormal children is capital: What distinguishes them from "normal" children; is it a difference of degree or nature? And how to define, in a general way, this concept of difference, and how to evaluate it? In 1904, he and Simon brought about the creation of a departmental committee, whose objective was the examination of two problems: the diagnosis of the states of mental retardation and the education of abnormal children.

Six months later, he presented his test of diagnosis at the International Congress Psychology (Rome, 1905), which was first version of the future "metric scale of the intelligence." In a clinical approach of epistemology, Binet transformed the diagnosis into numbers representing the intellectual level to make measurement an effective instrument of backwardness. The next few years were devoted mainly to the development of the famous test known as the Binet-Simon Test, whose centenary was celebrated during 2004. Binet died on October 28, 1911, at age 54.

—Henri-Jacques Stiker

See also IQ.

BIOETHICS

This entry reviews the major intersections of disability studies and bioethics, describing the principal issues that have sparked controversy between disability rights activists and scholars and mainstream bioethicists. The discussion lays out key arenas of struggle between those with a disability rights perspective and those within bioethics; it also comments on issues that have received less attention from within disability rights but that could benefit from a dialogue.

CONVERGENCE AND CONTRAST WITH DISABILITY RIGHTS

What characterizes the field of bioethics is its concern with fundamental questions of health and illness; life and death; autonomy, dignity, personhood, and humanity; the relationship of medicine to nature; the relationship of health to well-being. Both bioethics and the disability rights movement have appeared only in the past half-century, and each has emerged in reaction to a dominant paradigm in the medical and helping professions. Recognition of bioethical issues first arose when the public learned that physicians and scientists all over the world in the first half of the twentieth century engaged in widespread abuse of many classes of vulnerable citizens by failing to obtain their consent to serve as subjects in dangerous medical research. Prisoners, concentration camp inmates, residents of institutions for the psychiatrically and cognitively disabled, and African American sharecroppers had all been victims of government and professional research interests. Discovery of these abuses spurred demands for regulation, reform, and new oversight of governmental and professional behavior.

The early U.S. independent living and disability rights movements exemplified much the same challenge to professional domination and demands for self-determination and autonomy. Adults with disabilities and advocates for disabled children protested abuses by powerful government and philanthropic institutions that historically had usurped the decision-making authority of parents and guardians, using the same language as physicians, lawyers, philosophers, and theologians who questioned the power and paternalism of medicine in conducting medical research and using new life-sustaining technologies.

If disability and bioethics began with similar concerns, they have also broadened their focus in similar ways. As disability scholarship and activism have moved from demands for individual control and self-determination to calls for sweeping societal change, bioethics has recognized that the complex life-and-death decisions made by individuals and families cannot remain its only concern. Recent debate also focuses on the implications of life-creating and life-changing technologies, on questions of what constitutes a just distribution of resources for medical care, and on which life situations should properly come under the purview of medicine.

But if bioethics resembles the disability rights movement in its commitment to patient autonomy, its skepticism about professional authority and paternalism, and its support of consumer rights, it has never shared its understanding of disability or its valuation of lives with disabilities. The dominant bioethics voices have argued that human life has to be respected and valued, but not necessarily at any cost or in any state of impairment. Now that human mastery over nature permits lives to be sustained despite significant illnesses and disabilities, it is incumbent on individuals and societies to set limits on which medicine and technology should be used for these purposes. Instead of the medical question, "Can this life be saved?" bioethics invites the question, "Should this life be saved?" Bioethics challenges the disability community by asking whether it is appropriate to use medical technology to sustain the life of someone who would be left with a severe disability.

For disability scholars, these very questions, and the haste with which bioethicists have answered them negatively, reveal a fundamental misunderstanding of the nature of disability. Bioethics has presumed that impaired mobility, physical deformity, sensory deficits, or atypical learning style or speed explain why people with disabilities are less likely than their fellow citizens to be educated or employed, and more likely to live in poverty and isolation. Most bioethicists uncritically adopt what Gliedman and Roth (1980) and Bickenbach (1998) termed the medical model of disability, as contrasted with the social or minority group models. Disability critics of standard bioethics reject the medical model, with its assumption that functional impairment is the sole or primary cause of what is presumed to be an unacceptable, unsatisfying life.

HEALTH, NORMALITY, DISABILITY, AND QUALITY OF LIFE

Those who embrace either the social or the minority group model of disability contend that prevailing bioethics understandings of impairment rest on two erroneous assumptions. First, the life of someone with a chronic illness or disability is permanently disrupted, in the way one's life can be temporarily disrupted by the flu or a back spasm. Second, if a disabled person experiences isolation, powerlessness, poverty, unemployment, or low social status, these are inevitable consequences of biological limitation. Many bioethicists generalize from the problems and disorientation that some people experience at the onset of a disability and assume the disruption is unchanged by rehabilitation, adaptation, mastery of new means to accomplish desired ends, or changes in the life plans one pursues. Many bioethicists also fail to recognize the extent to which disadvantages experienced by people with disabilities arise through society's lack of accommodation to the different methods of performing valued activities such as learning, communicating, moving, or taking in the world. Disability scholars counter, first, that life with disability is not the unremitting tragedy portrayed in medical and bioethics literature and, second, that the culprit is not biological, psychic, or cognitive equipment but the social, institutional, and physical environment in which people with impairments must function—a world designed with the characteristics and needs of the nondisabled majority in mind. For the past three decades, disability scholars and activists have argued that the main problem of disability is, indeed, the denial of civil, social, and economic rights, not the lack of health or functioning.

A substantial body of literature reveals that even before legal and political advances in the United States and other nations, but certainly since then, many people with disabilities have found satisfaction in their lives that was far greater than anything expected of them by members of the health and rehabilitation professions. When people with disabilities report unhappiness or dissatisfaction (a minority in every study), the sources resemble those in the lives of nondisabled people—inadequacies in financial security, work, or social and personal relationships. While impairment-related factors, such as pain or fatigue, sometimes contribute to unsatisfying relationships or employment difficulties, the greater frustrations come from barriers to incorporating the impairment into existing interpersonal and institutional life.

There are several plausible explanations for the gap in understanding between bioethicists and disability scholars. Few bioethicists identify as people with impairments or as members of the disability rights movement. The emphasis on self-sufficiency of many bioethicists leads them to doubt that anyone who cannot execute "normal" life tasks of eating, walking, or managing personal hygiene could live as well as someone who performs these tasks without human assistance. And their focus on individual cases, often to the exclusion of social and economic background conditions, reinforces the impression that even satisfied people with disabilities are a burden to their families and society.

In one area, cognitive impairment, disability scholarship often displays the same limitations of experience and understanding as bioethics. Like bioethicists, disability scholars are typically highly educated individuals who prize rationality and intellect, place a premium on "autonomy," and tend to denigrate, or ignore, the interests and rights of people deficient in those characteristics. But this bias and oversight have not gone unnoticed. From within the disability rights and bioethics communities, researchers have complained that the esteem given to intellect, rationality, and self-awareness leads some scholars to question the moral status or life quality of people with cognitive impairments.

The gap in understanding about life with disability has surfaced in two controversial areas of health care policy: (1) deciding whether to initiate, maintain, or withdraw life-sustaining treatment for impaired patients, particularly newborns, who cannot decide for themselves or communicate their preferences; and (2) deciding whether to test for impairments prenatally, and whether to abort, or decline to initiate pregnancy, if they are detected.

EXTENDING AND CREATING LIVES WITH DISABILITIES

Extending Lives: Newborns with Impairments

In the early and mid-1980s, U.S. disability rights adherents first challenged bioethics over decisions about standards of care for infants with significant disabling conditions who required immediate medical treatment. Should physicians counsel parents of children with Down syndrome who also had heart problems to let the infant die rather than treat the heart condition, leaving the infant with Down syndrome? Should parents of a child with spina bifida be permitted to refuse surgery to close the child's spine and reduce the risk of infection? Should parents of a child with bowel obstruction consent to surgery to remove a necrotic bowel to save the child's life, although long-term survival of a child with such obstruction is estimated at less than 1 in 10,000? Should a severely premature baby be placed on a respirator against the wishes of the baby's parents if chances of survival are negligible?

Rationales for withholding treatment focused on the suffering caused by potential treatments and the impairments themselves; on the suspicion that technology was being used to sustain children who would have short, painful, and miserable lives regardless of what was done for them; on the reluctance to impose further anguish on parents who might have to watch their child die slowly after fruitless medical procedures; on concern for the disappointment of parents who would not have the healthy child they expected and would instead have to raise one never free of disabling conditions; and on the conviction that the millions of dollars spent for such treatments could be better spent in other ways.

Disability critics rejected these rationales as both mistaken and unjust—mistaken in their assumptions about the quality of life possible for impaired infants and the burden they imposed on their families; unjust in denying treatment to one class of human beings. Concentrating on infants with treatable medical conditions, they maintained that denials of beneficial treatment represented discrimination against people with disabilities by the medical profession and frightened parents. If denying beneficial medical treatment to a nondisabled infant constitutes child neglect or abuse, so does denial of that same treatment to one with a disability. These discrimination claims appear to have changed prevailing practice. In 2000, most infants with Down syndrome and spina bifida born in the United States received medically indicated treatments, as did premature and low-birth-weight infants who—if they survived—became part of the disabled population. Most U.S. bioethics literature now concentrates on other topics, although there are no public retractions of the views that enraged the disability rights movement.

Creating Lives: Prenatal Testing and Selective Abortion

By the 1990s, bioethicists, health professionals, and the public generally accepted the claim that a live-born infant should get medical treatment to provide a chance at life. However, the vast majority of theorists and health professionals still held that prenatal testing, followed by pregnancy termination if a potentially disabling condition was detected, promoted family well-being and public health—it was simply one more legitimate method of reducing disability in the world. Disability rights scholars and activists raised the question of how the increasing use of prenatal testing and selective abortion affected the place of people with disabilities in the world. Opposition to prenatal testing has led to no highly publicized court cases, but the themes in the prenatal testing debate echo those in the earlier debate about disabled newborns.

Standard justifications for prenatal testing and selective abortion invoke the suffering or hardships of both the disabled child and his or her parents, although most disabled children are manifestly happy to be alive, and the burdens on their parents appear to differ from those facing the parents of nondisabled children mainly in degree, if at all. Disability scholars have challenged the empirical and moral assumptions that lie behind such conventional views. Parens and Asch (1999) described the disability rights critique of prenatal testing as follows:

> Rather than improving the medical or social situation of today's or tomorrow's disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved. . . . In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics might occasion. (p. S12)

This disability critique, and the response from bioethicists, are discussed at greater length in the entry on reproductive rights. The debate illustrates the extent to which bioethics and disability scholars and activists continue to differ in their assessment of the quality of life with disability, a difference that recurs in two other contexts we will examine: life-and-death decision making by people with disabilities, and the relevance of disability to the allocation of scarce health care resources.

LIFE AND DEATH: DECISION MAKING

Most bioethicists oppose the medical treatment of patients against their expressed wishes, insisting on the right of competent adults to stop treatment, even if by doing so they ended their lives. The recognition of a right to self-determination concerning medical treatment has been partially extended to adults with cognitive impairments.

Most cognitive impairment leaves individuals with some means of understanding their situations and expressing preferences about how they are treated and who should decide for them when they cannot decide for themselves. It should be possible for people with nearly any disabling conditions to communicate about whether they find life and medical treatments worthwhile and acceptable to them. The bioethicists Buchanan and Brock (1989) recognized that persons unable to examine all long-range implications of a decision may nonetheless be able to provide valuable information to ultimate decision makers about their preferences and thus meaningfully participate in decisions about their lives and well-being. Several recent discussions by professionals familiar with people who have cognitive disabilities favor methods that would enable people who fall short of legal "competence" to reveal their decisional capacities, express their preferences, and, if possible, make choices about their medical treatment.

Many bioethicists, though, contend that difficulties in communicating preferences and making decisions can largely be preempted by using "advance directives" to express the prior choices of individuals who can no longer make their own wishes known. They also recommend the appointment of health care proxies to act on their behalf. Such legal devices might assist families and health professionals in dealing with treatment decisions for the millions of people who lose some of their cognitive and communicative abilities through stroke, Alzheimer's disease, or the like. However, they would be of no help to the lifelong disabled. Moreover, "living wills" or advance directives do not encourage people to think critically about which capacities and activities are essential components of an acceptable or good life.

From the standpoint of disability rights, the most serious flaw of advance directives is that noted by the bioethicists Dresser and Robertson (1989), who criticized the "orthodox" reliance on any advance statement of preferences. People who are not living with disabilities and cannot imagine that their lives as disabled would be satisfying make such statements in profound ignorance of relevant information and experience. Dresser and Robertson urged that nondisabled people evaluate treatment decision making from the perspective of the now-disabled individual. Their point is an important corrective to snap assessments that "Mom would hate living like this" or "my brother's advance directive was explicit about stopping life support if he could not hear or speak"—despite the fact that the mother or brother appears to take great pleasure in the activities and experiences that remain possible for them. Admittedly, as Buchanan and Brock and others argue, people care about more than their current experiences. Even an apparently content person with severe dementia might prefer that his or her wish not to live in a disoriented, demented state be honored by following a validly executed advance directive. In general, bioethicists are more inclined than disability scholars and activists to let clear, emphatic pre-impairment directives override post-impairments preferences, especially if the latter are uncertain or ambiguous.

Furthermore, most case law has concerned individuals very likely to die without treatment. More problematic, and more revealing of the continuing chasm of perception between bioethicists and disability scholars, are those cases where apparently competent patients with disabilities seek withdrawal of treatment or physician assistance in suicide for conditions that are not terminal in this sense; conditions with which they could live for decades with technological support, for example, with spinal cord injury or multiple sclerosis. Bioethicists often equate requests to die in such conditions as equivalent to the requests of imminently dying people who wanted to avoid prolonging their lives by a matter of days, weeks, or months.

Most disability theorists and activists, however, construe these decisions to stop treatment entirely differently. They agree that people with disabilities deserve to have their views respected. However, they argue that such decisions are often made because people with disabilities have experienced constant discrimination, denials of information about life possibilities, inability to obtain legally available services and supports, and abandonment by family and friends.

Key to the differing appraisal of these cases is the different understanding of concepts of dependence, independence, and interdependence. Like the newly disabled people themselves, professionals construe the inability to execute life tasks such as dressing, toileting, or moving from place to place as demeaning dependence and as leading to inevitable feelings of embarrassment and humiliation. Disability rights adherents contend that independence need not be viewed in physical terms; rather, self-direction, self-determination, and participation in decision making about one's life are more genuine, authentic measures of independence or, better, universal interdependence.

These themes play out in the broader physician-assisted suicide (PAS) debate of the past two decades. As the bioethics debate shifted from terminating life-prolonging treatment to PAS, the disability rights community sounded a cautionary note with some influence on the mainstream bioethics literature and the case law. But that community does not speak with one voice. Two ideological strands of the disability rights movement offer divergent responses to PAS. The strand of the disability rights movement that stresses self-determination argues that disabled people are no more vulnerable in general to coercion, pressure from family, or victimization by society than anyone else and may benefit from legalized assistance in dying. These theorists are offended by what they see as the paternalism that leads some prominent members of the disability rights community to oppose PAS.

In contrast, the ideological strand that stresses biased social arrangements for people with disabilities holds that the legalization of PAS in a world of harsh prejudice, inadequate health care, unreliable social services, and frequent familial rejection would inevitably lead to its widespread abuse to hasten the death of vulnerable patients seen by society, and often by their families, as burdens.

While recognizing the legitimacy of both perspectives within the disability community, the fact remains that support for PAS among bioethicists reflects troubling assumptions about the quality of life with disability. As Bickenbach (1998) noted:

> It is telling that . . . there is never any suggestion that the right to physician-assisted suicide should extend to people who do not have a severe disability. Implicit in the judgments themselves . . . is precisely the prevailing prejudicial social attitude that having a disability is a sensible reason for committing suicide. (p. 130)

JUSTICE IN HEALTH CARE ALLOCATION

The sharpest conflicts between disability rights and bioethics have occurred in life-and-death situations. But the stigma and devaluation of lives with disability can take subtler, or less explicit, forms than the outright denial of treatment or "assisted" suicide, and these other forms need closer attention from bioethicists. One historically freighted example is the recurrent medical abuse of people with cognitive impairments, who often become research subjects without informed consent. At present, however, people with disabilities are more likely to suffer from medical neglect than unwanted attention. This is apparent both in the provision of reproductive services and in the allocation of scarce health care resources more generally.

Bioethicists who consider reproductive liberty as a fundamental human right have largely neglected the obstacles facing people with disabilities in pursuing parenthood. Sterilization is still forced on people with many impairments, especially with cognitive or psychiatric impairments, in nations such as Australia, Spain, and Japan. But even in societies that have rejected involuntary sterilization, people who need assistance with household and daily activities face obstacles to parenthood if they cannot acquire any additional services for child care. Neither bioethics nor the disability rights movement has undertaken a sustained discussion of what social accommodations are owed to those people who can experience the rewards of parenthood only with some assistance or supervision. The lack of attention to reproductive and parenting support reflects a broader devaluation of the health care needs of people with disabilities.

A chief concern for the disability community arises in the context of access to health care itself and whether—if at all—an individual's existing impairments should influence the types of services he or she receives. Disability has sometimes been used invidiously to deny people available treatments from which they could benefit. For example, someone with Down syndrome may be denied a kidney transplant, based on the assumption that he or she could not comply with treatment requirements, or on an evaluation that rated life with Down syndrome as less worthy of scarce organs because of its presumptively low quality.

Several different methods have been proposed to allocate health care based on its presumed effect on the recipient's "quality of life," as Dan Brock argued in 1993. Should priority be given to those considered "worst off," or to those whose presumed quality of life after treatment would be high? Different allocation schemes would have vastly different results for the world's disabled population. If societies choose to provide care to improve the conditions of the worst off, people with disabilities could receive care based on being considered worst off. However, if they choose to provide care to those expected to derive the most benefit in terms of maximal quality of life, stereotypes about disability and life quality could severely limit the care received.

Even if experts or nations achieved consensus on the version of social justice that should guide allocation decisions, there would be conceptual and empirical difficulties in ascertaining quality of life. From whose perspective should life quality be judged? If people with disabilities consistently indicate that their lives—even with problems—are more satisfactory to them than nondisabled people or health professionals believe, should their judgments be used in measuring life quality? If, instead, health professionals and nondisabled people become the judges of future life quality with impairments, people with disabilities will fare badly in allocation decisions based on expected quality of life.

MEDICAL INTERVENTIONS AND "CORRECTION" OF IMPAIRMENT

What about possible efforts to "cure" disability by cochlear implants, spinal cord regeneration, fetal tissue transplants, or gene therapy? Such actual or potential medical interventions to reduce functional impairment or restore species-typical function raise the issue of what makes something an "impairment" that one ought to correct, as opposed to a characteristic that one has no reason to change. Is being "short" a biological impairment or exclusively a socially constructed disability in a society that prizes height? The new paradigm of disability must play a role in deciding when growth hormone is a legitimate medical therapy and when it is an inappropriate enhancement. If individuals can gain hearing from cochlear implants, are they morally obliged to have them, and should they lose access to interpreter services if they decline, as Tucker (1998) asserted? Are people morally obliged to obtain any therapy that reduces impairment or restores species-typical functioning? If the disability rights movement would endorse surgery for an infant with spina bifida to increase mobility, is it equally acceptable to support parental interests in providing some hearing by virtue of a cochlear implant? Is deafness properly considered a culture, not an impairment? If somatic cell or germ-line therapy could safely correct detectable impairments in eggs, sperm, or embryos, should they become standard parts of medical care? Should people with disabilities support or oppose such measures, which do not exclude or select against individual lives but reduce the incidence of disabilities? Is having an impairment just one desirable or inconsequential form of human variation, or, even with just or optimal accommodation, is impairment always undesirable? Bioethics and disability studies must work together to understand the apparent importance of health and normal functioning and to explore the meaning of impairment and disability.

It seems fitting to close this discussion of the intersections of disability studies with bioethics by affirming what bioethics can learn from disability studies. Paul Longmore's (1995) description of the values needed for people to accept the disabled are values that, he says, would change orientations toward another regardless of disability. They would change bioethics and society in ways that could surely promote human rights for everyone: "not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community" (p. 9).

—Adrienne Asch and
David Wasserman

See also Death; Ethics; Euthanasia; Family: Law and Policy; Health; Health Management Systems; Impairment; Normality; Physician-Assisted Suicide; Quality of Life; Reproductive Rights.

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BIOLOGICAL DETERMINISM

The term *biological determinism* refers to claims that most human characteristics—physical, mental, and personality based—are determined at conception by hereditary factors passed from parent to offspring during reproduction. Of course, all human traits are ultimately based in the material nature of our being organisms (e.g., memorizing a poem involves changing molecular configurations at synapses, where nerve cells interact), but the term *biological determinism* has come to imply a rigid causation largely unaffected by environmental factors. Prior to the turn of the twentieth century and the rediscovery in 1990 of Gregor Mendel's work on heredity, a wide variety of hereditary causes were postulated (such as direct environmental effects acting on the mother's or father's germ cells or indirectly on the fetus via the mother during pregnancy). After the rediscovery of Mendel, theories of biological determinism came more and more to be formulated in terms of the new science of genetics, so that today *biological* and *genetic determinism* are virtually synonymous.

In the eighteenth and nineteenth centuries, theories of biological determinism were based on vague, often highly controversial ideas about of the nature of heredity. Since the concepts and tools were not available during that period to study heredity directly, biologists and anthropologists measured physical features of humans, trying to associate mental and personality traits with some anatomical (occasionally a physiological) feature, such as facial angle (angle of slope of the face from chin to forehead) or cranial index (ratio of lateral to vertical circumference of the head). Certain physical features, such as high cheekbones or a prominent eyebrow ridge, were often said to be indicative of criminal tendencies. With the growing acceptance of Mendelian genetics in the first half of the twentieth century, most theories of biological determinism came to locate the causal element in defective genes. With the revolution in molecular genetics during the second half of the century, defective genes became identified with altered sequences of the molecule of heredity, deoxyribonucleic acid (DNA).

Throughout its history, theories of biological determinism have been particularly applied to what were conceived of at the time as negative physical traits such as cleft palate, clubfoot, dwarfism, gigantism, foreshortened appendages, and social traits such as criminality, feeblemindedness, pauperism, shiftlessness, promiscuity, "feeble inhibition," manic depression, and hyperkinesis (hyperactivity). Many of these later conditions or traits we would refer to as disabilities today, and the claim that most or all of them are inherited was, and is, highly controversial. This is partly a result of the difficulty in obtaining rigorous data about the genetics of such traits, especially when there is no established definition on which all investigators can agree. (What *is* criminality or alcoholism, or when does exuberance become hyperkinesis?) It is also a result of the fact that so many other factors interact with whatever genetic elements are present that it is difficult to tease them apart. Thus, throughout recent history, attempts to show that certain disabilities were genetic have had little success.

One of the most prominent movements to apply genetics to understanding social and personality traits emerged early in the twentieth century as the eugenics movement. *Eugenics* was a term coined by British geographer, statistician, and general polymath Francis Galton (1822–1911), first cousin of Charles Darwin. By "eugenics," Galton meant "well" or "purely born," and he argued for planned breeding among the "best stock" of the human population, along with various methods to discourage or prevent breeding among the "worst stock." It was the belief of eugenicists such as Galton, his student Karl Pearson (1857–1936), and their American convert Charles B. Davenport (1866–1944) that most social problems were due to the accumulation of genetic defects, producing an increasingly disabled, or "degenerate," population. Society was deteriorating through the increased reproduction of the disabled—particularly the mentally disabled. Various forms of inherited mental disability were said to be the root cause of social problems as varied as crime, alcoholism, and pauperism (in all cases, it was claimed that low mental ability led to inability to cope in a complex society, and hence the turn to antisocial behaviors).

Using the newly developed IQ tests in the 1920s and 1930s, eugenicists proceeded to rank people into categories based on quantitative scores (normal = 90–110, high-grade moron = 70–90; idiot = > 50; imbecile = no ranking). In most cases, especially in the largest categories, those individuals with scores between 70 and 90, who were claimed to be genetically disabled were not disabled at all, simply disadvantaged (the poor, the uneducated, the immigrant who could not adequately interpret test questions). Nor was there much sound evidence that such cases were in any way genetically determined.

The eugenics movement in the United States, and especially Germany after the National Socialist takeover in 1933, carried through legislation specifically aimed at taking action against the disabled of all sorts, but again the mentally disabled in particular. In the United States, laws were passed in more than 30 states by 1935 allowing for the compulsory sterilization of those deemed to be genetically unfit in state and federal institutions such as mental hospitals, asylums, and prisons. Overall, in the United States more than 60,000 people had been sterilized under these laws by 1963. In Germany, similar laws (actually based on ones in existence in the United States) led to the sterilization of more than 400,000 people by the early 1940s. Sweden and Canada had similar laws allowing for sterilization of the supposedly genetically disabled.

One of the major consequences of widespread belief in biological (genetic) determinism is the underlying assumption that if a trait or condition is genetic, it cannot be changed: "Genes are destiny," genetic determinists have claimed. However, the relationship between what geneticists call the genotype (the actual genes an individual inherits) and phenotype (what traits they actually show) has turned out to be far more complex and unpredictable than previously thought. For example, cystic fibrosis (CF) is a multifaceted disease that is present in about 1:2500 Caucasians and can be severely debilitating. It is due to a recessive Mendelian gene (meaning that for it to show up phenotypically, the individual has to inherit the defective gene from both parents), and it has now been completely sequenced (meaning that every base-pair in the sequence of nucleotides that make up the DNA of the gene has been determined). Moreover, more than 1,000 mutation sites are known, and most have been related to different manifestations of the disease. However, one of the startling findings has been that even with the same mutated site within the gene, different individuals will show remarkably different phenotypes. Some will show early onset, others, later onset; in some, the kidney is most afflicted, while in others, it is the lungs. In some individuals even with the most common mutation, the effects are severe, while in others they are mild to nonexistent. Although the reasons for these differences are not understood, it is clear that both genetic background and environmental factors (such as diet) must play an important role. In other words, genes are not destiny even in cases where the genetic basis of a disability can be well understood. It is certainly not destiny when the genetic basis is unclear or circumstantial.

With modern genomics, the science of understanding complex genetic interactions at the molecular and biochemical levels, the possibility exists of treating such genetically based disabilities, such as diabetes type I, cystic fibrosis, or sickle-cell anemia (a genetic defect in the hemoglobin molecule) either with gene therapy (much more difficult at present) or pharmacologically, prescribing drugs that can perform and carry out the normal biochemical function of the defective gene. Social attitudes about what constitutes a disability, and how economic and social resources are to be allocated to deal with disabilities, change over time. In hard economic times, the disabled tend to be written off as "too expensive," often justified on the basis of "genetic determinism" (whether scientifically valid or not). Throughout its history, arguments for biological determinism have been employed more to restrict than to expand human potential.

—Garland E. Allen

See also Eugenics; Eugenics: Germany; Feeblemindedness; Walter Fernald; Henry Herbert Goddard; IQ; Sterilization.

BIOMECHANICS

Biomechanics is the study of the structure and function of biological systems using the methods of mechanics. Although the ideas and investigations that can be classified as biomechanics go back to Giovanni Borelli (1608–1679), who first described the basis of muscular and skeletal dynamics, the term *biomechanics* and research performed in this field have became well known only in the past several decades.

Contemporary biomechanics is a multidisciplinary field of science that combines physical and engineering expertise with knowledge from the biological and medical sciences. Biomechanics includes several main directions of research, for example, cardiovascular biomechanics, cell biomechanics, human movement biomechanics, in particular orthopedic biomechanics, occupational biomechanics, and sport biomechanics. As an example, sport biomechanics deals with performance improvement and injury prevention in athletes. In occupational biomechanics, biomechanical analysis is used to understand and optimize mechanical interaction of workers with the environment. Development of the biomechanics of labor focused on increasing worker efficiency without sacrificing labor safety. It resulted in the design of new tools, furniture, and other elements of a working environment that minimize load on the worker's body. Another development was clinical biomechanics, which employs mechanical facts, methodologies, and mathematics to interpret and analyze typical and atypical human anatomy and physiology.

Beginning during and after World War I and especially World War II, the focus on development of prosthetic limbs for management of the many wartime amputations led to major progress in rehabilitation medicine as a result of the application of biomechanics. Work in this area focused on increasing the mechanical efficiency of orthopedic implants that, for example, allowed those undergoing hip or knee replacement surgery to walk again. A biomechanics-research-based approach generated a major step toward improving walking for individuals with lower-leg amputation and children with cerebral palsy. As an example, development of a new class of prosthetic feet that store and return mechanical energy during walking allowed for reduction of the metabolic expenditure in amputees and made it possible for individuals with amputation to participate in athletic activities. The biomechanically based design of assistive devices, such as wheelchairs, and the optimization of the elements of the environment allow individuals with disabilities to improve their lives.

Application of biomechanics is wide-ranging as its diverse topics include everything from human gait to blood-flow dynamics. During the past decade, growing public opinion favoring investment in medical and health care research contributed to opening of new avenues in biomechanics. Among these are the use of biomechanical analysis in artificial prosthesis design (e.g., artificial heart and small-diameter blood vessels), the engineering of living tissues and organs (e.g., heart valves and intervertebral discs), biomechanics of injury prevention related to labor safety and vehicle accidents (from low-speed collisions with minor soft-tissue injuries to high-speed collisions with severe and fatal injuries), and biomechanical aspects of disability with the ultimate goal of improving the lives of individuals with functional impairments.

—Alexander S. Aruin

See also Amputation; Veterans.

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BIPOLAR DISORDER

Bipolar disorder (BPD) is a chronic, recurrent, disabling illness characterized by mood instability and associated with significant morbidity and mortality. Both biological and environmental factors are critical to its development. BPD is frequently complicated by other comorbid conditions that can impede proper diagnosis and treatment. Optimal strategies to manage bipolar disorders require medication, psychotherapy, and attention to concurrent psychiatric disorders.

BPD includes symptoms of mania/hypomania, depression, or their combination (i.e., mixed states). While the defining characteristic of BPD is mania (i.e., elevated, expansive, or irritable mood state) or hypomania (a less severe form of full mania), depression is often the heralding symptom, and patients usually experience more time depressed than manic over the course of their illness. More severe episodes can also present with psychotic features (e.g., delusions of grandiosity) and impulsive destructive behavior (e.g., suicide). The suicide rate for BPD is about 10 percent in untreated patients and about 25 percent will attempt suicide at some point in the course of their illness. The risk for suicide is greatest during a depressed or mixed episode. Lack of treatment is also a major risk factor, since mood stabilizers appear to protect against suicide.

Classic *bipolar I* patients experience *full mania* and depression, while *bipolar II* patients experience *hypomania* and full depression. Associated symptoms may include hyperactivity, pressured speech, flight of ideas, inflated self-esteem, decreased need for sleep, distractibility, and excessive involvement in activities that have a high potential for painful consequences. The course of illness can vary from only few episodes to a more virulent pattern characterized by multiple episodes over short periods of time. One example is *rapid cycling* (i.e., four or more episodes per year), which is more common in females with bipolar II disorder; has a higher suicide risk; and may be precipitated by antidepressant use or thyroid dysfunction. The U.S. lifetime prevalence rate of bipolar I disorder is estimated to be 1.3 percent. When bipolar II and other more subtle forms of the illness (e.g., cyclothymic disorder) are also considered, the prevalence rate has been estimated to be about 3.7 percent. There is an equal distribution among ethnic groups and between men and women.

While BPD can occur at any time, the onset of this disorder is usually before the age of 20, with the peak period between 15 to 19 years. Initially, BPD may present as one or more depressed episodes, have psychosis as a prominent feature, or mimic disorders characterized by hyperactivity. As a result, it is often mistaken for other conditions (e.g., unipolar depression; schizophrenia; attention deficit hyperactivity disorder [ADHD]). This, in turn, can delay accurate diagnosis and implementation of appropriate treatment. In most individuals, BPD produces substantial disability and functional impairment in work, leisure and interpersonal activities, both during and between mood episodes.

Secondary mania is a condition separate from BPD that can be precipitated by a variety of medical conditions (e.g., hyperthyroidism and complex partial seizure); medications (e.g., steroids, tricyclic antidepressants); or drug use or withdrawal (e.g., amphetamines, cocaine). Further, substance and alcohol abuse or dependence frequently co-occur in this population, make accurate diagnosis more difficult, worsen the long-term course and compromise otherwise effective treatments. Other comorbid conditions frequently associated with BPD include obsessive-compulsive disorder, panic disorder, bulimia nervosa, impulse control disorder, ADHD, conduct disorder, and certain personality disorders. Recognition of the high rates of comorbidity in BPD is critical to developing treatment strategies that will address all existing disorders. For example, unless alcohol-related complications are adequately managed, it is unlikely that adequate mood stabilization can be achieved or sustained.

ETIOLOGY

As with most complex major psychiatric disorders, the cause of this condition is thought to involve both biological predisposition and environmental influences. Several hypotheses have been proposed to help elucidate the biological basis for BPD. They include abnormalities in: relevant neurotransmitter activity (e.g., norepinephrine, serotonin); second messenger systems (e.g., phosphoinositide cycle); biological rhythms (e.g., sleep-wake cycle); neuroendocrine function (e.g., thyroid system); neuroanatomy; neurophysiological activity (e.g., kindling phenomenon); and the immune system. The support for a genetic basis comes from family studies that establish a pattern of aggregation, linkage studies that can identify specific genomic regions associated with the disorder, and twin studies that estimate concordance rates to be 14 percent for dizygotic twins and 57 percent for monozygotic twins (whether raised together or separately). The absence of 100 percent concordance rate in monozygotic twins, however, indicates a role for other factors. Thus, a genetic-environmental interaction has been proposed in which a number of small susceptibility genes establish a gradient of liability that may trigger BPD in the context of various stressors. Other important risk factors include a family history of mood disorders, females who are postpartum, or a history of cyclothymic disorder (symptoms similar to but less severe than full bipolar disorder). Of note, linkage studies report a number of genomic regions that may represent susceptibility loci for both BPD and schizophrenia. This is also consistent with a number of observed characteristics that these two disorders have in common. They include a similar lifetime prevalence; onset in early adulthood; tendency to run a chronic, episodic course; high suicide risk; substantial overlap in symptom presentations; and response to antipsychotics. Such data speak to the possibility of greater commonalities between these two disorders than our present diagnostic system would indicate.

TREATMENT

The management of BPD is complicated, must encompass effective treatments for acute episodes of mania and depression, appropriately manage comorbid disorders, and should ensure long-term mood stabilization. In addition, education of patients and their families is crucial to long-term success. Since there is no ideal therapy, BPD often requires complicated strategies to achieve the optimal outcome. While *medication* has been the primary approach, various *psychotherapeutic interventions* (e.g., cognitive behavioral therapy [CBT] and interpersonal therapy [IPT]) may substantially enhance the beneficial effects of drugs. Group, family, marital, and other forms of individual psychotherapy may also be useful. For example, psychosocial interventions combined with pharmacotherapy have been found to significantly reduce any episode recurrence, hypomanic relapse, and depressive relapse when compared to drug treatment alone. *Somatic treatments,* particularly electroconvulsive therapy (ECT), may also be effective for both the manic and depressed phases in patients who are in an acute crisis or who are poorly responsive to or intolerant of medications.

Several classes of medications have been used, including mood stabilizers, antipsychotics, antidepressants, anticonvulsants, and anti-anxiety/sedative hypnotics. The exact definition of a mood stabilizer is still a matter of debate. However, most experts agree that such a drug should be effective for acute mania and depression, stabilize mood over the long term, decrease the impulsive suicidal propensity of bipolar patients, not cause a switch from one mood state to the other, and not worsen the course of BPD (e.g., induce rapid cycling). Mood stabilizers include lithium; divalproex sodium and lamotrigine, which are anticonvulsants; and second-generation antipsychotics (SGAs) such as olanzapine and risperidone. Until recently, most trials with these agents have involved treatment of the manic phase of bipolar disorder.

The ideal approach is to manage BPD with a single agent usually combined with some form of psychotherapy. Unfortunately, this is rarely possible. Thus, if adequate trials for *bipolar mania* with one of the two most commonly prescribed mood stabilizers (i.e., lithium *or* divalproex sodium) are insufficient, then various drug combinations are usually required.

This may include combining the primary mood stabilizer with an anti-anxiety sedative-hypnotic agent, an antipsychotic, or another mood stabilizer (e.g., lithium *plus* divalproex sodium). More recently, the newer generation antipsychotics (i.e., olanzapine, clozapine, risperidone, quetiapine, ziprasidone, and aripiprazole) have demonstrated antimanic properties separate from their antipsychotic effects. Thus, they may represent another strategy when used in combination with other agents or as a monotherapy for acute mania.

Unfortunately, much less data is available to guide treatment of *bipolar depression.* Antidepressant monotherapy is not recommended due to the high risk of mood destabilization. The best evidence to date supports monotherapy with lithium, lamotrigine, or carbamazepine. Other approaches include combining mood stabilizers (e.g., lithium plus lamotrigine); a traditional mood stabilizer plus antidepressant; or an SGA plus antidepressant (e.g., olanzapine plus fluoxetine). Potential biological, nonpharmacological alternatives for bipolar depression include ECT, bright light therapy, and possibly such investigational therapies as vagal nerve stimulation and transcranial magnetic stimulation.

Given the recurrent nature of BPD, *relapse* prevention and *prophylaxis* to prevent future episodes are critical. In this context, the best data support lithium, divalproex sodium, and lamotrigine. Other strategies include combining mood stabilizers, a mood stabilizer plus SGA, or a mood stabilizer with cognitive therapy.

—Philip G. Janicak

See also Depression; Psychiatric Disorders.

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BLACK REPORT

The Black report is the popular title given to the *Report of the Working Group on Inequalities in Health*, published in 1980 in the United Kingdom. The working group had been appointed by the Labour government in 1977 under the chairmanship of Sir Douglas Black.

The report brought together information about difference in health status between different social classes and examined the causal factors. It also suggested implications for policy and made recommendations for further research. The 30 recommendations for action, which can be summarized under the following four broad themes:

- Development of a comprehensive antipoverty strategy
- Development of policies aimed at giving children a better start in life
- Encouragement of good health among a larger proportion of the population
- Reduction of the risk of early death among disabled people in order to improve their quality of life, and to reduce the need for institutions as far as possible

This entry examines the link between social inequality and individual health, as outlined by the Black report.

BACKGROUND TO THE HEALTH AND DEPRIVATION DEBATE

Much previous research has sought to identify the links between social class and ill health. Indeed, differences in health and economic status have been noted as far back as the twelfth century. Prior to the Black report (1980), there had been a long tradition of health inequalities research in the United Kingdom, one of the earlier examples of which is Frederick Engels's *The Condition of the Working Class in England* published in 1845.

In this text, Engels presented evidence for widespread inequalities in health based on social class. He argued that the industrialized urban poor suffered much higher mortality rates than the wealthy. Engels attributed this inequality to, among other things, poor housing, ventilation, sanitation, environmental pollution, clothing, and working conditions. Contemporaneously with Engels, the early "modern" public health movement was emerging in Britain, with Edwin Chadwick as its leader. Unlike Engels, capitalism was the driving philosophy behind Chadwick and his followers: It was feared that ill health and premature death led to loss of worker productivity and lower profits. The public health movement argued that tackling social causes of ill health, such as poverty, poor sanitation, and poor housing, would eventually pay for itself. Public support for public health measures soon followed, and Britain embarked on a range of measures aimed at improving the living conditions of the urban poor.

These arguments around improvement of the public health resurfaced in Beveridge's 1942 *Report on Social Insurance and Allied Service.* This laid the foundations for the British Welfare State and the National Health Service, the first socialized health care system in the world. The Beveridge report claimed that "want" could be eliminated via the provision of a state-run insurance scheme to guard against interruption or loss of earning power and the provision of child benefits. Coupled with a new Health Service, this would eventually lead to an improvement in the public health and a reduction in expenditure. Inequalities in health would also be eradicated.

Conventional wisdom was that the establishment of the welfare state, despite soaring costs of health care, had at least gone some way to removing health inequalities. These beliefs started to be called into question in the mid-1970s: Britain was slipping behind some other countries in health improvement, despite 30 years of the welfare state. There were differences in mortality rates across social classes, and speculation that these persisting health inequalities were to blame for the lack of improvement in mortality rates. This led to the setting up by the government of the Research Working Group on Inequalities in Health in 1977, chaired by Sir Douglas Black.

THE BLACK REPORT AND ITS FINDINGS

The resulting Black report was the first time any government had attempted to explain trends in inequalities in health and relate these to policies intended to promote as well as restore health. The main findings of the report were as follows:

1. Men and women in social class V had a two-and-a-half times greater chance of dying before retirement age than class 1.
2. Inequalities existed throughout life and at all stages of the life course.
3. Risk of death for men was twice that for women.
4. There were major regional differences, both on a macro and a micro scale.
5. Mortality varied by housing tenure, owner occupiers having a lower mortality rate than local authority tenants.

The report noted the following trends:

1. Morbidity follows same general pattern as mortality.
2. Pre-1950s there was a long-term decline in death rate for males in all occupations.
3. Post-1960 social class V's health declined both relatively, when compared to social class 1, and absolutely.
4. A long-term decline in infant mortality.

EXPLAINING INEQUALITIES

The Black report identified four possible explanations for inequalities in health: that the findings were an artifact, that they arose because of natural or social selection, that cultural/behavioral reasons were to blame, or that they were due to materialist explanations.

Artifact

This explanation implies that there are no actual inequalities: The observed effect is the result of the way in which class and health are measured. It suggests that changes in social class and classification of occupations over time make such comparisons impossible. This explanation is confounded by work that found difference in mortality dependent on salary.

Natural or Social Selection

This explanation suggests that it is not class that determines health but health that determines class: The healthy experience upward mobility, and the ill slip down the social scale. There is some evidence to support this explanation, particularly for disabled people. Disabled people are more likely to be living on or below the poverty line. The Black report recognized this and argued for the implementation of a comprehensive disability allowance to pull disabled people out of poverty. More recent work has also highlighted this cause of inequality. However, the extent of social mobility in Britain is not sufficient to account for the large variations in health.

Cultural or Behavioral Explanations

This approach argues that people in lower social classes adopt a more risky lifestyle. These people adopt what are seen as reckless, irresponsible, or unthinking behaviors and place themselves at greater risk of ill health. Lifestyle explanations have considerable appeal to governments that may want to reduce public expenditure. If individuals are seen as responsible for their own health, then government inactivity is legitimized. It adopts what is termed a "victim blaming" approach in which individuals are seen as being responsible for factors that disadvantage them but over which they have little or no control. Victim blaming is applied both to individuals and to whole groups.

Material Disadvantage

In this explanation, inequalities reflect unequal distribution of resources in society. Those who experience ill health are those who have the least money, are lower in social hierarchy, are the least educated, and experience the most unemployment. These social factors make it difficult for them to implement what they know to be healthy choices. Social and health care provision also varies inversely with the need for it in the population served—known as the inverse care law.

The material disadvantage explanation was the one favored by the Black report. However, it did not find favor with the Conservative government of Prime Minister Margaret Thatcher, to which the working party reported in 1980, and for that reason the whole report was largely ignored. However, with the election of a Labour government in 1997, it could be argued that the agenda of the Black report finally began to be implemented in the United Kingdom.

THE BLACK REPORT AND DISABILITY

The Black report recommended that the government must take into account the material conditions of poorer groups, and it called for a reorientation of health and personal social services. Disabled people were one of the target groups identified by the authors. In addition to calling for the funding of a comprehensive allowance for disabled people, the report examined the inequalities in health and social care experienced by disabled people. It argued that class differences existed in the provision of care to disabled people. Disabled people who had been non-manual workers often lived in different accommodations than did manual workers. More often than not, non-manual workers who were disabled lived in their own homes while manual workers who were disabled were found in institutions. Those living in their own homes had better care and better rehabilitation. They were also more likely to be employed and have better social relations and experience greater privacy. The report argued strongly for a reduction of the number of people in residential care and called for the implementation of what is now termed *community care*. To enable this policy, the report also urged the government to increase home help services and expand the number of accessible private and public houses for disabled people.

Although there is little evidence that the recommendations of this report influenced government policy in Britain throughout the 1980s and early 1990s, its wider impact was widespread through public health debates in many countries. The report played a central role in the shaping of the Common Health Strategy of European Region of the World Health Organization; in particular, it located equity as a central theme in that document and a reduction in inequalities was the first of the 38 targets set as part of Health for All 2000.

—Nick Watson

See also Health; Poverty.

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BLADDER CONTROL

Urinary incontinence (UI) refers to a loss of bladder control. UI is considered a symptom rather than a disease. Causes are many and include infections of the urinary tract or vagina, weak or overactive bladder muscles, enlarged prostate, neurological diseases, pelvic or spinal injuries, aging-related degenerative changes, and problems resulting from pregnancy or childbirth. UI is categorized into the following types:

- *Stress* (damage to the sphincter or pelvic muscles results in leaking when the bladder is under pressure)
- *Urge* (sudden and uncontrollable bladder contractions due to illness or neurological damage result in an urgent need to pass urine)
- *Overflow* (blockages or injuries produce a situation where the quantity of urine exceeds the holding capacity of the bladder, causing leakage)
- *Functional* (bladder control is normal but medical disorders or disabilities, such as restricted mobility, make it difficult to get to an appropriate place for urination prior to loss of control)
- *Mixed* (two or more types)

UI is a dynamic condition, with continence status fluctuating throughout the life course. Treatments include behavior therapy (bladder control training, pelvic muscle exercises, biofeedback, and timed and prompted voiding); pharmacological therapy; and surgery. In addition, management techniques may be used such as implants, urethral plugs, and various absorbent devices.

UI appears to be highly prevalent worldwide, especially among women, with stress incontinence predominating and incidence increasing with age. Across cultures, quality of life has been found to decrease as UI becomes more severe. In the United States, up to 25 million people are estimated to be affected, including approximately 1 in 10 of those 65 years of age or older. In addition, 10 percent of children over age 5 have problems with bedwetting.

The meaning and significance of UI are linked to that of urination in general; these meanings vary by culture. Very little scientific or scholarly literature exists on how urination and UI are understood cross-culturally. That which does exist focuses primarily on urination, for example, practices related to urinary hygiene (such as where it is appropriate to urinate in a particular culture), attitudes toward urination (which range from nonchalance to humor to extreme shame), and painful/difficult urination and traditional treatments for these conditions. Discussions of incontinence in the ethnographic literature concentrate on its management among infants and young children, its role as a symptom of culturally specific illnesses, and ideas about behaviors that may cause or prevent the problem. As examples of the latter, the Iroquois traditionally believed that the use of clamshells as spoons could cause UI, while the Yakutat Tlingit reportedly thought that rotten wood under the toilet in the menstrual house would protect a teenager from incontinence in old age.

Despite variation in beliefs and knowledge about UI, in many cultures it remains underreported and undertreated, in part because affected individuals do not seek help. Hesitation with respect to seeking professional attention may be related to embarrassment, lack of resources, and doubts about the effectiveness of available treatments.

—Lori L. Jervis

See also Aging; Bowel Control.

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BLIND, HISTORY OF THE

The history of the blind is difficult to chart. There are few examples before the nineteenth century of sustained, organized efforts by the blind to act in concert to achieve collective goals. Rather what is left to the historian is a collection of biographies of "extraordinary" individuals, from Homer to Helen Keller, Louis Braille to Jorge Luis Borges, which provides little in the way of a narrative thread that one can pull together to create a tapestry of blind history. Prior to the eighteenth century, the history of the blind is atomistic, a collection of biographies, protagonists in religious and secular stories, weaving in and out of popular consciousness, serving as object lessons, or providing inspiration to the sighted. The negative historical assumption is of the blind as objects of charity rather than active agents in history. Occasionally, the blind could be found clustered in certain state- or church-sanctioned professions or guilds such as massage, minstrelism, and mendicancy, but in large part blindness is assumed to be a ticket to misery, a curse, a sentence to second-class status.

The blind, in truth, occupy no greater or lesser a place in history commensurate to their numbers in the general population. There are historical examples of blind teachers, soldiers, religious and secular leaders, scientists, philosophers, mathematicians, historians, and a variety of other professions. There are, as with the sighted, countless blind who lived out their lives in quiet obscurity. Thus, it can be said that while history offers a pantheon of blind characters, there exists nothing unique to blind people that is unknown to the sighted. Even so, the past 200 years have seen efforts by the blind to come together to improve their situation, share strategies of success, and have a voice in society, rather than to be objects of curiosity and speculation.

THE BLIND IN THE ANCIENT WORLD

In the preindustrialized world, it has long been assumed that the blind enjoyed few opportunities and lived out their days in penury as beggars, or wards of their families in the absence of any systematic state or government assistance. Historical knowledge of the lives of blind people in the premodern Western world is extremely limited, and it is strongly influenced by literary or religious texts. Traditional interpretations of classical literary representations hold that blindness is a punishment for social or religious transgressions or, alternatively, is the price one pays to gain spiritual vision and insight. Oedipus is often cited as an example of the former, while Tiresias may be seen as an example of the latter. There are 79 references to blind persons in classical Greek literature, all of which describe blindness as occurring through accident, through warfare, or as punishment for social or religious transgressions. Today, 2.9 percent of cases of blindness result from accidents, and there is no evidence to support the idea that the situation would be any different for those living in Greece or Rome. With so few examples to draw on, most of which falsely portray blindness as occurring from accident, literary sources do not provide good evidence on which to base broad assumptions about either how the blind lived or how the blind were popularly perceived as a class by their contemporaries.

Religious texts similarly provide little knowledge of actual blind people in the early centuries prior and subsequent to the Christian era. Biblical scholars debate whether blindness is to be interpreted in either spiritual or corporeal terms. Some New Testament scholars, for example, believed that depictions of Jesus healing the blind is meant to be seen as curing spiritual blindness, not physical blindness. Nonetheless, ancient and medieval depictions of the blind as either sinners or saints persisted into the modern era and continued to be the subjects of religious and philosophical inquiry.

While the Greek poet Homer is often assumed to be blind, there is no evidence of whether or not he could see, although Homer's *Odyssey* features the blind poet Demodocus. The names of a handful of other blind storytellers survive, such as Ossian, blinded warrior and son of the third-century BCE Caledonian King Fingal; and Torlogh O'Carolan, Gaelic poet (b. 1607). Better known are the blind scholars of the premodern era. Best known of these in the early Christian era is Didymus, born ca. 313 CE in Alexandria. Didymus used carved wooden letters and was the teacher of St. Jerome. St. Herve (b. 539) established a monastery in Brittany, which today is a shrine for blind musicians. In Japan, Prince Hitoyasu (b. 853), son of the emperor of Japan, established music and massage as designated professions for the blind and established the role of court historians as the purview of the blind. Abdul al Moiré (b. 973 CE near Aleppo) became a preeminent poet. His poetry transcended the mundane topics of love and war and reflected a skeptical view of the world. Prospero Faghani (ca. 1590–1671) was a canonical scholar who refuted the medieval Catholic Church's dispensation to the blind as outside the obligations of the church. Faghani asserted that the New Testament was more concerned with blindness of spirit rather than the body, and he brought the blind into the fold of the church. John Milton (b. 1608) is perhaps the best-known blind author of the late Renaissance/early Enlightenment. He was a well-known poet before going blind at age 44, although he wrote his masterpiece of epic poetry, *Paradise Lost,* after losing his sight.

THE BLIND IN THE AGE OF PHILOSOPHERS

The Enlightenment-era philosophers introduced new questions about blindness and the nature of the blind, moving the conversation away from strictly spiritual questions toward rational interpretations of understanding and knowledge. Enlightenment scholars debated whether or not the blind were more likely to be atheists due to their presumed bitterness against God over their condition. Others argued that the blind were closer to God, as they were spared the burden of earthly distractions owing to their blindness. John Locke, in *An Essay Concerning Human Understanding* (1690), considered the question of whether a person born blind who became sighted would be able to recognize objects previously known only by touch. Locke asserted that newly sighted people would not be able to understand the world using their new vision. Bishop Berkeley in 1709 disagreed with Locke, arguing that what one saw with the eye was merely the inference, not the essence, of a thing. The question was a favorite among philosophers long after Locke, as the rhetorical scenario allowed speculation as to the nature of learning and understanding.

The debate was not merely rhetorical to the blind, however, as there were direct implications as to whether or not the blind could or should be educated in reading and writing and the classics. If sight was required to understand the essence of a thing, as Locke argued, then educating the blind was a futile enterprise. If understanding was generated from within, as Berkeley argued, then there was no reason a blind person could not learn as well as the sighted.

Nicholas Saunderson (1682–1739) lost his sight at the age of one from smallpox. Saunderson went to Cambridge University to study mathematics, but he was not allowed to matriculate as a student. He was given access to the library, where he used a tactile ciphering board to work out mathematical formulas. Saunderson's advanced mathematical acumen gained him the attention of Sir Isaac Newton, then at the height of his fame. Newton personally lobbied to have Saunderson given a chair at Cambridge, despite the lack of formal credentials, as he was one of the few who Newton felt truly understood the ideas expressed in *Principia Mathematica.* Saunderson became one of the Enlightenment's foremost mathematicians and philosophers.

EDUCATION AND THE BLIND

Denis Diderot penned one of the most influential treatises on the blind and education in 1749 with his "Letter on the Blind," which he revised in the course of his lifetime. Diderot met and was deeply impressed by the Parisian music sensation, Melanie de Salignac, who had devised a tactile form of print to both read music and correspond with friends. Diderot saw de Salignac as an example of what was possible, and he argued that the blind could be educated so long as the educator focused on what skills the blind person possessed and not on the lack of sight. As one of the most influential philosophers of the French Enlightenment, Diderot provided a philosophical foundation for the education of the blind.

It was Valentin Haüy (1745–1822), however, who opened the first school for the blind in Paris in 1784. Haüy had been influenced by the Abbé de l'Épée, who had opened the first school for the deaf in the 1770s. Haüy, like Diderot, was inspired by a talented blind pianist, Maria Theresa von Paradis (b. 1759). Von Paradis showed Haüy the tactile alphabet she had developed, which she used to read and write. Von Paradis had been corresponding with a German man, George Weissenbourg, who in turn had taught other blind students the finger alphabet the two used to write one another. Haüy appreciated that the blind could learn by reading with their fingers. The school for the blind in Paris soon had more than 50 students. Haüy developed a raised alphabet system to teach his students. Haüy's methods would become the standard and the model adopted by educators of the blind for the next half century. Unfortunately, reading raised roman letters was a very inefficient system of reading. Haüy wanted a system that looked attractive to the sighted as much as he was interested in what actually worked for the blind.

This conflict between what the sighted educators asserted the blind needed and what the blind themselves insisted really worked became the central organizing force of blind people in the coming two centuries. By the early nineteenth century, several schools appeared in Britain: Liverpool (1791), Edinburgh (1793), and Bristol (1793), among others. These schools were developed along English trade school models, where students were taught a trade rather than to read and write. Johann Wilhelm Klein founded a school in Vienna in 1804. Klein believed that blind students should be integrated into the classroom with their sighted peers. These three models—Haüy, English trade schools, and Klein in Vienna—drove the debate for the next century about what blind children should learn. Some educators believed it was better to teach a trade in order that the blind could support themselves as adults, while others asserted that a classical education would propel the blind into more esteemed professions, as well as provide examples of the potential of the human capacity for learning.

Just as the blind sparked a debate among Enlightenment philosophers over the nature of understanding in the seventeenth and eighteenth centuries, social reformers of the nineteenth century argued over the degree to which the blind could be "rehabilitated" or trained to take their place in the broader community as contributing citizens. Samuel Gridley Howe (1801–1876), who opened the Perkins School for the Blind in Boston in 1831 (the second school of its kind in the United States), argued that the blind could be educated and trained to become independent members of society, earning their own way in the world. The education of the blind for these reformers was akin to an experiment in human engineering to prove broader philosophical points about the redemptive powers of social programs.

Howe's School for the Blind in Massachusetts became a model for schools all around the United States. In part, Howe's success derived from his famous pupils. Laura Bridgman, a deaf-blind girl, arrived at the Perkins school in 1832 and would become one of the most famous women in the world by the 1840s. Howe wanted to prove that anyone could learn to read and write, and he set out to teach Bridgman language through finger spelling and raised type. Bridgman would live her life out at the school and would in 1876 meet the next century's most famous deaf-blind girl, Helen Keller, who would also go to Perkins to study.

In 1837, Ohio established the first state-sponsored school for the blind. By the time of Howe's death in 1876, there were 23 schools for the blind, most of which were state funded, marking a change from the education of the blind as a charitable enterprise to an entitlement paid for with tax dollars. Blind children would continue to be educated at residential schools, apart from sighted children, until well into the twentieth century. By the 1920s, educators and blind advocates began to argue forcibly that the blind ought to attend school with their sighted peers. By 1970, this idea would become a movement known as mainstreaming. With the passage of the Education for All Handicapped Children Act in 1975 (now known as the Individuals with Disabilities Education Act [IDEA]), the mainstreaming of blind children became a right, not a trend. Schools for the blind diminished in importance in favor of integration of the blind with the sighted.

THE BLIND ORGANIZE

Much of the debate about the abilities of the blind in the years from Diderot to Howe occurred among the sighted. The actual voices of the blind were not part of this debate. However, the advent of schools and institutes for the blind afforded the blind an opportunity to organize as a group for their own interests. The blind were able to talk to one another and learn strategies of success for living as a blind person. Schools and institutes served as hothouses for the development of and experimentation with new devices and systems of writing.

Louis Braille (1809–1852), a student at the Royal Institute for the Blind in Paris in the 1820s, took a raised-dot system of code brought to the school in 1821 and turned it into the most important advancement in blind education. Charles Barbier, a sighted military officer, had invented a raised-dot system intended to allow officers to communicate with one another in the dark. The French army never adopted the system, nor did the Paris School for the Blind at first. However, Louis Braille took the eight-dot system proposed by Barbier, reduced it to six dots, which was easier to read with the fingertips, and created a system of abbreviations and shorthand symbols that would allow the blind to read at a much faster rate. The dots looked nothing like the roman letters they replaced, but the system was much easier for the blind to read. The school rejected Braille's system, in part because school administrators were reluctant to replace all the raised-alphabet volumes created at great expense under Haüy and his successors. Braille was a teacher at the school, however, and taught his system to his blind students. By the time of Braille's death in 1852, the school finally accepted the superior Braille method of transcription.

Braille's system also made it possible for the blind to be teachers of the blind, further strengthening resistance to the raised-dot system by sighted teachers. The introduction of Braille not only revolutionized education for the blind, it allowed the blind to communicate with one another without sighted intervention, creating a community of blind alumni. In addition, the blind began to publish their own stories in the form of memoirs intended to capture the interest of a sighted readership. Such narratives were a combination of religious inspiration and titillating details about the life of blind people.

By the end of the nineteenth century, the blind were organizing into professional associations, such as the American Association of Workers for the Blind (AAWB), and began to agitate for more overtly political objectives in such publications as *The Problem* and *The Outlook for the Blind*. Advocacy groups organized by blind activists flowered in the 1920s and 1930s in a number of states. Blind activists in Wisconsin, Pennsylvania, Colorado, and California were successful in agitating for pensions for the blind and public awareness efforts to inform their communities about the needs and interests of the blind. These state affiliates came together in 1940 to charter the National Federation of the Blind (NFB). The NFB would organize affiliates across the United States to become the largest advocacy group of blind people. The NFB began publishing the *Braille Monitor* in 1957, and it is still in print today. The NFB produced a number of leaders in what would be called the "blind movement" by those who advanced the objectives of the NFB and its supporters. Jacobus tenBroek, president of the NFB from 1940 to 1960, and Kenneth Jernigan, president of the NFB from 1968 to 1986, were galvanizing figures in the blind movement. TenBroek was a constitutional law professor who agitated on behalf of a blind pension divorced from the social security system, and Jernigan was a teacher, who transformed rehabilitation services for the blind as the director of the Iowa Commission for the Blind from 1958 to 1978. In 1960, the American Council of the Blind (ACB) was established by former members of the NFB who disagreed with the direction and leadership of that organization. The ACB publishes the *Braille Forum.*

World War I prompted the rise of national efforts to provide services to blinded veterans, which would eventually morph into the dense network of state rehabilitation and private welfare programs for the blind in the twentieth century. The Smith-Fess Act of 1920 expanded the range and scope of rehabilitation services available through the states to the blind. In 1948, the Hines Training Center was opened outside of Chicago. Named after Frank Hines, Secretary of Veterans Affairs, the Hines Center was an innovative program that sought to train blinded vets to transition back into their communities. Students at the center were given long white canes, known as Hoover canes—named for their inventor, Richard Hoover in 1944. The Blinded Veterans Association (BVA)—founded in 1945—was active at Hines and in progressive politics for many decades. Rehabilitation programs became increasingly important to all blind Americans and would become the focus of advocacy groups such as the NFB, BVA, and ACB, which agitated for better services from the agencies that were charged with providing help to the nation's blind.

—Brian R. Miller

See also Advocacy; Blindness and Visual Impairment; Louis Braille; Laura Dewey Bridgman; Denis Diderot; Valentin Haüy; History of Disability: Ancient West; History of Disability: Early Modern West; Visibility and Invisibility.

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BLINDNESS AND VISUAL IMPAIRMENT

Throughout recorded history, the eyes—the sense of sight, of looking and seeing, of vision and blindness—have been a fascination for artists and scientists alike. Writings about blindness as symbolic of human traits and action or as a sign of divine intervention are found across many cultures and societies, and they date back to ancient times. Science and medicine developed specializations in eye diseases as far back as the Ebers papyrus, an Egyptian medical textbook dating from the Eighteenth Dynasty (ca. 1500 BCE), which has an entire chapter devoted to eye diseases (Monbeck 1973). Blindness and visual impairment have important socioeconomic implications for blind people and for the societal structures in which they live. Blind people are treated differently because of their blindness—they face environmental, economic, social, attitudinal, and educational barriers. Nowadays, blindness is thought to be a major public health problem, which is being addressed by governments, health, economic, and charitable organizations at international, national, state, and local levels. The costs of rehabilitation and care may be the most apparent, with indirect costs resulting from loss of productivity. Modern medicine has developed specific definitions of blindness and visual impairment within which they frame data collection, research findings, and public policy.

DEFINITIONS OF BLINDNESS AND VISUAL IMPAIRMENT

The World Health Organization's (WHO) International Statistical Classification of Diseases and Related Health Problems (ICD-10) defines blindness as visual acuity of "less than 3/60 (0.05) or corresponding visual field loss in the better eye with best possible correction" (visual impairment categories 3, 4, and 5 in ICD-10). This corresponds to loss of walkabout vision. "Low vision is classified as visual acuity of less than 6/18 (0.3) but equal to or better than 3/60 (0.05) in the better eye with the best possible correction" (visual impairment categories 1 and 2 in ICD-10). The international medical community generally accepts the ICD definitions of disease and uses it to describe and diagnose medical conditions, diseases, and disabilities.

Almost all U.S. government agencies have adopted medical measurements broken down into three categories of visual impairment, which are used to determine eligibility for services and financial compensation:

1. Totally blind
2. Legally blind (20/200 or less visual acuity in the best corrected eye [20/200 visual acuity means that what a fully sighted person sees from 200 feet away, a person with 20/200 vision sees from 20 feet away], and/or 20 degrees or less in the visual field)
3. Partially sighted (20/70 visual acuity in the best-corrected eye or 20 degrees or less in the visual field); the U.S. Bureau of the Census simplifies its definition into lay terms (unable to see regular-size newsprint)

All of these definitions of blindness and visual impairment determine eligibility for financial support, social services, and government-funded medical services, including research studies, treatment, cure, ocular prosthetics, rehabilitation training, and job placement. Given these governmental definitions of blindness, it is commonly assumed (particularly by sighted people) that someone would only identify as "blind" if they had no vision at all. However, many people categorized as "legally blind" actually identify as blind. These people challenge traditional notions of blindness because they retain some usable vision, demonstrating that blindness, like sight, is a continuum. Many people identified as "legally blind" or "partially sighted" greatly benefit from standard accommodations for blindness, such as audio description of environments, access devices and technology, books on audiotape or compact disk, and universal design.

Even though the degree of blindness is calculated in a very functional way by government agencies and many other institutions, it cannot be assumed that there is a simple relationship between the difficulties individuals face in their lives and their level of blindness. Many other factors intervene in this process, such as the accessibility of their environment, the degree of support they have, and their financial resources. While magnifiers; monoculars; talking watches, personal digital assistants (PDAs), and portable global positioning systems; and large-print and speech output software can significantly facilitate blind people's inclusion into everyday activities of living, costs are often prohibitive, even for those who are working. In addition, many technological and optical devices are largely unheard of, and certainly unaffordable, in developing nations where 90 percent of all blindness and visual impairment occur.

COMMON CAUSES OF BLINDNESS

The most common causes of blindness vary according to geographic location, socioeconomic status, and age. Largely preventable and treatable, bacterial diseases such as onchocerciasis, otherwise known as river blindness, and trachoma are leading causes of blindness in the developing world. Many international health-promoting organizations have blindness prevention programs. They work in rural, poverty-ridden communities to improve hygiene education, sanitation conditions, and access to health care.

The U.S. Centers for Disease Control and Prevention (CDC) reports that many causes of blindness occur before birth, although some conditions clear up over time. Older children (between 3 and 10 years old) have more vision impairments than do children younger than 3 years old. Nearly two-thirds of visually impaired children also have at least one other impairment. This may, in part, be due to the fact that some diseases have visual impairment as secondary effects. Diabetes, glaucoma, and cataracts are the most common causes of blindness among adults in Western nations. Because more people are living longer than did earlier generations, age-related macular degeneration is becoming more prevalent.

PREVALENCE OF BLINDNESS

The World Health Organization estimates that there are about 148 million blind or visually impaired people around the world, with 9 of 10 cases occurring in developing nations. There is a strong link between poverty and blindness. Of the more than 100 million blind children around the world, more than 80 percent live in underdeveloped countries. The majority of cases are preventable, but adequate financial commitment to prevention and treatment programs, healthier agricultural practices, and more attention paid to nutritional deficits is needed (World Bank 2003b). Current available studies estimate that there are, at minimum, 1.5 million blind children in the world; 72,000 of them live in Europe, the United States, and Japan (Kocur and Resnikoff 2002). The level of ophthalmic health care is shaped by each country's political system. For example, countries that were part of the USSR are currently grappling with shifting their socialist (free) health care to non-government-subsidized health care systems, for example, private health insurance; hence, health care, including ophthalmic care, is in transition and so is not always adequate (Kocur and Resnikoff 2002). In North America, there are between 10 and 11 million blind or visually impaired people (American Foundation for the Blind [AFB] 2001; U.S. Bureau of the Census 1996) with the large majority having some residual vision.

The Royal National Institute for the Blind (RNIB) in the United Kingdom reports that it is difficult to know exactly how many blind and visually impaired people there are in European Union countries, but the most widely used estimate is 7.4 million out of a general population of 385 million. In the United States, approximately 1 million people over age 40 are blind (National Eye Institute and Prevent Blindness America [NEI] 2001). One problem gathering accurate data is that people who begin to lose their vision as part of the aging process often do not register for social or rehabilitation services (RNIB 2003). In addition, different countries have different data collection methods, which makes it difficult to estimate total numbers of blind and visually impaired people.

EMPLOYMENT DATA

Employment figures as well as prospects for future employment of blind and visually impaired people are dismal in every country across the globe. Public policy toward blindness is measured in terms of economics—cost-benefit ratios. Statistics are gathered about how much blindness prevention, treatment, and rehabilitation costs, and then are analyzed in comparison with productivity levels to determine if governments are making a good capital investment. Blindness and blind people are characterized as "financial burdens."

No other socioeconomic group in the Unites States has more unemployment than do blind people (AFB 2001). Less than 50 percent of all blind/visually impaired Americans are employed. More than one-third of those who are employed report being underemployed (U.S. Bureau of the Census 1996).

ATTITUDES TOWARD BLINDNESS AND BLIND PEOPLE

The World Health Organization (WHO) began its fact sheet on blindness, "The loss of eyesight is one of the most serious misfortunes that can befall a person" (WHO 1997a). The World Bank uses "suffering" and "overcoming" in its reports about projects "fighting blindness." Many medical, humanitarian, and philanthropic organizations describe blindness as a "tragedy." The idea that blindness is a horrific fate is long-standing and well documented. Blind people are often portrayed within such negative stereotypes as "deserving of pity and sympathy; miserable; in a world of darkness; helpless; fools; useless; beggars; unable to function; compensated for their lack of sight; being punished for some past sin; to be feared, avoided and rejected; maladjusted; immoral and evil; better than sighted people (idealized); mysterious" (Monbeck 1973:25). Writers of ancient biblical texts used metaphors of illness and impairment to dramatize moral, ethical, and religious lessons as well as to inscribe exclusionary laws.

BLINDNESS AND EDUCATION

In many countries, blind (and other disabled) children have systematically been subjected to school segregation. Even though the curriculum was purposefully similar to general public education, blind children were segregated into their own schools, and many of these schools are still in existence. The first school for the blind in America was founded in Baltimore, Maryland, in 1812. In 1832, a school named the Massachusetts Asylum for the Blind opened. It later changed its name to Perkins Institute (and is currently named Perkins School for the Blind) (Shapiro 1994).

BLINDNESS AND RELIGION

While it is so that the writers of the Bible used earthly language to describe and explain the inexplicable (God), one need only scratch the surface of metaphors of impairment to unearth negative attitudes toward and societal stereotypes of the blind and the damaging consequences of being blind. "You shall not curse the deaf or put a stumbling block before the blind" (Leviticus 19:14) has been interpreted throughout the centuries to symbolize various negative actions. The Bavli (Babylonian Talmud) used the stumbling block metaphor in cases of serving wine to those who ascribe to prohibitions against drinking wine (Avodah Zarah 6a-6b); lending money without witnesses (B. Baba Metsia 75b); or deliberately irking someone to test their temper (B. Kiddushim 32a). In these examples, blindness is used to illustrate enticement and temptation, inability to control one's desires, or deliberately acting cruelly toward another human being. All the examples equate blindness with helplessness. Blinding someone seems to be the weapon of choice in the following examples: In Genesis 19:11, young and old alike were struck with blindness so that they would wear themselves out groping for the exit; Samson was blinded by the Philistines (Judges 21).

The stigma ascribed to visual impairment is found, for example, in the story of Leah, who was devalued as a potential wife because she had "weak eyes." Under the cover of darkness, Leben, Leah's father, deceived Jacob into marrying Leah (Genesis 29:16–25). The inference is that blind people are easily tricked and that sight is the most valuable sense despite evidence that touch is the most reliable of all the senses. Exodus 23:8 warns, "And you shall take no bribe for a bribe blinds the officials, and subverts the cause of those who are in the right." Again, blindness represents corruption and deceit. By sheer number of mentions, blindness appears to be the favorite disability metaphor in Scripture.

The use of blindness metaphor in religious contexts is not confined to Judeo-Christian texts. The Qur'an uses allegorical descriptions of eyes to connote faith in Allah, e.g., "Thus Allah strengtheneth with His succour whom He will. Lo! herein verily is a lesson for those who have eyes" (The Family of Imran, The Third Surah of the Qur'aan [verse 13], Pickthall Translation). Thus, impairment, illness, and disability have become bound up in institutionalized religious doctrine of sin, evil, God-decreed punishment, uncleanness, sorrow, and pity. However it is talked about, blindness is almost always perceived to be a "tragedy."

Blindness has been used as a metaphor to describe ignorance, denial, stupidity, naïveté, prejudice, drunkenness, carelessness, unconcern, thoughtlessness, and unawareness. "Blind" has represented something tricky that is intended to conceal the true nature of a thing, as in "blind taste test" and "double blind" research study. And, in botany, a plant is "blind" when it fails to flower.

MODELS OF BLINDNESS

Until the advent of disability studies, blindness was conceptualized only as catastrophic. Artists and writers used blind figures to represent either pitiful, lost creatures groping their way through an unseen world or vessels of supernatural powers. Blind people were to be avoided because they could see inside your thoughts (Barasch 2001).

Research on blind people has been dominated by literature written from the perspectives of medicine, rehabilitation, and psychology. The focus of these studies has tended to be disease and its effects, psychological aspects of blindness (loss, grief, and eventual "acceptance"), adaptation, and coping strategies.

Blindness is positioned absolutely on the individual with little societal context taken into consideration, as if blindness occurs in a social vacuum. This approach tends to assume that blindness is solely a physiological event, and not a social process. One exception to this pattern was Scott's (1969) pioneering social constructionist approach to blindness and society. Scott's phrase "blind men [*sic*] are born, not made" emphasized the role of blindness workers in the socialization of blind people. Scott's work has been built upon in the past decade by interdisciplinary blindness literature, strongly influenced by blind disability studies scholars (e.g., Michalko 1998, 1999; Kleege 1999; Kudlick 2001; French 1993, 1999, 2001).

CURRENT TRENDS IN BLINDNESS LITERATURE

Type in "blindness" on any Internet search engine and the typical search results mainly concern disease, rehabilitation and counseling services, product catalogues, blindness "etiquette," blindness prevention, and medical research. There is a sparse sprinkling of information about organizations *of* the blind, which are initiated and controlled by blind people themselves and are consumer and rights oriented. More common, however (and more well funded), are associations *for* the blind, which have deep historical roots in the medical model and are usually administered by sighted people. These organizations are often charities that promote blindness prevention media campaigns, information about specific eye diseases and related services and product information, and reports of medical research aimed at prevention and cure. Generally, neither type of blindness organization conducts independent social or medical research.

Some charity-based organizations may raise money to help fund prevention and/or cure research (and to fund their own jobs). However, the actual protocol decision-making and research work in these cases is usually left to medical and educational establishments. Medical institutions typically devote their energies to prevention, diagnosis, treatment, and cure. On the other hand, educational institutions tend to address matters of adaptation, accommodation, and rehabilitative training.

Many medical, rehabilitation, and educational establishments have laudable achievements in helping to improve the lives of blind people. However, the gaze of medical model research is on the function of the eyes, so it largely fails to inquire about social processes or even about the personal experience of blindness. The new interdisciplinary discipline of disability studies is changing all that by re-theorizing blindness within sociocultural contexts.

Disability studies tends to promote work *by* organizations of disabled people, as opposed to organizations *for* disabled people. There is a significant distinction between the two types of organizations in that disabled people themselves organize, lead, and set their own purpose and policy agenda in organizations *of* disabled people. On the other hand, organizations *for* disabled people are most often administered by nondisabled people who speak for and assert authority over disabled people.

At present, disability studies literature tends to be dominated by projects based in the humanities, so actual participant research projects are rare. Until now, the most common genres for addressing issues of blindness have been historical literary analysis, memoir, autobiography and autoethnography.

The writings of a young blind girl in post-revolutionary France were translated by Kudlick and Weygand in 2001. The first half of the book contains Thérèse-Adèle Husson's writings about her experiences, while the translators devote the second half to commentary. What is most remarkable and valuable about this brief story of one person's blindness experience is how little things have changed with regard to dominant societal attitudes toward blindness and blind people. Husson (2001) wrote:

> When they [blind people] appear in public the stares of the multitude are fixed upon them, and agonizing words strike their ears: "what a shame!" "How unfortunate!" "Death would be preferable to such a cruel privation!" There are even some people who seek out the blind to tell them these things so that they don't miss any of the sad exclamation. (p. 25)

Kudlick (2001) framed blindness within the cultural context of Victorianism by analyzing historical documents. She explores the origins of an important ideological split within the blindness community, which continues to this day. Some blind people believe that to be perceived as equal in a sighted society, blind people should not seek environmental accommodations such as audible signage or tactile warning strips. They also believe that only blind people can help other blind people and have instituted their own vision training centers run entirely by and for blind people. Conversely, other blindness organizations actively advocate for environmental access, accept training from sighted guides, and perceive blindness as more of a medical and consumer issue than one of social acceptance. Kudlick's commitment to recording the cultural aspects of blindness history is important, because it is a marker of the growing respect for disability studies as a legitimate, serious discipline, as well as a reflection of the strength of the disability civil rights movement. Social movements are often measured by new interest in their histories.

In *Sight Unseen,* Georgina Kleege (1999) described her experience of growing up with progressive vision loss. Throughout this memoir, Kleege used examples from her own life to place blindness within a cultural context. Her book is divided into three main sections: Blindness and Culture, Blind Phenomenology, and Blind Reading: Voice, Texture, Identity. These topic headings might convey the idea that the book is oriented within the social model of disability. However, Kleege's exaggerated emphasis on impairment rather than disability often contradicts such an approach. For instance, she stated, "Writing this book made me blind" (p. 1), "This book made me understand for the first time how little I actually see" (p. 2), and she characterizes the book as "my attempt to specify my own visual experience" (p. 103) and "a coming out narrative." Clearly, the main theme of her memoir is identity formation.

Rather than embracing blindness as an alternate way of being in and knowing the world, Kleege writes that blindness "really isn't as terrible as you were always led to believe" (p. 34) and that it is "not so bad" (p. 32). Throughout *Sight Unseen,* Kleege often uncritically reproduced the concept of normativity—a problematic concept for the discipline of disability studies. She often used the word "normal" in a phrase without italics or quotation marks to contest the concept. For instance, she refers to "normal daily activities" (p. 167). This uncritical citation of the term "normal" seems to indicate that she accepts the notion of normality, which is highly problematic from a social model perspective. By using such controversial terms in her descriptions of the blindness experience, Kleege may be unconsciously endorsing a nondisabled, medicalized discourse that positions blindness as a loss and an exclusively negative experience. Other personal narratives from blind people suggest that the experience is far more complex and nuanced than such simplistic descriptions would suggest.

The humanities play an important part in the interdisciplinary nature of disability studies, and *Sight Unseen* is a significant contribution in that regard. In her review of this memoir, Sally French (2002) said she found *Sight Unseen* "unsurprising," but she states that it "provides good material for anyone interested in the meaning of visual impairment and the growing field of disability studies" (p. 859).

Given that she uses the genre of memoir, it should not be surprising that Kleege's work focuses largely on the individual's adaptation to blindness rather than turning the gaze back onto society's treatment of blind people. Nevertheless, from the perspective of disability studies, memoirs can be problematic because readers may understand them to be "inspirational" stories about personal triumph over tragedy, or as reinforcing other medical model stereotypes about disability as an individual problem.

A memoir such as *Sight Unseen* can also be criticized for relying solely on one individual's perspective, which could be seen as enabling the author to develop theoretical generalizations without being required to apply the rigors of social scientific citation, which builds on prior academic knowledge and requires the author to substantiate such positions. Consequently, even when an author committed to the social model of disability writes a memoir, the danger is that the theoretical reframing of disability and impairment from the perspective of the social model of disability may fail to be noticed or understood.

In contrast to literary analyses and memoir writing, White (2003) relied on an interdisciplinary approach that combines queer theory, disability studies, and blindness literature. White examined the social construction of blindness as a heterosexual experience by critiquing the social construction of heterosexuality in blindness sex education for young blind people. White delved into dominant beliefs about sexuality being a visual process, and how this construct frames young blind people as sexually underdeveloped. He wrote, "Blind people are in a sense queer, in that heterosexuality, at least in its institutionalized forms, presumes a sighted subject" (p. 134).

Sally French (1993, 1999, 2001) used prior social model of disability literature to buttress her analysis of how society disables blind people. She stated that "conflicting discourses arise when sighted people define what is 'acceptable' and 'normal' behavior for a visually disabled person and use these definitions to contest that person's identity" (1999:21). French (2001) used a grounded theory approach in her study of visually impaired physiotherapists so that she could address issues of both impairment and disablement. French relied on the use of questionnaires and semistructured interviews to examine such issues as how society has perceived physiotherapy as a legitimate profession for visually impaired persons, and she uses participant interview transcripts to elucidate how visually impaired physiotherapists perceive their engagement in the profession as points of advocacy. Her informants describe how they meet and manage barriers that arise in their everyday work lives. French's growing body of work combines both her personal experience of blindness and a social model analysis; thus, her work helps shape the future of disability studies literature, in general, and blindness research in particular.

Rod Michalko, a postmodern sociologist, deconstructs medical, psychological, and societal ideas and practices around blindness. In particular, Chapter 4 of *Mystery of the Eye and the Shadow of Blindness* (1998) is devoted to a critical examination of blindness rehabilitation. Noting that once ophthalmologists have diagnosed their patient as destined for permanent blindness, they refer the patient out for rehabilitation. Michalko wrote, "Ophthalmology is recommending *agency* as an *actor* presented as qualified to speak about, and act upon, permanent blindness. This suggests that blindness requires agency and needs to be acted upon in order for it to be lived with. . . . Rehabilitation, too, conceives of the seeing life as the only good life" (pp. 66–67).

In another book, *The Two in One: Walking with Smokie, Walking with Blindness* Michalko (1999) used autoethnography as a methodology so that he could describe and analyze his experience of vision loss and his acquisition of a guide dog. He relied on postcolonial concepts of "home" and "exile" to describe his personal experience of living in a world built by and for sighted people and explained how his dog, Smokie, lives in exile in a world built by and for humans, but how their relationship brings "home" into both of their lives. Michalko also examined how the dog guide school creates expectations of blind students' behavior and the school's physical environment based on sighted notions about the blindness experience. Sherry (2003) argued that Michalko's most important contribution to blindness and disability studies literature is his postmodernist deconstruction of the blindness/sightedness binary, which extracts blindness from its perceived "lack" and places it, instead, on its own merit as an alternate way of knowing the world. Michalko (1998) wrote: "Blindness, when compared with sight, becomes a thing of shadows . . . anything seen as a mere shadow of its former self is understood as less than or not as good as the original. . . . Sight *is* status and is a status *former* to blindness. Sight is not a mere shadow of its former self since it has no former self. Thus sight is not regarded as needful of restoration" (pp. 67–68).

Michalko's work is important and will have far-reaching impact on both blindness research and on how societal institutions perceive, teach about, and treat blind people. However, one largely ignored theoretical approach to blindness is materialism, which is important in several other areas of disability studies. Although a materialist approach has been adopted by disability scholars such as Oliver (1990), Gleeson (1999) and Thomas (1999), it is a relatively underexplored perspective within studies of blindness. Oliver (1990) argued that material factors are fundamental to understanding the social model of disability. In this regard, it is important to note that blind people experience economic oppression and social isolation in even larger percentages than other disabled people, through higher unemployment and underemployment rates and lack of access to basic print information and accessible transportation. Potential employers, community development and urban planners, mainstream technocrats, rehabilitation agencies, and retailers alike often balk at the financial cost of environmental barrier removal and universal design, leaving blind people stranded in or altogether shut out of the workplace and, therefore, exiled from a consumer economy. In addition, government agencies, nonprofit charities, and for-profit businesses employ tens of thousands of sighted workers engaged in maintaining institutionalized oppression of blind people. Failure to examine these factors as influences in blind people's lives is failure to mine a deep and rich source of research data.

Another flaw with some of the blindness literature is that it generally focuses *either* on impairment or disability, but not both. In addition, distinctions between impairment and disability are muddied because authors often use these terms interchangeably. Such conceptual blurring can cause confusion and linguistic chaos because it becomes difficult for readers to grasp theoretical concepts when key terms such as *disability* or *impairment* are being used in inconsistent or ambiguous ways.

FUTURE DIRECTIONS

Advances in technology and medicine, demographic trends, a global economy, and political developments can be expected to shape the futures of blind and visually impaired people around the world. Technological advances will assist in agricultural practices reform and improvements in sanitation, which will further the current trend toward reduction in cases of bacterial-related blindness. On the other hand, medical advances continue to prolong life; therefore, a steady rise in cases of age-related blindness such as glaucoma, macular degeneration, and cataracts is expected. Coupled with general population gains, the overall number of blind people will most likely increase, especially in the developing world. The WHO (1997) estimated that by the year 2020, 50 million blind people will be living in developing countries, which will put a tremendous strain on eye health care and social service monetary and human resources. More cost-effective technologies such as outpatient cataract surgery may help alleviate the strain on service provision.

Gene therapies and genetic counseling may play a role in the future size of the blind population, especially in the majority world. Genetic manipulation of the human race is a controversial topic. Societal attitudes about disability and disabled people strongly influence decisions about which children are worthy of existence. Disability studies as a discipline is addressing the ethical issues and implications for disabled people and the science of genetic manipulation. Because many eye diseases are genetic, it is likely that those interested in the social model of blindness will participate in the discourse.

CONCLUSION

There are approximately 148 million blind people in the world, with most of them living in underdeveloped countries, and many international health promotion organizations are implementing blindness prevention and treatment programs. Blindness is a continuum, which can be measured according to different scales. For instance, most government departments distinguish between people who are totally blind, legally blind, and partially sighted, and they use these categories to determine eligibility for services. However, these definitions of blindness rely on a medical model of disability, which places most emphasis on measuring impairment levels, but which does not focus on the experience of disabling barriers.

It should not be assumed that there is a direct relationship between a person's degree of blindness and the difficulties he or she faces in everyday life. Some of the factors affecting the social inclusion and exclusion of blind people include the accessibility of their environment, the degree of support they have, and their financial resources. For many blind people, the experience of disabling barriers greatly limits their rights and freedoms. Some of those barriers include discrimination in employment, exclusion from regular education, and stigma. Prejudice and stereotypes affect many perceptions of blindness and are present in religion, education, charities, the media, and many other areas of life. In response to these barriers, organizations of blind people have been struggling for increased rights, and blind authors within disability studies have made an important contribution to the cultural reevaluation of blindness.

—Beth Omansky

See also Autobiography; Blind, History of the; Disability Studies; Religion.

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BOBATH, BERTA AND KAREL
(BERTA, 1907–1991; KAREL, 1906–1991)

English (German-born) physiotherapist (Berta) and neurologist (Karel)

Mrs. Berta Bobath, physiotherapist, and her husband, Dr. Karel Bobath, originated a therapeutic approach to the treatment of persons with neuropathology and resultant sensorimotor impairments currently called the neuro-developmental treatment approach (NDT). Berta and Karel Bobath were born in Berlin, Germany, but developed these therapeutic concepts after they immigrated to London, England, prior to World War II. The treatment approach grew out of Mrs. Bobath’s astute observations of normal posture and movement and Dr. Bobath’s belief that scientific evidence must support clinical practice. They published many books and journal articles, teaching doctors and therapists their methods of examination and treatment from 1948 through 1990.

Although the Bobaths did not conduct any original research or collect clinical data in ways that offered the medical and scientific community evidence for the effectiveness of their treatment approach, NDT continues to be a commonly used method for the management of motor dysfunction following adults who have had a stroke or children who have cerebral palsy. The Bobaths committed their time and energy to developing their treatment approach, which, while it has evolved over the years, includes the following characteristics. Examination and treatment strategies target the neuromuscular and musculoskeletal impairments that interfere with functional skills in clients with neuropathology. Treatment includes hands-on facilitation of selective posture and movement and inhibition of unnecessary, inefficient motor responses so that ultimately the client can develop effective movement synergies that are in tune with task demands and contextual requirements. Treatment outcomes are defined as measurable, observable functional changes made in meaningful contexts.

—Janet M. Howle

See also Cerebral Palsy; Neurological Impairments and Nervous Disorders; Neuropathy; Stroke.

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BODY, THEORIES OF

"Body theory" is shorthand for a nexus of contemporary scholarship concerned with the definition, tracking, and management of kinds of bodies and the social ideas about bodies that configure self-perception. Work in body theory resists the Enlightenment idea that human definition should be based on a quality of consciousness. Instead of the often cited conceptualization of humans in the terms espoused by the Enlightenment-era philosopher René Descartes, "I think therefore I am," body theorists take human commonality to reside in the inhabitation of bodies. Rather than participating in a lengthy philosophical tradition (largely Western) that eschews bodies as secondary to the intellectual life of the mind, body studies reintroduces the materiality of lived experience as a significant site of analysis.

Premises in body theory have provided a basis for scholars to study the effects of management practices. Most important, in studying discourses and ideas about bodies, a scholar does not need to simply oppose or endorse institutional practices as necessary for the conduct of institutional life. Michel Foucault, a post-Holocaust historian of confinement practices, evaluation methods, and professional discourse, often receives mention as formative to body theory. Partially as a result of Foucault's methods, many contemporary policy studies, for example, now also investigate social ideas about the means for regulating the conduct of bodies without having to endorse them. Foucault himself studied the origins of disciplinary and regulative techniques for the operation of institutional life in schools, hospitals, prisons, asylums, and clinics. When social workers and prison guards complained that his book *Discipline and Punish* did not have much use for them, Foucault replied that he had not written it for them.

In work that theorizes the dynamics of power, Foucault contended that public executions, inasmuch as they directly display brutality and torture, deliberately expose the violent operations of a state in seeking compliance from its citizens. Rather than implicate the state in practices presumably enacted to deter transgressions, the Victorian era sought to conceal the workings of state power upon bodies: Executions became sequestered, judicial affairs as the product of massive deliberations that conceal directly punitive acts. Within this approach, oppression occurs as a matter of excessive evaluation, regulated body life, and administrative protocols so that the operations of power become diffuse. Increasingly, punitive bureaucracies came to implement such operations. During this period, definitions of a variety of "mental defects," in a casebook that is put to use by medical and judiciary organizations alike, subjugate citizens by casting an ever-expanding number of human characteristics as abnormal. Discussion of human abnormalities is entered into wholesale by the judiciary and a field of psychiatry that grows up as an adjunct to the courts, in France, and as the operators of institutions in the United States. Psychiatry was a field that had taken discourses about human pathology as a primary domain of expertise and qualification. In part, because of the collusion of German psychiatrists in eugenics and murder practices of disabled persons during the period of National Socialist Governance, psychiatry was also in general disrepute after World War II.

Contending that professional discourse about anomalous bodies such as the kind undertaken by rehabilitation and medical professions had become a "monologue," and one that had literally silenced subjects to death in state-mandated evaluation procedures in Germany, many of Foucault's writings contemplate the silencing of the voices of objects of study by discourses ostensibly "about" them. Body theory thus resists the idea that one can ascertain the views of the confined, the subjugated, the studied, and the disciplined from the case notes and judiciary records of those who write about them. Nonetheless, scholarship can effectively study the confinement of bodies and the techniques to control and illicit kinds of "abnormality" that make manifest the operations of power in a social order.

A principal innovation of institutional life was to develop a written case study, and maintain observational notes, on each client. This is likewise the case for the advent of contemporary practices in judiciaries that are also concerned with identifying and punishing abnormality. With these notes from psychiatric institutions now making up a substantive archive of collected materials, other scholars have also sought to find ways to listen to the voices of confined objects of medical observation and scientific study. Some study the discursive patterns of expression that have been recorded by professional observers in order to contemplate the messages avowed by, for instance, someone termed "schizophrenic." Others study locations in clinics and hospitals as spaces for the performance of anomaly and abnormality, noting, for example, that the performance of hysteria in the famous medical school of Jean Martin Charcot often entailed inciting an epileptic seizure in one of the subjects.

Hence body theory has provided for a means to study the classification of bodies and their performance of symptoms without having to validate (nor necessarily refute) medical findings. Many subjects viewed as abnormal also expressed symptoms bound up with violation of feminine norms and standards. Understandably, then, body theory is also largely associated with feminist and gender studies. This line of thinking contends that, under patriarchal societies, women experience disqualification from tasks on the basis of perceptions concerning attributes associated with an inferior biology. Feminist scholars thus research historical and professional locations that gauge equal participation in terms of body qualification. Cast as the "weaker sex," women have historically struggled with being limited and defined on the basis of bodies that were rigidly classified in terms of reproduction, as well as feminine norms and expectations. Body theory might say that humans with feminine reproductive organs, under a gender classification system that divides the world into those with wombs and those without them, will view women's bodies as making them innately unsuited for leadership, moral vision, certitude, or professional life. Intimately bound up with body theory, gender studies researches the ways in which different reproductive anatomies in bodies have been opposed in a dualistic fashion. Herein, masculinity comes to define a specific set of qualifications associated with body features whereas femininity offers a contrasting, and frequently less stable, range of possibilities.

Existentialism, a significant branch of philosophy during the first half of the twentieth century, grounds a substantial part of theorization about gender and the body. The primogenitor of existentialism, Jean-Paul Sartre, formulates feelings of emancipation in terms of the success of exceeding limits so that one experiences momentary escape from one's body demands. In contrast, Simone de Beauvoir, Sartre's partner, and the author of *The Second Sex* (1949), demonstrates how a masculine subject's sense of liberation from material constraint casts women in perpetual association with the fleshy, immured life of bodies. Within this patriarchal schema, women are made secondary by their continual association with the fluids and constraints of bodies while male agency occurs through its dominion and escape from the body into the life of the mind.

As a rejoinder to this detrimental tradition, a school of thought termed *l'ecriture feminine,* or "writing the body," is associated with feminist philosophy in France from the late 1960s to the present. Preeminently, Helene Cixous, in pieces such as "The Laugh of the Medusa" (1975), sought to expand imaginary associations between feminine body elements such as breast milk and the act of written expression. Whereas the classical story of the Medusa involved a male hero who turned the tables on a gorgon who had an appearance that, when gazed upon, turned men to stone, Cixous rewrites mythology from the perspective of a femininity that was only perceived, by masculine storytellers, as monstrous. Her philosophical tracts are thus also explicitly efforts to refigure denigrated and mythological female bodies by pressing the limits of poetics.

The feminist philosopher and gender ethicist Luce Irigaray, in many of her philosophical works, but most explicitly in *The Sex Which Is Not One* (1985), casts femininity as a purely negative, nonexistent state supplied only as a contrasting "other" to masculine subjectivity. She points out, for example, that a masculine philosophical tradition sees women's sexual organs in terms of mere absence of a phallus. Since femininity exists only as negation, one can attempt to realize a feminine subjectivity through interrogative questions and bodily experiences that escape masculine definition. The semiotics theorist and philosopher Julia Kristeva famously recorded her experience of embodiment during parturition in "Stabat Mater" (1983). In doing so, Kristeva reclaims feminine fluidity as a value rather than an abject vehicle. While influential in vastly divergent fields, all these writings nonetheless seek to expand imaginative thinking about the bounded nature and singularity of bodies. They also seek to resist equations of femininity with less and masculinity as the ideal of normative embodiment.

In a significant divergence from *l'ecriture feminine,* transgender theorist Judith Butler challenges the political utility of inverting values associated with a masculine/feminine dualism. Instead she argues against the existence of any embodied experience not already filtered by language. For Butler, gender is not the cultural layering of meaning upon the raw material of sex, but rather sex itself proves fully conditioned by cultural investments in naturalized bodily capacities. Studies of transgender experience interpret the effects of dualistic gender thinking upon bodies that do not suit an either/or classification of masculine/feminine. Instead a transgender studies approach analyzes the production of ambiguously gendered bodies that exceed inflexible sex/gender divisions. Transgender theorists analyze the resistant potential of gender ambiguity as undermining of normative heterosexual conventions.

Since body theory undertakes a historical tracing out of the ways in which bodies are viewed in different societies, analyses of racial discourse are also key to the field. Such an undertaking immediately necessitates parsing out the operations of racial and ethnic thinking in body image production. As late-eighteenth- and nineteenth-century ideologies produced gender-related pathologies, race itself moved from a marker of cultural difference fueling ethnic tensions to a physical sign of biological inferiority itself. Increasingly, one finds justifications for enslavement, for instance, based on paternalistic models of racialized populations' presumed inability to care for themselves. African and South Asian societies in particular came to be referenced by European anthropologists as evolutionary throwbacks. Freud, for instance in *Totem and Taboo* (1913), identified Maori communities in New Zealand and Zulu peoples in Africa as evidence of premodern totemic societies that had not effectively repressed their baser, primeval impulses. In addition, some ethnic populations such as Jews were cast under suspicion because they were thought to be hyperequipped to handle the demands of rapid industrialization and modern economic orders. Consequently, scholars examine the ways in which Nordic Western races have historically bolstered their biological superiority through the denigration of other bodies as inherently deviant based on subjective racial characteristics.

Outside of more psychoanalytic models, other traditions in body theory interpret the role of body classification in terms of economic and class-based effects. Second-wave feminism, for example, explored how Karl Marx, in *Das Kapital* (1867), conceived of the worker's body under industrial capitalism as inherently male. As a result, feminist socialist theory has worked to expand definitions of labor by querying formerly unrecognized modes of labor such as the role of reproduction as erased under capitalist economies. Theorists in this tradition have pointed out that work in the domestic space, though not usually and directly remunerated under professional business practices, qualifies nonetheless as expended labor and thus should be recognized as work that results in use value.

Likewise, disability body theory examines how Marx's conception of workers' bodies necessarily excludes from labor participation those bodies deemed less evidently productive by ableist labor orders. Indeed, the enemy element under industrial capitalism is the capitalist himself who parasitically invests capital but does not expend his own labor in the production of commodities. The capitalist's body is thus traditionally depicted as corpulent and excessive while the debilitated laborer's body provides evidence of capitalist indifference. While unbridled industrialism would therefore be culpable for disabling otherwise healthy worker bodies, there is also little room to discover alternative routes of employment for disabled bodies if they do not pass muster as "able" laborers from the start.

In a parallel effort to body studies, disability studies takes up the necessity of evaluating the often restrictive location of bodies identified as nonstandard. In doing so, disability scholarship often investigates sites of transportation, sequestration, confinement, seclusion, disenfranchisement, regulation, display, promotion, and clustering of disabled bodies. Like studies of obesity or age, disability studies analyzes the social world, from airplanes to classrooms, to discuss the ways in which an environment is built to anticipate some bodies while excluding others. Just as the politics and oppression of prostitution became a central concern for feminism, so does the history of employment in freak shows galvanize scholarship for disability scholars. Some kinds of disabled bodies, like racialized and exotic "others," seem particularly qualified for employment as an exhibition or freak act. These include bearded women, atrophied men, obese persons, those possessed of extraordinary height, persons of short stature, conjoined twins, and persons who appear to lack arms, legs, or body sections. Toward the end of the nineteenth century, medical researchers sought to examine persons employed in freak show exhibits. Discussion abounds concerning the efforts of sideshow barkers and managers, such as Phineas Taylor (P. T.) Barnum, to protect his band of freaks from them.

Cultural theorists such as Leslie Fiedler propose that the attainment of freak spectacle was reserved for only a special class of human anomalies and that the rest were simply consigned to the experience of regular disability and social suffering. Objecting, most of all, to being called a "freak," transgender and disabled commentator Eli Clare examined the economic realities that would bring about employment as an exhibited "extraordinary" human. She likens work in freak show industries to labor as a prostitute—drudge labor that nonetheless pulls one out of life as a beggar or a charity case. Then, in a key turn for disability studies, she returns to the insights of body theory and queries the medical team approach to examination that continues as a common practice in hospitals. Disability studies braves the radical insights of body theory by asking about the value of gait training examination and medical theaters from the perspective of those who have experienced being exhibited in these forums. For example, the gaze of medical and therapy practitioners upon different bodies may result in more harm than good and be utterly ancillary to the supply of a useful brace or mobility aid. Thus, disability studies also begs a question of political economy at its foundation in its querying of the necessity of medical evaluation regimes and the experimentation entailed by treatment plans, such as limb casting. How much does medical discourse have to produce "proof" of unacceptable traits and features in bodies? How much of the habit of gazing on body features involves merely assuring the professional gazer about their own normalcy? How much do professional practices rely on demonstrating the unacceptability of different body traits and features in terms, not only of standards of health, but merely for aesthetic purposes? And what are the implications of the rampant medical photographing of so many abnormal bodies during the twentieth century?

In addition to these methodological alliances, disability studies also reviews the significant absence of disability awareness in contemporary body theory. After all, body theorists may reference "cyborgs" as exemplary of a highly technological postmodern subject and toss in examples of someone "with detachable parts," without contemplating the sudden appearance in public of post-deinstitutional-era disabled persons. In other words, body theory often dematerializes into elegant discussions of the ascription of homophobic, racist, and sexist associations onto bodies in order to show that queer, racialized, and gendered bodies are socially produced. In many ways, this means that such bodies are not really "defective" or insufficient but only perceived as such by unjust social views of them.

Embodiment analyses in disability studies propose that physical disabilities are perceived as a private room in a public space—and that ideologies of disability assume a transparency to the motives and psychic life of physically disabled subjects. Thus, while disabled bodies have been rendered largely invisible historically, popular literary and media texts often present such bodies as readily interpretable. A prime example occurs when malevolency and vengeance are easily assigned to persons with physical anomalies or illiteracy to someone who may be hard of hearing. A simple discounting of disabled persons occurs as the result of onlookers making assumptions about someone's "inner" disposition and thus rendering them transparent. Because such simplistic ascriptions between psychological deviance and physically disabled bodies are common, these representational tactics constitute a significant layer of oppression for physically, cognitively, and sensory disabled persons alike. This historical intertwining of forms of deviance that seem to mutually reference each other has resulted in the deepening debasement of all bodies, particularly given that oppressive and discriminatory treatment often proceeds by making one form of devalued difference underwrite another.

Disability body theory has recently begun to analyze the degree to which eugenicist writings depend on the diagnosis of cognitive defects through scrutiny of physical anomalies and vice versa. Practices under eugenics where syphilis in one generation was argued to result in cerebral palsy and a propensity for promiscuity in the next provide a potent instance of cross-referencing practices that devalue bodies. Another area of interest is the degree to which racialized populations have been socially disqualified due to presumed inferior intelligence. Thus, one of the key insights of disability body theorists is that social disqualification occurs in a stigmatizing process whereby multiple identities are cross-referenced, and insomuch as these traits are configured in the same body, family, or communal unit.

—Sharon L. Snyder

See also Feminism; Michel Foucault; Freak Show; Gender; Gender, International; Identity; Racism.

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BORDERLINE PERSONALITY DISORDER

The term *borderline* was first brought into psychiatric terminology by A. Stern in 1938 to describe patients "on the border" of psychosis, and it has since been used to define alternately a clinical entity, a syndrome, or a personality organization. For roughly 70 years, the diagnosis of borderline personality disorder has been and still is a subject of intense debate.

Personality disorder is characterized by chronic instability in the individual's sense of identity, mood, and relationships. Afflicted individuals exhibit a deep lack of confidence and instability in relation to their sexual, professional, and social identities. They frequently experience disappointments and are prone to express anxiety and depression symptoms. Antisocial acts, affinity for psychoactive substance abuse, erratic lifestyles, a tendency for self-mutilation, and suicide attempts are common, and a sense of emptiness and meaninglessness prevails all along. The clinical presentation may show wide variability depending on the cultural background.

In individuals younger than age 18, these symptoms warrant a diagnosis of identity confusion. The prevalence of borderline personality disorder is in the order of 0.2–4 percent in the general public overall and 15–25 percent among hospitalized psychiatric patients. It is two to three times as common in women as in men. Alcohol and substance abuse and eating disorders are commonly co-diagnosed.

Etiologic explanations vary. Some hypotheses focus on constitutional defects in the brain's various neurotransmitter systems such as the adrenergic, cholinergic, dopaminergic, and serotonergic systems. Other hypotheses examine the association of this disorder with past or present history of head trauma, epilepsy, encephalitis, severe hyperactivity, distractibility, and learning disabilities. From a developmental perspective, arrest in normal development, excessive frustrations in early childhood and constitutional predisposition (weak ego structure prone to regression), disturbed separation-individuation process, early parental loss, traumatic separation from parental figures, and childhood physical-sexual abuse leading to ongoing posttraumatic stress disorder are all considered to be possible contributing factors.

Long-term analytic or reality-oriented supportive psychotherapy is a therapeutic mainstay along with the use of a wide range of pharmacologic agents including antidepressants, antipsychotics, and mood stabilizers for specific symptoms, often used in low dosages.

—Selahattin Şenol

See also Psychiatric Disorders.

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BOURNE, RANDOLPH
(1886–1918)

American literary critic and essayist

Randolph Bourne was born in New Jersey in 1886. Facially disfigured as a result of a "messy birth," he was further impaired by spinal tuberculosis, which developed when he was four years old.

In 1911, while still a student at Columbia, his essay "The Handicapped—By One of Them" was published anonymously in *The Atlantic Monthly.* After graduating from Columbia University in 1913, he began to write for *The New Republic.* His first book, *Youth and Life*—which included a revised version of his essay "The Handicapped"—saw young people as a force for social change and prefigured many ideas about youth culture that would gain currency in the 1960s. His strong opposition to growing militarism and to World War I resulted in the end of his association with *The New Republic.* The crucial essay that marked this break was "The War and the Intellectuals," which appeared in *Seven Arts.* Bourne saw war not as an aberration but as an inherent feature of the modern state.

Following Bourne's death from influenza during the 1918 pandemic, two more volumes of his writing appeared: *Untimely Papers* (1919) and *The History of a Literary Radical and Other Essays* (1920).

—Anne Finger

See also Journalism.

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BOURNEVILLE, DÉSIRÉ MAGLOIRE (1840–1909)

French scientist and activist

Désiré Magloire Bourneville was an influential neurologist and pediatrician who made numerous contributions to the disability field in medical science, intellectual disability, clinical care, rehabilitation, and social policy. He was born in the village of Garancières in Normandy, studied in Paris with Charcot, and became an *interne des hôpitaux* at the Bicêtre, the Salpêtrière, the Hôpital St. Louis, and the Pitié. He served as a surgeon in the Garde Nationale during the Franco-Prussian War. After receiving his doctorate in 1870, he was physician at the pediatric service of the Bicêtre from 1879 to 1905 where he advanced the current understanding of pediatric neurological conditions. In 1873, Bourneville founded the journal *Progres medical* and in 1880 the *Archives de neurology*. Besides his own work, he facilitated publication of the works of the famous French neurologist Jean Martin Charcot (1825–1893). He also met with and was influenced by the work of Maria Montessori.

Bourneville founded the first French school for mentally retarded children and directed Fondation Vallée where he focused his energies on the treatment of mentally retarded children. On Saturdays, he held open house at the Bicêtre, where his disabled charges performed exercises and dances for the staff and public. In 1873, he became a member of parliament and in 1876, a member of the Paris City Council. In these capacities, he advocated for disabled people, created a school for the education of nurses, and championed special wards for sick children.

—Henri-Jacques Stiker

See also Maria Montessori.

BOWEL CONTROL

Controlling the elimination of rectal contents at socially acceptable times and places is called fecal continence. The loss of this control is a major personal and social disability. In some cultures, loss of fecal continence is cause for being ostracized from the community; in U.S. culture, many consider fecal incontinence indicative of a quality of life not worth living. Factors affecting continence include normal function of the entire muscle mechanism, adequate rectal capacity, normal stool consistency, and normal anal sensation.

Synchronized function of all components results in normal control of defecation and includes several elements: The rectum must fill, then sense the contents of the rectum; there must be relaxation or actually un-contraction of the entire sphincter mechanism, and at the same time there is a voluntary increase of intra-abdominal pressure.

Several problems can occur with the synchronized musculature: It may be cut, stretched, dented, diseased, or tired as a result of the aging process.

Cut muscle results from childbirth, surgery for abscess or fistula disease, or controlled muscle incision used to treat anal ulcer or fissure. The muscle may also be stretched or dented from obstetrical injury, extreme sex, surgery, or obstructed defecation (a malfunction of the entire pelvic floor). The mechanism is especially fragile in women, where there is only one small anterior muscular loop, which if injured, results in incontinence. The use of a midline episiotomy during childbirth, a common procedure in the United States, is a major source of injury.

The muscle may be diseased by such processes as inflammatory bowel disease, especially Crohn's disease, collagen or vascular disease, radiation injury, cancer, AIDS, or congenital abnormality. Muscle malfunction is also related to the aging process and is becoming more important with an aging population. Aging can cause overflow incontinence, which is frequently seen in combination with the pelvic floor malfunction of obstructed defecation. Special considerations exist for the surgeon who is treating a patient with Crohn's disease. Usual surgical procedures may not be safe because the future risk of incontinence necessitates preservation of all muscle function. Radiation injury to the muscle also disturbs normal function, now more common as adjuvant radiation therapy is used for various forms of pelvic cancer.

Other sources of incontinence result from disease processes in the neighboring organs, for example, in the large intestine; the small intestine, which may be shortened or diseased; Crohn's disease or ulcerative colitis; radiation injury; or irritable bowel syndrome. Another major source of lost control stems from injured nerves supplying the muscles of continence. Neural injury occurs with trauma as above, or with diabetes, spinal cord injury, multiple sclerosis, or congenital defects.

A process to differentiate causes of incontinence leads to proper treatment. Mechanical defects are sought first, but if absent, a diffuse impairment is sought. Specific diagnostic studies help in the process. The necessary studies include systemic evaluation, digital rectal exam, sigmoidoscopy or colonoscopy, and sometimes a small retention enema, which tests the function of the entire mechanism. Specialized diagnostic procedures include transrectal ultrasound, manometry, nerve function studies, defecography, and psychological studies.

Incontinence has various therapies. The simplest is an attempt to control bowel function, dealing with such problems as constipation and fecal impaction. Next is treating such diseases as Crohn's disease, colitis, radiation injury, or irritable bowel syndrome. If simple measures fail, biofeedback can be used to retrain the muscle and allow relearning of the process of defecation.

Should these simple measures fail, surgical correction becomes a consideration. If it is a straightforward problem, reconstruction of the sphincter mechanism is possible, as in the case of obstetrical injury in healthy women or acute trauma to the muscle itself. The issue becomes more complicated with sphincter reconstruction complicated by previously unsuccessful repairs, an elderly patient, or systemic diseases, as above. In these cases, specific diagnostic procedures are selected, especially to evaluate nerve function, quantity of muscle, and function of the organs of the pelvic floor.

In some cases, surgical repair is not a possibility, as when the nerve is severely damaged, when there is severe scar tissue, or when there is inadequate muscle to allow repair. In these cases, special complex surgery is a final recourse. These include encircling the incontinent muscle, a special repair of the muscle itself, bringing in muscle from elsewhere in the pelvic region, insertion of an artificial mechanical anal sphincter, or construction of a good colostomy. It is important to realize that in desperate cases with complete fecal incontinence, the patients have a de facto colostomy because they have no anal muscle control; these patients are better served with a well-constructed colostomy on the abdominal wall where they can affix an appliance, and live an otherwise normal life.

In summary, to understand bowel control, disability, and their relationship, it is important to know the cause of the disability, to diagnose and treat any systemic disease, to verify the presence of muscle and adequacy of nerve function before contemplating any surgical correction, and to remember that the quality of life of the individual is paramount.

—Ira Kodner

See also Aging; Bladder Control.

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BOWEN, ROBERT WALTER "MIKE"

(1887–1948)

South African lawyer and politician

Robert Walter Bowen, "whom everyone called Mike" (Lord Fraser of Lonsdale 1961: 208), began work as a railway clerk in Natal, South Africa, and served in the militia. He was blinded during war service at Ypres, Belgium, in 1917, after which his life changed gear. He passed through St. Dunstan's in London, studied at Cambridge University, became a barrister in 1920, and practiced in Cape Town. There he did some important legal work for black South Africans. By 1925, he was in the Cape Provincial Assembly, and from 1929 until his death he was a member of the South African Parliament. A skilled Braille user, Bowen worked tirelessly for educational and vocational training for blind people of whatever race. Together with Reverend Arthur Blaxall, Bowen set up the National Council for the Blind, which he chaired from 1929 to 1948. Blaxall (1965) noted Bowen's typical response on hearing of obstacles in starting a first school for blind African children: "Mike Bowen said forthrightly, 'It is a damn shame,' picked up the telephone receiver and dialled a number. That same day we were sitting with the Minister for Education" (p. 34).

—Kumur B. Selim

See also Blind, History of the; Experience of Disability: Sub-Saharan Africa.

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BRAILLE

See Blind, History of the; Blindness and Visual Impairment; Braille, Louis

BRAILLE, LOUIS (1809–1852)

French teacher and organist

Louis Braille was born in Coupvray (Seine et Marne) in 1809. Blinded in childhood, he created a writing system for the blind consisting of raised (embossed) dots. His system was an immediate success and today bears the name of the Braille alphabet.

At the age of three, Louis Braille was injured, and he progressively lost his sight. He was totally blind by the age of five. In 1819, he enrolled as a pupil at the Royal Institute for Young Blind in Paris, where he became a teacher in 1828. He modified a raised-dot system of code invented by Charles Barbier, and it became a new means of writing that permitted his pupils to take notes during his lessons. His system makes silent reading possible for people without sight and facilitates written communication with the sighted. It is based on an alphabet consisting simply of two vertical rows of three raised dots. Reading is effected by passing the fingertips over the raised dots. To write manually, heavy paper and a punch are used.

In 1854, two years after Braille's death in Paris, his system was officially recognized in France. In 1878, the Universal Congress for the Improvement of the Lot of the Blind came out in favor of using the Braille system in all countries. There were problems with the lack of uniformization and, in part to resolve this, the World Braille Council was officially created by UNESCO in 1952. The remains of Louis Braille, a historical figure in the world of the blind, were moved to the Panthéon in Paris at that time.

—*Jean-François Ravaud*

See also Blind, History of the; History of Disability: Early Modern West.

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BRAZIL

See Experience of Disability: Brazil

BREAST CANCER

One in eight American women will be diagnosed with breast cancer during her lifetime, and in 2001, more than 40,000 women died of the disease (men are also occasionally diagnosed with breast cancer, and make up about 1 percent of all cases). Most physicians and cancer advice books urge breast cancer patients to think of the disease as a chronic, rather than a terminal, condition. For this reason, one can understand breast cancer in many of the same ways one understands disability—as a state of physical difference that may require some accommodations in order to function in particular physical environments. The connections between breast cancer and disability go deeper, however, especially when one considers some important moments in the history of cancer activism and disability rights in the United States: the public acknowledgment of breast cancer as something that is not shameful, the emergence of organizations of patients dedicated to activism on behalf of other patients, the appearance of art and literature specifically dealing with the disease, and the specific link made between breast cancer and the Americans with Disability Act in *Alabama v. Garrett* in 2001.

Breast cancer diagnoses have been rising since 1900. There is much debate over whether the increased incidence of the disease is due to better detection methods (mammography), longer lifespans, or increased toxicity in the environment and food supply. Breast cancer is the most common cancer among American women (excluding skin cancers). It is second only to lung cancer as the leading cause of cancer deaths among women, but even though diagnosis rates have been steadily rising, mortality has declined throughout the twentieth century and into the twenty-first century, underscoring the status of the disease as a chronic condition.

Even though many famous women writers in the twentieth century were diagnosed with (and often died of) breast cancer—most notably reform writer Charlotte Perkins Gilman and environmentalist Rachel Carson—it was not until 1974 that breast cancer became a public topic of conversation. During that year, the year after Section 504 of the Rehabilitation Act was passed (though not signed), both First Lady Betty Ford and Rose Kushner, an investigative reporter, were diagnosed. Ford broke the public silence about breast cancer by acknowledging her disease on national television. Thereafter, she worked to increase public awareness of the disease. Kushner began a campaign to work on behalf of patients' rights that did not end until her own death from breast cancer. Starting with her book in 1975, *Breast Cancer: A Personal History and Investigative Report,* and ending with her advocacy of a congressional bill to provide Medicare coverage for screening mammograms, Kushner argued for the rights of patients to have a say in their treatment, to be allowed options and choices when it came to surgery, and to fund breast cancer research.

Another important figure in the history of breast cancer advocacy is Audre Lorde, whose *Cancer Journals* serves as a touchstone for disability studies. In addition to recording some of the journals she wrote during her treatment and recovery, the book includes essays about the silence that surrounded breast cancer and mastectomy in the 1970s, and about the falseness of prosthesis and reconstructive surgery. Though Lorde does not mention disability explicitly, much of the book resonates with the disability theory and activism of that era. She argues that prosthesis is a means of silencing bodily experience, a way of hiding women with breast cancer from each other, and of keeping them from being able to share their sense of rage and the knowledge they have gained from the experience. She argues further that prosthesis hides breast cancer from public awareness, allowing people to ignore its politics. Lorde claims that prosthesis works as a lie, a way to avoid the reality of amputation, and that the emphasis on "looking normal" after mastectomy works to keep women within a stereotypical femininity, treating their bodies as aesthetic objects. It is perhaps this last argument, against the falsity of "the normal," that connects Lorde most clearly to contemporary disability studies. Lorde lays the groundwork for a theory of bodies that emphasizes diversity and difference in both appearance and experience. Furthermore, she argues for a politicized understanding of illness that likewise connects to disability studies, urging an awareness of environmental factors that cause cancer, and political coalitions to work against pollution and carcinogenic working conditions.

Following Ford's, Kushner's, and Lorde's leads, many women who had lived through breast cancer or who had lost close friends and relatives to the disease undertook conscious campaigns of activism in the late 1970s and early 1980s. In 1978, Mimi Kaplan and Ann Marcou founded the Y-Me organization to provide support to breast cancer patients; in 1982, Nancy Goodman Brinker founded the Susan G. Komen Breast Cancer Foundation to raise funds to study and eradicate the disease. Since then, more than 60 other nonprofit organizations have been formed around the disease, to promote research, environmental health, patient support and information, and financial assistance for poor patients. By the early twenty-first century, breast cancer may well be the most publicized disease in the United States, with innumerable products marked with pink ribbons, and with fund-raising events modeled after the Komen Foundation's "Race for the Cure"—"Shop for the Cure," "Plant for the Cure," "Art for the Cure"—becoming ubiquitous.

Breast cancer has also become a frequent subject in the arts and literature. Since the appearance of Deena Metzger's 1988 poster, "I Am No Longer Afraid" (also called "The Tree" after her book of that name), and Matuschka's self-portrait of her postmastectomy body on the cover of 1993 issue of the *New York Times*

Magazine, artists have not shied away from representing bodies affected by breast cancer. Often this art joins with activism, as in the collection *Art.Rage.Us.* Writers have also followed Audre Lorde's lead in resisting silence about breast cancer, often writing about it directly, as in autobiographies such as Christina Middlebrook's 1996 *Seeing the Crab: A Memoir of Dying before I Do,* collections of stories, poetry, and essays, and Hilda Raz's *Living on the Margins* from 1999, or documentaries such as Gerry Rogers's *My Left Breast,* released in 2000. Breast cancer may also play an indirect part in fiction, as it does in Margaret Atwood's *Bodily Harm* or Jane Smiley's *Thousand Acres.*

During the 2000 term of the U.S. Supreme Court, breast cancer and disability activism became firmly linked, when the Court ruled that the Americans with Disabilities Act (ADA) does not give anyone the right to sue a state. Patricia Garrett was a nurse at the University of Alabama hospital and was asked to take a lesser position because she was in treatment for breast cancer, despite having been acknowledged to be able to perform her job adequately. On the face of it, *Alabama v. Garrett* was decided as a states' rights case, the Court arguing that Congress did not have the right to pass a law that would award money damages to a citizen from a state unless it had clear evidence that the states had historically violated their citizens' constitutional rights. The language of the decision and concurrence, however, suggest to some that the decision has broader ramifications for people who would bring suit under the ADA, since Justice William H. Rehnquist argues that the ADA does not provide for "special accommodation" and since Justices Anthony Kennedy and Sandra Day O'Connor argue against using the law to redress discrimination by the states and suggest that it may be instinct to recoil from people who are different from ourselves. Despite the work of breast cancer and disability activists, there is still much to be done to challenge public attitudes about chronic disease and difference.

—*Diane Price Herndl*

See also Autobiography; Cancer.

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▣ BRIDGMAN, LAURA DEWEY
(1829–1889)
American deaf-blind pioneer

Laura Dewey Bridgman was the first deaf-blind person to receive a formal education. Bridgman achieved worldwide notice for her accomplishments. Charles Dickens visited her one time and then wrote a chapter about her in *American Notes* (1842).

Bridgman was born in Hanover, New Hampshire. She contracted scarlet fever at two years of age, which left her without vision, hearing, and sense of smell or taste. Her only mode of communication with the world around her was through her sense of touch. By touching her mother as she went about the daily household chores, Bridgman learned how to clean, sew, and knit. When she was seven years old, Dr. Samuel Gridley Howe took Bridgman to live at the Massachusetts Asylum for the Blind (later renamed Perkins Institute, and currently known as the Perkins School for the Blind) in Boston. Like other blind children, Bridgman was made to wear a green scarf around her head to cover her eyes. Through a progressive series of exercises and grooved paper, she learned the manual alphabet used by deaf-blind people. When she learned something new or repeated a lesson correctly, her teacher patted her on top of her head. If she answered incorrectly, the teacher struck her on her left hand.

Bridgman lived out the rest of her life at the institution, and died on May 24, 1889. Six of her letters, photos of Bridgman, and a piece of lace she made are preserved at the Leonard H. Axe Library, located at Pittsburgh State University, in Pennsylvania.

Many educational publications have been written about Bridgman's life. Current deaf-blind education methods can be traced back to those used to teach Bridgman communication and daily living skills.

—Beth Omansky

See also Blind, History of the; Blindness and Visual Impairment.

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BRIGHAM, AMARIAH (1798–1849)

American institution administrator

Amariah Brigham was one of the leaders of the asylum movement in mid-nineteenth-century America who sponsored the creation and public support of specialized, congregate insane asylums led by experts in the emerging profession of psychiatry. His approach characterized the powerful optimism of these early asylum superintendents. As superintendent of the Utica State Asylum in New York from 1842 until his death in 1849, Brigham was also one of the 13 founders (along with Thomas Kirkbride, Isaac Ray, Pliny Earle, and others) of what is now known as the American Psychiatric Association. Brigham himself began publication of the *American Journal of Insanity* (printed with the help of inmates at Brigham's asylum in Utica), one of the first English-language journals devoted exclusively to mental illness. The scientific optimism of the era is illustrated in this passage from Brigham's introductory essay to the initial issue of the journal: "Insanity is but a disease of that organism [i.e., the human brain], and when so regarded, it will often be prevented, and generally cured by the early adoption of proper methods of treatment."

—Philip M. Ferguson

See also Mental Health.

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BROCA, PAUL (1824–1880)

French surgeon and anthropologist

Paul Broca was a French surgeon, pathologist, anatomist, and anthropologist. Today, he is best remembered for localizing speech in the frontal lobes, recognizing cerebral dominance, performing the first surgery based on localization, studying race and intelligence, and investigating ancient trepanned (opened) skulls.

In 1859, Broca founded the world's first anthropological society, the Société d'Anthropologie. It was here that scientists discussed human origins, intelligence, and the functional organization of the brain. In 1861, he used the case of Leborgne to argue for localization of fluent speech in the anterior lobes of the brain (Broca's area). A few years later, he recognized that the left hemisphere is more important than the right for speech (cerebral dominance).

Broca hypothesized that the right hemisphere may be able to take over for a damaged left hemisphere, particularly if brain damage occurs early in life. He also recommended speech therapy for aphasic patients. In 1868, Broca conducted the first successful brain surgery based solely on functional localization.

In the late 1860s and 1870s, Broca concerned himself with ancient trepanned skulls. One of his theories was that cranial openings were made during the New Stone Age to treat childhood seizure disorders. At the time of his death in 1880, he had more than 500 publications.

—Stanley Finger

See also Aphasia; Speech and Language Pathology; Traumatic Brain Injury.

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BROWNING, CHARLES ALBERT "TOD" (1880–1962)

American filmmaker

The 1930s Hollywood horror film director Charles Albert "Tod" Browning was born in Louisville, Kentucky. Best known for *Dracula* (1931) and *Freaks* (1932), Browning's career was clearly influenced by a childhood interest in carnival life. His experience acting in nickelodeon pieces and D. W. Griffith films is often overshadowed by his later directorial success. His early work in silent cinema, especially directing the esteemed character actor Lon Chaney, prepared him for his most famous portrayal of people with disabilities in the most controversial Hollywood feature film to depict people with disabilities playing themselves. In addition to his time spent traveling with circus performers, the year Browning spent hospitalized after a serious car accident (1915) may have affected his characterization of people with disabilities in *Freaks.* During his recovery, he penned film scripts leading to his feature film debut, *Jim Bludso* (1917).

Throughout his career, Browning challenged acting norms by having actors play Harlequin puppets (1916), by using double-exposure techniques so that Mabel Taliaferro could play opposite herself (1917), by casting Lon Chaney as more than one principal character in the same film (1925), and by casting circus sideshow artists in a cinematic treatment of their world (1932). Browning was nicknamed "Hollywood's Master of the Macabre" and "The Wizard of Odd."

—*Sally Chivers*

See also Film; Freak Show.

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BUCK (EAGLE DETAMORE), CARRIE (1906–1983)

American sterilization plaintiff

Born to Emma Buck, an unmarried and institutionalized woman, Carrie Buck was raised by J. T. and Alice Dobbs in Charlottesville, Virginia. At age 17, she was assaulted by a nephew of the Dobbses and became pregnant. Mr. Dobbs then had her committed to the Virginia Colony for Epileptics and Feebleminded in Lynchburg. There, in 1927, she was sterilized against her will, in compliance with the Virginia Statute for Eugenical Sterilization, upheld by the U.S. Supreme Court earlier that year in the *Buck v. Bell* decision. Carrie Buck married her first husband William Eagle in 1930 (he died in 1966), and during her middle years worked as a housekeeper and agricultural laborer. Buck's only daughter, Vivian, was raised by the Dobbs family until she died of an acute illness in 1932. Buck's younger sister, Doris Buck Figgins, was also sterilized as a teenager. Carrie Buck Detamore died as a result of poverty-related exposure and malnutrition. Her second husband, Charles Detamore, survived her. In 2002, a roadside historical marker was erected in Charlottesville, marking the 75th anniversary of the *Buck v. Bell* decision and telling Carrie Buck's story.

—Penny L. Richards

See also Sterilization.

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BUCK, PEARL S. (1892–1973)

American author

Pearl S. Buck was an American writer and Nobel Prize winner for literature in 1938. Buck described her own experience as the mother of a child with mental retardation in the widely read "The Child Who Never Grew," an essay for *Ladies' Home Journal* in 1950, which was later expanded to book length and translated into many languages. Along with other mid- twentieth-century parent narratives, it increased visibility for middle-class families of children with developmental disabilities while assuring parents that institutionalization was the best possible solution. (It is still in print today.)

Buck also wrote themes of family and disability into her fiction. Her best-known novel, *The Good Earth,* published in 1931, concerns a Chinese family in which the eldest daughter has developmental disabilities and cannot speak. Other works share this concern for the care of children, especially girls, with disabilities, among them, *The Mother* (1934). Buck's literary success allowed her to fund research that eventually discovered the metabolic cause of her daughter's developmental disability—phenylketonuria—which, in turn, led to universal newborn PKU testing and food labeling in the United States. Buck's daughter, Carol (1921–1992), lived at Vineland Training School in New Jersey for most of her life.

—Penny L. Richards

See also Developmental Disabilities.

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BULWER, JOHN (1606–1656)

English physician and author

Influenced by Francis Bacon, who criticized Aristotle for his inattention to gestures and the role of the body in rhetorical delivery, and also apparently influenced by contact with his deaf daughter (named Chirolea) and his work as an early deaf educator, John Bulwer wrote three late-Renaissance texts that called on his knowledge of deafness and sign languages: *Chirologia, or, The naturall language of the hand* (1644); *Philocopus, or the Deaf and Dumbe Mans Friend* (1648); and the unfinished *Pathomyotamia, or, A dissection of the significative muscles of the affections of the minde* (1649).

Chirologia is an important text in the history of elocution, a movement in rhetorical theory and practice that focuses on the effects of gestures, expressions, and body language on persuasion. *Philocopus* explores the "philosophical verity" of lipreading, which, according to the book's frontispiece, is "that subtle art, which may enable one with an observant eye, to hear what any man speaks by the moving of his lips." *Phathomyotamia* was intended to further the work of *Chirologia* and to do for the head—and its affective powers of movement—what Bulwer had already outlined for "the naturall language of the hand."

—Brenda Jo Brueggemann

See also Deaf, History of the; Sign Language.

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BUNKER, CHANG AND ENG

(1811–1874)

American (Thai-born) performers

Conjoined twins Chang and Eng Bunker were nineteenth-century freak show performers who were known as the "Original Siamese Twins." They were born in Thailand, which was then known as Siam. For much of their childhood, they worked as duck egg merchants until they met Robert Hunter, a British merchant based in Bangkok. In 1829, Hunter and his associate, Abel Coffin, secured permission from their mother and Siamese King Rama III to take Chang and Eng to the United States to undertake a touring career. They became naturalized U.S. citizens, adopting the surname Bunker.

The twins took a break from performing in 1843. Chang married Adelaide Yates, and Eng married Sarah Yates in a double wedding. They settled in Wilkes County, North Carolina, bought a plantation with slaves, and had 22 children between the two of them. The end of the Civil War brought Chang and Eng out of their temporary retirement, and they reentered the touring circuit. Over the course of their career, they traveled throughout much of the United States and Europe, along with engagements in Canada and Cuba. They died in 1874 with Chang expiring first and Eng following a few hours later.

—*Cynthia Wu*

See also Freak Show.

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BURNOUT

See Stress

BURNS

Burns injuries are traumatic, functionally impairing, excruciatingly painful, and cosmetically disfiguring. The key to minimizing disability after injury is rapid wound closure and early aggressive rehabilitation. Burn severity and outcome are directly related to the depth and percent total body surface area burned.

Burn depth is measured by degree. First degree is a superficial burn involving the epidermis. Second degree is partial thickness involving part of the dermis. Third degree is a full-thickness burn involving the epidermis and all of the dermis. A fourth-degree burn extends to muscle, tendon, or bone. Full-thickness burns need to be grafted with skin taken from another part of the body. With this depth of burn, hair follicles, sweat and sebaceous glands, and nerve endings are destroyed and do not regenerate. Therefore, areas of full-thickness burn do not have hair or normal sensation and do not perspire or self-lubricate.

A major disability after burns is scarring. Areas of burn can be lighter or darker than normal skin. Scars can also become thick and dense (hypertrophic). Although pigmentation may improve and thick scars may soften, it is important to recognize that most burn scars are permanent. Pain in the scars and itching may persist for years. Custom pressure garments or silicone patches may help flatten scars and decrease pain and itching.

The key to maximizing outcome and minimizing disability after burn injury starts with aggressive prevention measures. Contractures, which limit joint range of motion, are a common complication following major burn injury, affecting 30–50 percent of patients. Treatment focuses on stretching and proper positioning. If full range of motion cannot be obtained, the patient can be treated with splinting or serial casting. If a scar band is unresponsive to conservative treatment, surgical release will be necessary.

Neuropathy, a nerve injury, with associated weakness occurs in 10–15 percent of patients after major burn injury and is more common with an electrical etiology. Amputations are necessary following burns that involve muscle and bone. Careful prosthetic fitting is essential to avoid skin breakdown over the stump. A silicone sleeve can be used to maintain moisture and decrease shear forces across the residual limb.

Psychological distress following burn injury is common. Severe pain can escalate anxiety. Sleep disturbance, itching, and nightmares may add to distress. Posttraumatic stress disorder is rare but can be seen particularly in those patients injured by electricity.

Most burn patients perceive themselves as having a good quality of life. Return to work usually occurs in 14 to 17 weeks. Ninety percent are back to work at 24 months, but only 37 percent return to the same job with the same employer.

Burn care has changed dramatically in the past century with a significant improvement in overall survival. Patients with much larger burns now are surviving the acute care treatment but are often left with significant long-term functional impairment including decreased hand function, amputations, heat intolerance, cosmetic changes, pain, itching, and psychological difficulties. These can be limited by aggressive early comprehensive care.

—Karen J. Kowalske and
Phala Helm

See also Amputation; Neuropathy; Pain.

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BYRON, LORD (GEORGE GORDON) (1788–1824)

English poet

The celebrated English Romantic poet Lord Byron enjoyed substantial renown during this lifetime. He became a cult personality of sorts and often found himself condemned for questionable morality by his peers. Diagnosed with "clubfoot" at birth, the label seems to cloud rather than reveal much useful information about the nature of his impairment. For instance, whereas his mother referred to the affected foot as his right one, his prosthetics manufacturer of the time claimed to have constructed a raised shoe for his left foot. Furthermore, his close military colleague Edward Trelawny, who fought with Byron in the war for Greek independence, claimed that both feet exhibited the effects of spasticity. Most contemporary researchers now suggest that Byron had Little's disease (an early diagnostic category for cerebral palsy). Many friends and relatives have claimed that Byron proved particularly sensitive about his disability. He would act defiant and melancholy when others discussed his lameness.

These descriptions of his attitude toward his disability bear much in common with the extreme sensitivities of the "Byronic hero," a characterization method he created in his poetry and fiction. Yet one might argue that such parallels are merely the product of a conflation of author with character; or, it might be equally insightful to identify something of the Byronic sentiment as akin to a defiant disability demeanor toward the world. In either case, Byron only wrote about his disability explicitly in his final, unfinished work published posthumously as *The Deformed Transformed.* In this play, the hunchbacked protagonist, Arnold, despairs about his disability status as a socially maligned condition and considers suicide. A "stranger" appears just as he is about to commit this desperate act and offers him a deal of Faustian proportions: Trade his disabled body for a more able-bodied prototype from history. Arnold accepts the offer immediately. After rejecting a number of possibilities on the basis of superficial defects, he chooses the physically idealized body of Achilles from Greek mythology. Ironically, the stranger dons Arnold's former disabled body to demonstrate that one can navigate the world successfully despite a visible disability. In fact, Byron's ironic commentary in the drama turns on the idea that once Arnold adopts an "unblemished" masculine exterior, he runs off to fight a war and puts his new, able body immediately at risk. This text further contextualizes Byron as one who did not despair over the presence of impairment as much as he condemned the false superiority that sometimes attends able-bodiedness itself.

—Sharon L. Snyder

See also Poetry.

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C

CAMPANELLA, ROY

(1921–1993)

American baseball player

Roy Campanella was one of the best offensive and defensive catchers in professional baseball in North America. After seven years in the Negro Leagues with the Baltimore Elite Giants (1937–1941, 1944–1945) and two in a Mexican league (1942–1943), Campanella joined the Brooklyn Dodgers not long after Jackie Robinson. One of the first African Americans in the major leagues, he was a leader by successful example who helped to integrate baseball. In his 10 seasons with the Dodgers (1948–1957), Campanella made the All-Star team eight times and won three National League Most Valuable Player (MVP) awards. Campanella helped the Dodgers win five pennants and the 1955 World Series. Although his Major League career was plagued by injuries, he batted .276 with 242 home runs and 856 runs batted in. In his 1953 MVP season, he led the league with 142 RBIs, batted .312, and set a record for catchers with 41 home runs.

On January 28, 1958, Campanella's car skidded on a patch of ice and crashed into a telephone pole. He broke his back between the fifth and sixth vertebrae and was paralyzed from the chest down. Through physical therapy Roy learned to move his arms and hands, feed himself, and use a wheelchair. On May 7, 1959, "Roy Campanella Night" was held at the Los Angles Coliseum with record attendance of 93,103 fans. In 1964, he began working as a catching instructor for the Dodgers and was inducted into the Baseball Hall of Fame in 1969. In 1978, he joined the Dodgers Community Service team and was active in providing support for youths with disabilities. He worked and spoke for the Dodgers and on disability issues until he died of a heart attack on June 26, 1993. The Roy and Roxie Campanella Physical Therapy Scholarship Foundation provides support to physical therapy students whose cultural competence and ethics aid patient well-being.

—Daniel J. Keys, Christopher B. Keys, and Robert I. Westerholm

See also Paralysis; Sports and Disability.

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CANADA

See Disability Law: Canada

▣ CANADIAN CENTRE ON DISABILITY STUDIES

The Canadian Centre on Disability Studies (CCDS) is a nonprofit, consumer-directed, university-affiliated center dedicated to research, education, and information dissemination on disability issues. Using a participatory approach to research, CCDS promotes full and equal participation of people with disabilities in all aspects of society. Members of the disability community are key participants in directing CCDS activities: 51 percent of the CCDS Board of Directors are designated persons with disabilities.

Housed in Winnipeg, CCDS works in concert with academics, government, and the disability community. CCDS has participated in the development of an interdisciplinary graduate program in disability studies at the University of Manitoba and is currently working in partnership with the University of Winnipeg to develop an undergraduate interdisciplinary degree in disability studies.

Research by CCDS is known nationally and internationally, with projects in Russia, Mexico, Ukraine, and Thailand. In 2002, the Canadian International Development Bank announced the approval of the Canada-Russia Disability Program, a four-year, $4 million project, focusing on education, disability studies, social work practice, social policy, and information dissemination. CCDS is involved in a variety of innovative projects such as the Arts Ability Project and the Pan-Canadian Leadership Project—Creating Opportunity and Sharing Knowledge: Leadership Development in the Canadian Disability Movement, which takes a social rather than medical approach to integrative programming.

See also Disability Studies; Research.

—Canadian Centre on Disability Studies

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▣ CANCER

Some nine million people living in the United States today have a history of cancer. These people, of course, do not have a universal disability, though cancer is clearly associated with a range of physical, psychological, and other disabilities. When all cancers are combined, 62 percent of the people diagnosed with cancer in the United States will still be alive five years after the initial diagnosis. In 1996, the National Cancer Institute established the Office of Cancer Survivorship "in recognition of the large number of individuals now surviving cancer for long periods of time and their unique and poorly understood needs."

The concepts of cancer-related disability and rehabilitation developed in the 1970s, as cancer survival rates rose and research studies started to examine the psychosocial and economic ramifications of cancer diagnosis and treatment. Issues of disability linked to cancer, however, are not always openly discussed, and this silence may have contributed to the relative dearth of knowledge about the health and disability of cancer survivors. Large cancer organizations, both now and historically, have tended to downplay discussion of disability to focus on hopeful, positive messages for those diagnosed with the disease. Many of the now ubiquitous cancer fund-raising feats of physical endurance, from walks to runs to mountain climbs, are done "for the cure" and display celebratory, athletic images of winning cancer survivors. An emphasis on survivorship and returning to normality can overshadow those with long-term disabilities.

Physical disability and rehabilitation needs vary greatly with the type of cancer, the choice of treatment, and the extent to which normal functioning is affected. Cancer resulting in loss of a limb has long been recognized as an obvious disability. But a person with colon cancer may need a colostomy, a person with prostate cancer may experience sexual dysfunction, or a person with head or neck cancer may lose the ability to speak. Cancer treatments, including surgery, chemotherapy, and radiation, are often debilitating and difficult, with some treatments themselves resulting in long-term disabilities. Physical, emotional, psychological, sexual, and financial problems can persist for years. On a more practical note, cancer survivors may have difficulties obtaining health and life insurance coverage or experience employment discrimination.

CANCER SURVIVORS AND DISABILITY

National Cancer Survivors Day was founded officially in 1988 with a goal of demonstrating "that a diagnosis of cancer is not an automatic death sentence." Since then, the term *cancer survivor* has permeated the national vocabulary. Typically, people who have had cancer and are now free of disease are described in popular literature not as passive cancer sufferers or victims, or even as neutral "former cancer patients," but as active cancer survivors. *Coping,* a consumer magazine widely available in waiting rooms of oncology treatment centers, for example, instructs its writers to be "informal, upbeat and positive (assume that everyone diagnosed with cancer has a chance to beat the odds)," avoiding "grim statistics" and "lengthy treatment descriptions." Writers are also advised to avoid the words *death*, *dying*, *suffering*, *victim*, and *patient*, substituting more positive words such as *coping* and *survivor*. As the website notes, "*Coping* challenges readers to develop a positive, proactive attitude for a better quality of life by becoming cancer survivors, rather than remaining patients and victims." This is not the language of disability awareness.

It does not matter when the cancer diagnosis was made, or how long the cancer has been in remission, or whether any physical disability resulted; the patient is considered a cancer survivor until the end of his or her life. This lifelong association with disease and the fear of recurrence and metastasis may give cancer survivors a different psychological outlook than survivors of many other disability-causing conditions. Patients can be cured—go into remission and live cancer-free lives—but are always called survivors. Unlike many other conditions that cause disability, cancer survivors may not have obvious physical signs of their history of cancer. They do, however, continue to have higher rates of recurrence and delayed sequelae of treatment.

McNeil estimated in a 1999 study (McNeil and Binette 2001) that 792,000 adults living in the United States have been disabled by cancer, making it the 13th leading cause of disability in this country. To better understand the nature of cancer survivors' disabilities, a 2003 study used data from more than 95,000 Americans enrolled in the National Health Interview Study. The study found that cancer survivors (as compared to people without a history of cancer) were significantly more likely to be in poor or fair health, to have a psychological disability, to have physical limitations, and to be unable to work. The researchers concluded that chance of poor health and disability are doubled by a history of cancer. In addition, cancer survivors had significantly lower self-reported measures of physical functioning, with nearly one in six (16.8 percent) of the survivors of working age saying they were unable to work due to a physical, mental, or emotional problem.

BREAST CANCER

Breast cancer is the most common cancer diagnosis in women in the United States (excluding skin cancer) and is the second leading cause of cancer death among U.S. women. For many patients, sobering mortality and morbidity statistics combine with concerns about sexuality, mothering, or body image. Physical limitations after treatment of breast cancer can be significant, as arm mobility and lifting ability may be affected. If a woman has the lymph nodes under the arm surgically removed or radiated, lymphedema, a sometimes severe swelling of the arm caused by a buildup of lymph fluid in tissues, can result. The affected arm may swell significantly, and it will need protection from infection, cuts, sunburn, and trauma. In addition, a 2003 study by Hewitt, Rowland, and Yancik comparing long-term breast cancer survivors to women with no history of cancer found that the cancer survivors reported significantly worse sexual functioning, using indices ranging from a lack of sexual interest to an inability to relax and enjoy sex, to difficulty becoming aroused or achieving orgasm.

Historical shifts in the surgical treatment of breast cancer and the attention to emotional and psychological effects of the disease illuminate the increasing awareness of disability concerns in breast cancer. Operations that would now be considered unnecessarily disfiguring and needlessly aggressive in removing muscles and lymphoid tissue were the standard of care for decades. In 1882, William Halsted, a professor of surgery at Johns Hopkins University, developed an operation for breast cancer that removed not only breast tissue and lymph nodes under the arm but also chest wall muscles. Eighty years later, through the 1960s, most American breast cancer patients were still treated with Halsted's radical mastectomy. This operation, however, caused considerable disfigurement and disability. Removing the muscles resulted in a deformed chest wall and limitations in arm motion, and the aggressive operation sometimes resulted in long-standing pain at the site of operation and an increased likelihood of lymphedema. But these disabling effects were considered less important in the calculus of survival, and concern over what came after surgery was downplayed.

Some surgeons turned to even more aggressive "superradical" surgeries in the years after World War II, trying to halt future spread of the disease by removing more and more tissue. In the 1960s, for example, George Pack, a surgeon at Memorial Sloan-Kettering Hospital in New York, sometimes performed interscapulothoracic amputations, in which he, in effect, removed a quarter of the body, taking the collarbone, scapula, and arm along with the affected breast. Other surgical procedures targeted additional lymph nodes that required rib removal and splitting of the sternum. In this manner, some surgeons caused permanent disability in their breast cancer patients. Ironically, this disfigurement was for naught. Studies eventually showed that superradical operations did not effect significant improvements in lifespan.

During these years, cancer was a diagnosis to be concealed. Stigma surrounding the disease was very high, and women typically accepted physicians' treatment plans without question. But after the mid-1970s, breast cancer entered the national dialogue, fueled in part by national figures, such as Shirley Temple Black and Betty Ford, who disclosed their own diagnoses. Some feminists saw the treatment of breast cancer as a prime example of problems within the male-dominated, authoritarian medical system. They called attention to the disability that resulted from radical mastectomies and the lack of research testing the efficacy of such aggressive operations. A modified radical mastectomy, which removed the breast but left one or both chest muscles intact, had been developed in the 1950s, and some women started demanding this operation with a goal of reducing postoperation disability. Today, patients very rarely undergo radical mastectomies, and they often have partial mastectomies (lumpectomies), which remove only a small area of tissue around the tumor, accompanied by radiation therapy and sometimes chemotherapy or hormonal therapy. While a significant advance over radical surgery, these adjuvant treatments can also contribute to disabilities and have their own short- and long-term side effects, such as an increased risk of other cancers.

PATIENT-CENTERED REHABILITATION: REACH TO RECOVERY

Individual patients played a large role in changing the system and bringing emotional and psychological issues into the medical realm. After undergoing a radical mastectomy in New York in 1952, Terese Lasser became frustrated when she received no answers to her questions: How should she obtain a prosthesis, explain her breast cancer diagnosis to her children, or return to sexual activity with her husband? As Lasser later wrote, "When told that my right breast had been removed, I wanted to shrivel up and die. How could I face life, a scarred woman? . . . How could such a life be worth living?" She worried that her husband would be repelled by her or would only feel pity for her, asking, "Was it possible for a man to desire a woman who wasn't whole?"

In time, Lasser's concerns motivated her to begin Reach to Recovery. In this program, volunteers without medical expertise who had previously undergone radical mastectomies visited and provided emotional support to hospitalized women who had just had the operation. These volunteers were encouraged to stay upbeat and positive and to dress in attractive clothing that emphasized the bustline to demonstrate that women could return to their "normal lives." The Reach volunteers gave the newer breast cancer patients temporary prosthetics, answered their personal questions, offered a "Letter to Husbands," and served as a source of information outside the medical establishment. The name of the organization came from the reaching arm exercises used to improve recovery.

Lasser had established 300 chapters of Reach to Recovery by the time the American Cancer Society took control of the program in 1969. Within five years, half of all women having mastectomies in the United States received a visit from a Reach volunteer. Today, Reach for Recovery continues its work under the auspices of the American Cancer Society with the slogan "No one should have to face breast cancer alone." The program emphasizes that its volunteers "offer understanding, support, and hope because they themselves have survived breast cancer and gone on to live normal, productive lives." Today, some 87,000 women in 44 countries are visited by 16,000 Reach to Recovery volunteers each year. In recruiting volunteers, the program asks, "Are you a breast cancer survivor who has overcome cancer to regain a well adjusted and emotionally stable everyday life?"

Reach to Recovery was one of the first programs to focus on what came after a cancer operation, using a particular psychological slant to enhance the physical recovery. Its emphasis on returning women to "normal" life, with an emphasis on continued attractiveness, was a theme that would continue in later programs. Currently, the American Cancer Society sponsors Look Good . . . Feel Better for women with all kinds of cancer. As noted on its website, the program is a "community-based, free, national service that teaches female cancer patients beauty techniques to help restore their appearance and self-image during chemotherapy and radiation treatments." This emphasis on normality and attractiveness, of course, also downplays disability awareness.

Until the 1970s, such a high percentage of breast cancers quickly killed women that reconstruction was not a priority. During that decade, however, surgery became more commonplace, and today, most women who undergo mastectomies choose reconstructive surgery.

EMPLOYMENT AND DISCRIMINATION ISSUES

Our understanding of how a history of cancer affects workers remains incomplete. While the great majority of cancer survivors who were employed before their diagnoses return to work, they may find it difficult to obtain or change health insurance and therefore may find themselves unable to switch jobs.

While the Americans with Disabilities Act of 1990 (ADA) does not mention cancer explicitly, the act has been used to protect cancer survivors from discrimination in the workplace. Each year, individuals with cancer or a history of cancer bring approximately 2 to 3 percent of the complaints brought under the ADA.

The Rehabilitation Act of 1973, which covers federal employees, specifically mentions cancer. It also discusses the "perception of disability," an important topic for many cancer survivors. Even if employees with a history of cancer have no physical or emotional disability from the disease, the act recognized that employers could still discriminate against them based on the perception of disability.

In 2002, cancer accounted for 4.2 percent of the total lost workdays in the United States, with an incidence of 35 days per 100 workers.

FUTURE

Today, surgery, chemotherapy, and radiation therapy remain the main treatment options for cancer. Some breast cancer researchers have turned to genetic studies to help discover which women are more likely to respond to specific types of chemotherapy, and to modify treatments accordingly. The aggressive nature of treating breast cancer has been tempered by some measured concern over the long-term physical and psychological effects of treatment. Also, the treatments are now all less toxic.

Much is still unknown about the biology of cancer. Early detection has long been touted as the key to improving cancer outcomes, and Americans in recent years have become more willing to discuss prostate cancer and colon cancer and to undergo various cancer screening tests. When breast cancer is detected while still localized to the breast itself, 97 percent of patients will be alive five years later. If the cancer is found at the regional stage, before further metastasis, the five-year survival rate is 79 percent. Today, in part due to screening mammography, 9 out of 10 breast cancers are detected at one of these stages.

Yet early detection, while potentially limiting the amount of aggressive treatment, does not eliminate it altogether. Indeed, we should not lose sight of the fact that lumpectomies or less toxic radiotherapy and chemotherapy still cause disability. And so, from the psychological standpoint, does any diagnosis of cancer.

—Allison Arwady and Barron H. Lerner

See also Breast Cancer.

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CANGUILHEM, GEORGES

(1904–1995)

French philosopher and physician

Trained as a philosopher (at the École Normale Supérieure, 1927) and medical doctor (1943), Georges Canguilhem devoted himself to medical practice and to the life sciences. His philosophical work was as an epistemologist. He reexamined notions of the norm, normality, and normativity.

According to Canguilhem, the normal is always secondary in relation to the exception. Normality is relative, since the norm is a statistical average. As for the normativity of a human being, it rests in the capacity to create norms that are otherwise without a common measure among living creatures and are organized in a relationship of force that fully informs the individual human being. Health is the risk recognized and accepted by the individual to go beyond personal limits to open a perspective on new horizons, since the threat of death, which is the true antithesis of health, constitutes "the limitation from without, the negation of the living by the non-living" (Canguilhem 1962:31). Disability is a limitation from within the living, or rather "an order other than the most probable order" (p. 29).

By renewing the notions than inform the life sciences, Canguilhem made it possible to abandon the traditional categorizations of disabled people. His principal works are *La connaissance de la vie* (1965), *Le normal et le pathologique* (1966), and *Études d'histoire et de philosophie des sciences* (1970).

—Henri-Jacques Stiker

See also Normality; Normalization.

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CAPACITY BUILDING

Capacity building is a term used to describe the process by which individuals with disabilities and/or their organizations develop their ability to solve problems, address unmet needs, and maintain their well-being with less dependency on outsiders or professional help. The construct has special relevance to individuals with disabilities because of a long history of social biases and misperceptions about the "lack of capacity" of most people with disabilities to take charge of their own destinies, solve their own problems, and meet their own needs. The process of capacity building is central to the development of community supports and services for individuals with disabilities moving away from institutional settings and into community and independent living. It is also important for the empowerment of individuals with disabilities.

There are several important premises to capacity building: (1) the mobilization of existing resources (either at the individual or organizational level) to pursue a desired objective, (2) the development or improvement of social networks or coalitions (addressing affective or instrumental needs), (3) the emergence of leaders and/or the development or improvement of leadership skills, and (4) the active participation of individuals with disabilities or groups in solving problems through collective action. In addition, the construct of capacity building generates expectations for greater participant involvement, fairness, efficiency, democracy, and cost savings. Capacity building can take place at the individual, group, or organizational level.

Capacity building at the individual level implies the development of skills and competencies that allow individuals to increase the degree of control and influence they have over relevant aspects of their lives. This includes greater involvement in selecting services and treatments, as well as pursuing satisfying life outcomes. Individuals are encouraged to lessen their one-way dependence on outsiders in order to meet their own needs. Greater self-reliance and interdependence become desirable outcomes of the capacity-building process at the individual level. In this framework, the service provision is seen as an opportunity for the individual with a disability to learn and become competent in managing the particular situation. It is an opportunity to work with others as a contributing partner rather than only as a passive recipient of services. For example, instead of relying on an agency to manage their attendant care needs, individuals with disabilities learn to recruit, hire, manage, pay, and fire their own personal care attendants. People with disabilities learn to function more independently of service providers and instead, take control of the situation for their own benefit. Individuals learn to live and work interdependently with others.

Capacity building at the group level reflects the needs of most consumer-directed organizations to improve effectiveness for advocacy and social action. The process may imply training at the organizational level but also coalition building as a strategy to enhance the influence of consumer groups at the local, state, and national levels. Grassroots organizations often develop and grow over time, but they can also stagnate and die if they fail to develop their capacity to have an impact or to achieve intended goals. Learning to lead action-oriented meetings, to plan actions, and to promote change are all relevant aspects of capacity building at this level. Coalition building has demonstrated that it is a very useful strategy to multiply the political influence of advocacy organizations of people with disabilities. Such coalitions are more likely to influence policy and to demand compliance with established policies or procedures.

At the organizational level, capacity building requires significant changes in the way many helping professionals deliver their services. Such changes may include (1) the preparation of practitioners who facilitate and encourage local experts (e.g., paraprofessionals, peers, and family members) to be the primary care providers; (2) a professional mission that promotes innovation and community collaboration; and (3) new theories that recognize capacity building and economic and occupational development as key aspects of the functioning and well-being of people with disabilities. Building the capacity of local communities to better serve individuals with disabilities is a central goal of independent living centers (ILCs). These agencies encourage consumers to participate actively in advocating for their own needs and services. ILC consumers are also expected to learn skills that would allow them to become more independent and interdependent in the future. In the United States, the ILCs are often at the forefront of capacity-building efforts at the local level, working in collaboration with other social service agencies. Capacity building at the organization level also affects the way in which an agency operates. For instance, a rehabilitation hospital implemented a peer-mentoring intervention in which trained peer mentors with spinal cord injury (SCI) interacted with new SCI patients to help them better understand the rehabilitation process and set goals for the future. The mentors became an integral and valuable part of the services provided by the hospital.

It should be noted that capacity building represents a paradigm shift taking place both in developed and developing nations. It is reflected in practices such as person-centered planning, individualized supports and individualized funding projects, community-based options, and multiple consumer-driven initiatives in the areas of housing, transportation, attendant care services, accessibility, employment, and education. Community-based rehabilitation has been proposed by the World Health Organization as a low-cost way to reach out to people with disabilities by integrating rehabilitation services in already existing infrastructures of health service delivery. This approach has been supported in many developing nations by nongovernmental organizations (NGOs) that are helping governments develop community-based services for people with disabilities. Two of the main challenges of these efforts have been the lack of sufficiently trained professionals in promoting community participation and organizing and the limited involvement of community volunteers and leaders who may see disability and rehabilitation as low priority among other community needs.

There are multiple approaches for promoting capacity building. People with disabilities can develop new competencies either through formal training or by learning new skills as they perform a particular function or pursue new services. They can also engage in advocacy activities to develop greater capacity in local organizations to address unmet needs and honor unrecognized rights. Depending on the anticipated receptivity of those in power, disability advocates can use either conflict strategies such as protests, boycotts, or sit-ins or consensus strategies such as identifying opportunities for mutual benefit and promoting mutual respect to advance their capacity-building agenda. On the other hand, people with disabilities can strengthen existing organizations or help start alternative organizations when the existing ones are not willing to change. Local governments can also foster collaboration among community organizations by promoting the creation of broker agencies such as clearinghouses that are effective for sharing information. They could also support the creation of coalitions and partnerships among multiple organizations to improve coordination of services, reduce costs, and improve quality.

A capacity-building intervention designed to empower ethnic minorities with disabilities to address issues of independent living and disability rights was developed and tested by researchers at the University of Illinois at Chicago. This model has been used effectively to influence decisions about programs, policies, budget allocations, accessibility modifications, and issues of independent living for various organizations of people with disabilities. Capacity building, in this case, involved multiple agents working together in an organized coalition to meet identified needs. The process follows a participatory action research methodology that requires the active involvement of people with disabilities in identifying needs, and prioritizing and analyzing the dimensions of such needs. People with disabilities organize action groups to seek solutions to their most critical needs. In Chicago, these efforts resulted in an increased level of involvement of Latinos with disabilities and family members in determining the services and decisions made to address employment and educational needs and advancing their agenda at the local level.

Capacity building offers the promise of increasing the degree of awareness and self-sufficiency of people with disabilities both nationally and internationally. It can contribute to improvements in their quality of life and the availability of services. Only through active consumer involvement and organized advocacy can individuals with disabilities influence local politicians and community leaders to move disability-related issues and service needs to the forefront of public agendas. Researchers in this area recognize that strengthening associational networks among individuals with disabilities and their supporters is critical to foster communication and mobilize the participation necessary to achieve desired community change.

—Fabricio Balcazar

See also Activism; Advocacy; Consumer Control; Empowerment and Emancipation; Independent Living; Peer Support.

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CARDIAC CONDITIONS

Heart disease remains the leading cause of death and disability in affluent societies for both men and women. According to the World Health Organization, one-third of global deaths are attributable to cardiovascular disease, and it is projected to be the leading cause of death in developing nations by 2010. According to the American Heart Association, 64.4 million Americans have some form of cardiovascular disease, which may include congenital cardiovascular defects, coronary artery disease, cardiac arrhythmia, heart valve disease, and stenosis, among others. Individuals with severe heart problems may require intensive long-term care, restrictions of activity, or restructuring of lifestyle. Others may be able to return to a near-normal lifestyle as a result of adequate treatment and monitoring of their cardiac conditions.

Decades of heart research involving animals and patients have been devoted to learning heart anatomy, physiology, and dysfunction to diagnose and treat heart disease more effectively. Clinicians gained knowledge about heart function through the use of the stethoscope, pulse-recording devices, and the electrocardiograph (a recording of the heart's electrical activity). Physicians explored various drug regimens to relieve symptoms, to remedy malfunction, and even to fight causes of the disease. Surgeons adopted the procedures of cardiac catheterization and angiocardiography to detect heart defects and obstruction, and they devised procedures to repair and replace damaged hearts. Mortality from cardiovascular disease is declining, not as a result of these medical innovations, according to some health experts, but due to the success of preventive measures. This entry focuses on both congenital and acquired heart diseases, their resulting levels of disability for people with these diseases, and methods of treatment and prevention.

Congenital heart diseases are those present at birth. Minor defects may not warrant intervention, and in fact may correct themselves over time. In cases of severely malformed hearts, such as holes in the interior heart walls (atrial and ventricular septal defects), open fetal ducts, or transposed heart vessels, the child's skin, lips, and fingernails turn blue because of the insufficiency of oxygen in the blood. Blue babies may suffer unusual murmurs or thrills of the heart, a slow or stunted rate of growth and development, and/or an alternation in the size, shape, and/or position of the heart. With age, they suffer increasing shortness of breath, dizziness, spells of unconsciousness, chest pain, and respiratory distress from oxygen deprivation. Most cyanotic children are not capable of participating in such normal activities as playing outside or walking to school. Historically, few of these blue babies lived to adulthood. Open-heart surgery, developed in the 1950s, made it possible for surgeons to correct many congenital heart malformations, rerouting the blood to the lungs, closing openings, or replacing damaged valves. These operations usually take place at an early age and may require multiple operations, but aim to enable these children to lead unrestricted lives. Some complex heart defects still cannot be cured, limiting these children in their activities and opportunities.

Acquired heart disease refers to disorders of the heart contracted after birth. The most common acquired heart disease conditions are coronary artery disease and cardiac arrhythmias. As the coronary arteries become clogged and then narrow, blood flow to nourish the heart muscle is impeded, particularly during stress or physical activity. An accumulation of plaque may result in clogging the coronary arteries completely, thus stopping the flow of blood to the heart muscle that the artery services. The result is a myocardial infarction (heart attack).

Individuals with cardiac arrhythmias have a heart that beats either abnormally fast (tachycardia) or abnormally slow (bradycardia). An irregular heartbeat interferes with the contractions of the heart muscle to pump deoxygenated blood to the lungs and to pump oxygenated blood to the body. With unsynchronized contractions, the heart does not pump blood effectively.

In some cases, the coordinating electrical pulses within the heart are blocked altogether (referred to as "heart block"), also impeding pumping blood.

Congestive heart failure (impaired contraction of the heart resulting in congestion of blood in the heart and lungs) is the end result of many diseases affecting the heart. Like individuals with congenital heart defects, those with acquired heart disease experience symptoms of breathlessness, tiredness, and sometimes chest pain. Some experience painful swelling of the feet and ankles. These symptoms can escalate with increased levels of disability such as inability to climb stairs easily, limited exercise tolerance, or difficulty in performing daily dressing, washing, or preparing meals.

Drugs are the dominant treatment for acquired heart disease. Various medications are prescribed to improve heart contraction, to reduce heart work, and to protect against blood clots. For the treatment of chronic heart failure, digitalis, a derivative of the foxglove plant, is the most frequently used drug to assist the heart muscle's contraction. Other similar drugs include dopamine, terbutaline, and levodopa. Many patients, however, experience difficult side effects, possibly increased heart rate, palpitations, and nervousness. Vasodilator drugs, such as hydralazine, pinacidil, dipyridamole, and the nitrates, act to decrease the work of the heart by widening blood vessels, making it easier for blood to flow. Antithrombotic drugs or blood clot inhibitors, such as aspirin or heparin, help prevent obstruction of the circulation from blood clots. Drug therapies seldom reverse heart damage but can successfully stabilize the disease for patients to carry on a near-normal lifestyle.

In addition to prescribing drugs, cardiologists and cardiac surgeons offer a range of interventional procedures to repair, pace, assist, or replace the damaged heart. For individuals with irregular heartbeat or heart block, internal pacemakers (in use since the 1960s) can be implanted to deliver a controlled electric shock to pace the heart. More sophisticated pacemakers introduce a sensing function activating the device only when needed. To treat arrhythmias, implantable defibrillators and cardioverters also administer electric shocks to restore heart rhythm. For individuals with coronary artery diseases, intra-aortic balloon pumps and cardiac stents dilate and keep open blood vessels to prevent blockage as well as to facilitate blood circulation and demands on the heart. Coronary bypass operations since the late 1960s have helped mitigate the damage from obstructed arteries feeding the heart. After many of the above interventions, cardiac rehabilitation programs contribute to improved recovery, strength, and functional stamina.

For individuals in end-stage heart failure, heart transplantation, first introduced in 1967 with limited success, has become the treatment of choice today. With the development of more effective antirejection drugs in the 1980s, the majority of transplant patients survive at least five years and sometimes longer. However, there is a chronic shortage of donor hearts to meet demand. For those patients on heart transplant waiting lists, mechanical artificial hearts may replace or assist the natural heart. The total artificial heart replaces the failing ventricles (pumping chambers) of a damaged human heart, which is removed from the body. In 1982–1983, the first patient to receive a total artificial heart as a permanent implant was Barney Clark, who lived 112 days with the Jarvik-7 artificial heart. A partial artificial heart or ventricular assist device attaches to a failing heart (which remains in the body) and serves to assist in the pumping function of the heart. Over time, both total and partial artificial hearts have changed from large devices situated outside the body (paracorporeal and extracorporeal) to smaller devices intended to be placed inside the body (intracorporeal and fully implantable). Although the total artificial heart still remains experimental, several ventricular assist devices have been approved as temporary, bridge-to-transplantation devices with ongoing studies for their use as permanent devices.

Despite the introduction of new drugs, improved surgical procedures, and more reliable devices to treat cardiovascular disease, the medical community urges people to take preventive measures. As a result of the Framingham Heart Study, one of the most important twentieth-century epidemiological health studies, a new emphasis on preventing heart disease emerged. Beginning in 1948, the Framingham Heart Study examined 5,200 men and women in Framingham, Massachusetts, at regular intervals for decades. From this data, scientists were able to identify major risk factors including diet, nutrition, stress, obesity, smoking, and others that contribute to cardiovascular death and disability. National awareness campaigns distributed information to the public on how to control heart disease risk factors, recommending that individuals monitor high blood pressure, lower high cholesterol levels, stop smoking, watch their diet, and exercise more. As these campaigns warned, heart disease does not discriminate by race, gender, or socioeconomic status. As a result of preventive measures and early detection of heart disease, the prognosis for the next generation's battle with cardiovascular disease and disability continues to improve.

—*Shelley McKellar*

See also Exercise and Physical Activity; Health Promotion.

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▣ CAREGIVING

Caregiving is the act of providing hands-on or supervisory assistance to an individual with a disability who has difficulty performing the basic tasks needed to sustain life in the community. Millions of individuals worldwide, both young and old, have physical, mental, and/or emotional problems that make it difficult or impossible for them to perform the day-to-day tasks of life. While a minority turn to formal caregiving services to assist them with these tasks, the typical type of care that persons with disabilities need on a regular basis does not require specialized training and more often family members and friends take on the role of caregiver. A large percentage of caregivers are women in midlife who have competing demands of family and work. The care that is provided can be as limited as running errands for an elderly person who has difficulty getting around outside, or as intense as around-the-clock care for a child with a developmental disability. At particularly high levels of need, caregiving responsibilities create a great level of burden for the caregiver.

The majority of individuals with disabilities are cared for within the community, rather than in institutions. This has been true throughout history. While institutions exist for children with developmental disabilities, individuals with persistent mental illness, and frail elderly persons, the disability rights movement of the twentieth century paved the way for deinstitutionalization. Today, it is a worldwide priority to provide community, rather than institutional, support to individuals in need. A minority of this support is provided formally through federally subsidized home- and community-based services. In addition, some individuals with disabilities hire personal assistants to attend to their needs. For the most part, these formal services are used when there is no informal support available or when the care needs of an individual are too great for family or friends to handle on their own. The vast majority of community-based support is provided informally by family members and friends, and this is what is referred to as informal caregiving. In the United States, it is estimated that as many as one in five adults provide care to someone age 18 and older with a disability. This estimate does not include the many who care for the approximately 400,000 children with chronic care needs in the United States. Rates are comparable in other countries.

Informal caregiving is a gendered role, falling primarily on women. While women are entering the workforce at increasingly steady rates and dual-earner families are common, they are still considered the primary caregivers to those in need. They are often mothers of children with special health care needs, spouses of adults with disabilities, or adult daughters of frail elderly persons. Men do assume the role of caregiver, but they do so much less frequently than women. Sons, for instance, are more likely to provide care to elderly parents when there are no daughters available. Men also provide fewer hours of care overall, and less intense care than women. There are two groups of care tasks that are commonly referred to in the literature on disability. These are activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs consist of personal tasks such as dressing, bathing, transferring out of bed, eating, toileting, walking, and going outside. IADLs, though less essential on a daily basis, are important for adults to maintain independence in the community and include grocery shopping, housework, using the telephone, and managing money or medications. Male caregivers are more likely to provide assistance with these less personal IADL tasks than with ADLs. In addition, male caregivers tend to receive more help from others in their caregiving responsibilities than do females. Finally, mothers are more likely than fathers to adjust their work schedules or leave the workforce altogether to care for a child with special health care needs.

Caregiving is an extremely personal and varied experience. The impact of the experience on the caregiver depends on the characteristics of both the caregiver and the care recipient, as well as their relationship with one another. Responsibilities and experiences differ for those caring for children with mental retardation, adults with persistent mental illness, and frail elderly adults. The average caregiver is a woman in her 40s caring for an elderly parent. However, even children take on the role of caregiver to parents with a disability, chronic condition, or mental illness. Australia, for example, has estimated that 10 percent of all 15- to 25-year-olds have been identified as caregivers. Among caregivers to adults with disabilities in the United States, while nearly half provide fewer than 8 hours of care per week, almost one in five provides greater than 40 hours per week. At these more intense levels of caregiving, caregivers are often given the added responsibility of acting as case managers for the care recipient, having to navigate through an often complicated and disjointed health care delivery system. They may also receive minimal specialized training in order to perform specific tasks in the home such as replacing a catheter or fitting a prosthesis.

The care needs of a person with disability can be temporary and sporadic, as with the intense bouts of assistance a person going through cancer treatment might require. Caregiving, however, can also last for years. An increasing concern for parents of individuals with Down syndrome, for example, is who will care for their children once they pass away. Where those with Down syndrome once died at a young age, many are now living well into adulthood largely as a result of improvements in the management of heart disease. So, too, elderly persons with Alzheimer's disease often live for many years with progressively debilitating effects of the disease.

Individual experiences of caregiving can be rewarding, strengthening the bond between caregiver and recipient, but the reality is that caregiving responsibilities create a great level of burden for many. The transition to a caregiving role may be unexpected and involuntary, as when a parent suffers from a sudden and debilitating stroke. At other times, though an increasingly greater caregiving role is expected and perhaps prepared for by a caregiver to someone with Alzheimer's disease, the difficulty of watching someone lose all memory of you can be intense. Isolation, depression, financial hardship, emotional and physical strain, and disruption in workforce participation are some of the hardships associated with the caregiving experience.

The provision of appropriate social support to caregivers is critically needed. The Third International Conference on Family Care that took place in October 2002 and included participants from 22 nations worldwide recognized the important role that family caregivers occupy within society. Many nations are taking steps to develop federally subsidized means of supplying at least a minimum of support to those who take on the role of caregiver. For instance, Sweden, which has one of the oldest populations in the world with an expectation that 21 percent of their population will be 65 and older by the year 2020, offers two types of caregiver income support, as well as a family leave program for workers caring for terminally ill relatives. Grants have been established in the United Kingdom to offer respite services to caregivers. Other countries such as Israel, Canada, the United States, Australia, and Japan are also developing programs to offer various degrees of support to caregivers. No country believes, however, that the needs of caregivers are being adequately met.

The importance of caregiving will only continue to grow. So, too, will its potential burden. The majority of care recipients are elderly adults. The population is aging worldwide, with the proportion of the population age 85 and older growing at the most rapid rate. While there are numerous debates as to whether the elderly population is getting healthier, sheer increases in the number of individuals living well into old age will dictate that the need for caregivers will increase. Reduced fertility rates across much of the developed world and a continued increase in female workforce participation will decrease the availability of adult children, particularly women, who are available to care for aging parents. As advancement in science and medicine continue to be made, children with special health care needs will undoubtedly age into adulthood, bringing with them the concern for availability of caregivers over their lengthened lifespan. Caregivers will increasingly balance caregiving responsibilities with other family and work obligations. The profile of caregivers will undoubtedly change, with more men assuming the role. Efforts to support the needs of caregivers must improve as informal caregiving will continue to play a dominant role in the long-term care experiences of individuals with disabilities worldwide.

—Julie C. Lima

See also Child Care; Family; Family, International.

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CARROLL, THOMAS J.
(1909–1971)

American priest and advocate

Long an advocate for newly blinded individuals, the Catholic priest Father Thomas J. Carroll was born in Gloucester, Massachusetts, and attended Holy Cross College before his ordination in 1938. His first assignment was to the Boston Archdiocese's Catholic Guild for the Blind, where he became assistant director, and in 1947, director. He worked extensively with the blinded American veterans of World War II, serving from 1944 to 1947 as a chaplain at the Army's blind rehabilitation facility at Avon, Connecticut, and from 1944 to 1949 as a chaplain at the Army's preliminary blindness treatment center at Valley Forge General Hospital. He was for years chaplain for the Blinded Veterans Association. In 1954, he established the diocesan St. Paul's Rehabilitation Center, one of the first civilian facilities offering comprehensive rehabilitation, including white cane training, for newly blinded civilians. In 1963, he founded the American Center for Research in Blindness and Rehabilitation, which was merged into St. Paul's in 1973. In 1977, St. Paul's became the independent, nonsectarian Carroll Center for the Blind. Carroll served on the President's Committee on Employment of the Handicapped and on the Special Legislative Committee on blindness of the Massachusetts legislature.

The philosophy guiding Carroll's work was rooted in his Catholic faith and was presented in his *Blindness: What Is It, What It Does, and How to Live with It* (1961). Carroll believed blindness incurred in adulthood led to the death of a former self and the necessity of a type of rebirth. Rehabilitation had to be more than the learning of skills and involved the nurturing of emotional as well as physical resources.

—David A. Gerber

See also Blind, History of the.

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CARTAGENA, TERESA DE
(1415–1420 TO ?)

Spanish nun and author

Very little is known about Teresa de Cartagena outside of her authorship of two treatises, *Arboleda de los enfermos* (*Grove of the Infirm*) and *Admiraçión operum Dey* (*Wonder at the Works of God*), written most likely in 1452 and 1454, respectively. In both treatises, her deafness figures prominently. She was a Catholic *converso* (convert) nun, whose grandfather had converted from Judaism to Christianity in 1390/1391, and whose father was active in both literature and the Church. She was born in Burgos, Spain, and lost her hearing, probably through illness, when she was very young.

In her first treatise, often labeled "consolatory," de Cartagena claims she belongs to a "convent of the suffering," and she works to address her place in the world and with God through her deafness: "What I used to call my crucifixion, now I call my resurrection." This treatise prompted a reaction from those who read it, as de Cartagena was discredited for authoring it, considered incapable (both as a woman and as deaf) of such learned expression. In response, she wrote the second treatise, *Wonder at the Works of God,* to defend herself from the "malicious wonder" surrounding her authorship.

—Brenda Jo Brueggemann

See also Deaf, History of the.

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CARTOONING

In a sense, cartoons have been around as long as the ability to draw. Thus, painting England's Richard III as a hunchback, or drawing New York City politician William "Boss" Tweed as fatter than he was, was part of a long and universal tradition of emphasizing or altering one body part or another for purposes of commentary. Any comprehensive list of such art would be a separate volume; this entry will look only at some examples from the latter part of the twentieth century, from the contrasting cultures of America and Japan.

THE UNITED STATES

Comics in America are a relatively marginalized medium of popular culture. Since the 1950s, comic books have been increasingly relegated to children's literature, and even the four-panel gag strip of the daily newspaper is being squeezed out by space and money constraints. The following comics can generally be divided into two categories: disability as a minor nuisance at best and disability as meaningless or irrelevant.

Disability as Nuisance

The Marvel comics website describes the setup of Daredevil thus: "A Good Samaritan act stole young Matt Murdock's sight, but also enhanced his remaining senses to superhuman level! After becoming a lawyer—and suffering the murder of his father—Matt now uses his powers to protect the innocent in New York City's Hell's Kitchen as Daredevil, the man without fear!" Conventional wisdom has it that losing one sense heightens the others, but this is a bit extreme. Written and drawn by a variety of writers and artists of the Marvel stable over the decades since its premiere, Daredevil started out as relatively benign, in the words of writer Jeph Loeb:

> There was a time when [Daredevil] was about the *joy* of being a hero. . . . He was not only able to do things that no blind person could do; he was doing things that *no* person could do. . . . Stan Lee's Daredevil took to his role like a duck to water. And I think it very much had to do with being blind. He saw being Daredevil as liberating. But, unlike Spider-Man where [Spider-Man alter ego Peter Parker]'s home life and school life was [*sic*] incredibly oppressive and depressing (for Peter, not the reader) and in turn, being Spider-Man was a party, [Daredevil alter ego Murdock] had it pretty good. He was with his best friend, starting a business where he was a terrific lawyer. They hired this wonderful, bright ray of sunshine named Karen Page. And together, they won in the court room and Daredevil won as a hero. New York loved him. He had none of the problems that Spider-Man had. (http://www.manwithoutfear.com/interviews/ddINTERVIEW.shtml?id=Loeb)

Apparently, blindness didn't qualify as a problem.

"The Aesop Brothers: Siamese Twins" by Charles Rodrigues ran for years in the *National Lampoon*. Rodrigues created the Aesop Brothers to explore exactly those questions of sex, hygiene, intimacy, and privacy that lurk in the back of many minds when faced with conjoined twins. Of course, the answers here are not meant to inform but to amuse, and in the *National Lampoon* tradition, amusement and outrage are often conjoined.

Cartoonist John Callahan has continued the *National Lampoon* tradition of outrageous humor, some of it inspired by his own quadriplegia. Disabled in 1972 when a drunken friend drove into a telephone pole, Callahan continued drinking heavily himself. His account of his transition to a disabled life and transcendence of alcoholism, told in cartoons, was published as *Don't Worry, He Won't Get Far on Foot*. His style is limited by his disability, but his humor has stayed in the "sick" category.

In 1998, the "Luann" comic strip by Greg Evans included a story-arc in which one character, an African American high school student named Delta James, is diagnosed with Hodgkin's lymphoma. Yet the worst that we see her suffer is fatigue and hair loss as a result of chemotherapy. She maintains a positive attitude throughout the treatment because she does not want to depress anyone else. In a way, it is not surprising that her diagnosis of remission was announced around the Christmas holidays; Delta endured a very reader-friendly cancer. The series also gives Luann's friend Bernice a wheelchair-bound boyfriend named Zane, who is described on the comic's website (ostensibly in Luann's words) as "cute and funny and interesting and cute and kind and sensitive and cute"—without mentioning his chair, although it does mention his service dog, Monroe.

Berkeley Breathed's "Bloom County" (1980–1989, 2003–) is actually based on another strip by Breathed, "Academia Waltz," which appeared in the *Daily Texan*, the newspaper of the University of Texas at Austin, beginning in 1978. The wheelchair-bound "Cutter John" first appeared in "Academia Waltz" (as "Saigon John") and made the leap to national syndication. In "Bloom County," Cutter John has a girlfriend, schoolteacher Bobbi Harlow, but he seems to prefer spending time with the critters of the strip, fantasizing that he is Captain James Kirk in command of the Starship *Enterprise*.

Disability as Irrelevant

Cartoonist Bill Griffith created Zippy the Pinhead in 1970, shortly after joining a San Francisco community of "underground" cartoonists. A microcephalic who always wears a clown suit (and named after a microcephalic man exhibited at the Barnum & Bailey Circus between 1864 and 1926 as "Zip the What-Is-It"), Zippy became a comic icon with the slogan, "Are we having fun yet?" The comic, which went from a one-shot to a weekly to a daily, still runs, showing the title character in surreal environments, uttering non-sequiturs (not unlike actual microcephalics, who often parrot back whatever they hear). Whatever the rest of us may think, Zippy seems to be having fun.

In 1964, African American cartoonist Morrie Turner began his "Wee Pals" daily strip. Predating debates on "diversity," "political correctness," and other buzzwords, "Wee Pals" resembles Charles Schulz's "Peanuts" given a collection of multiethnic children (black, white, Asian, Jewish) just living life and getting along, occasionally stopping for a didactic tribute to someone (usually) of color. One of the children, Charlotte, is in a wheelchair, but she has had relatively little strip time, and even that has been cut into by her parrot, Polly Esther.

The Exceptions

Shelley in "Omaha the Cat Dancer"

One singular depiction of a disability in comics was the odyssey of Shelley Hine in "Omaha the Cat Dancer." Writer and artist Reed Waller began this sexually explicit example of the "furry" genre (animals given human characteristics) in 1981; after a few years, Waller's lover Kate Worley took over the writing of the comic. Omaha continued sporadically until 1995, when both the comic and the relationship between Waller and Worley ended.

The title character in this elaborate and erotic picaresque is Omaha, a voluptuous feline exotic dancer whose circle of friends includes Shelley. Intelligent but easily misled by her emotions, an avid bisexual, Shelley was mistress to the father of Omaha's lover, Charles Tabey. The elder Tabey had created a club/brothel for the corrupt politicians of Mipple City (a disguised version of Minneapolis-St. Paul, Minnesota). An assassination attempt by one of Tabey's partners left Shelley with a bullet in the back.

Shelley's story is unsparingly accurate in its description of her mood swings; her quest for adapted housing, physical therapy, and social services; the mutual attraction between Shelley and Kurt, her personal care attendant (a Vietnam veteran); and her desires for women outside of her relationship with Kurt. She has her small triumphs, such as rolling her wheelchair over the feet of paparazzi who invade Tabey's funeral, or her rejection of older rehabilitation models (Interviewer: "What is your religious affiliation?" Shelley: "Pagan.") in favor of a doctor who himself wears a leg brace. She even gets to point out to the clerk at a feminist bookstore that its books on disability are on a shelf out of reach to anyone in a wheelchair. The story was left unresolved, and the final image is of Shelley, after an argument with Kurt, alone in bed, her crutches on the floor, crying into her pillow. "Omaha the Cat Dancer" is a one-of-a-kind portrayal of physical disability.

BD in "Doonesbury"

Cartoonist Garry Trudeau has never been a stranger to controversy, and his reaction to the 2003 invasion of Iraq was as visceral as could be: He had the comic strip's character BD (who fought in Vietnam) go to Iraq. His Humvee was hit by a rocket-propelled grenade, and he lost his left leg below the knee. A few months later, while in rehab at a German hospital, postoperative infection caused him to lose more of his leg above the knee. It's an ongoing plot-thread of loss, adjustment, and attitude.

JAPAN

During the 1950s, when comic books in America began to be marginalized, Japanese comic books (*manga*) exploded with a postwar vitality and immediacy. The medium in Japan is now comparable to television in America, with various target audiences of all ages and both genders. This section is a necessarily abridged look at disabled people as portrayed in Japanese manga, or comics.

The revitalization of Japanese comics is due in large part to the innovations of a medical student named Tezuka Osamu. Dr. Tezuka's medical background appeared in some of his comics, especially "Black Jack," the story of a gifted but renegade surgeon who was himself in a disabling accident as a child; he was confined to a wheelchair for a time. He also had to receive a skin graft on his face from a Negro friend, which gave rise to his nickname and established him as a member of the out-group. The medical establishment refuses to sanction some of his more unusual surgical methods; consequently, although he may be the most skilled surgeon on Earth, he still lives the life of a lone wolf, a prominent archetype in Japanese culture. Even though Black Jack may be a heroic character with a disability, the comic also includes messages, implicit and explicit, warning readers away from trying to imitate his life.

Some of the medical problems portrayed in the hundreds of episodes of “Black Jack” are, to put it mildly, fantastic—exotic diseases either seldom encountered or dreamed up by Dr. Tezuka, or bizarre societal situations in which the doctor becomes involved. One episode in which the disability is real, the solution is far-fetched, but the social orientation underlying it is essentially Japanese, hence at least true in the idealized world of popular culture, is titled “Kaizoku no Ude” (The Pirate’s Hook). Its protagonist, Ichinoseki Kazuo, is an impressive high school gymnast. Because of his prowess, acquired by constant practice, he is popular with his classmates—including an overweight girl, whom he ignores. The girl, Furukawa (who Kazuo describes as “that pig”), warns Kazuo’s mother that his constant practice is bad for his arm. This is confirmed by a doctor (who is a character of cartoonist Tezuka). The doctor warns Kazuo that the arm is becoming gangrenous; if he doesn’t give it a rest, the arm will have to be amputated. Kazuo keeps practicing, the arm reaches the point of amputation, and the doctor calls in Black Jack. After stating that his fee would be 7 to 8 million yen, Black Jack says he will operate anyway “to reintegrate Kazuo into society.”

When Kazuo returns to school, with a mechanical claw instead of a hand, he is greeted by fear from the girls and ridicule from the boys; they give him the name “Kaizoku,” meaning “pirate.” Kazuo bitterly blames his hook, beating it against a fence—until the hook cries out in pain and tells him to stop. The hook suggests that Kazuo can assert himself in another way: the traditional board game shogi. The hook tells him that, with practice, he can become the best student player in Japan. This he does, ultimately confiding to the hook that he owes everything to its friendship; he says that the hook is the only real friend he has.

It doesn’t occur to him until this moment, however, to explore the nature of a talking prosthesis. Actually, Kazuo’s conversations with a prosthetic device are perfectly natural, when seen in the context of Shinto, Japan’s native animistic religion. In Shinto, *kami*, which can be translated as “gods” or “spirits,” inhabit literally everything, from plants and animals to inanimate objects. Kazuo discovers that the hook contains a two-way radio, and on the other end of the circuit is Furukawa. The close-up on his teary-eyed smiling face as he realizes this is a manga convention: Kazuo is in love.

In this case, Black Jack’s vow to “reintegrate Kazuo into society” was deliberately ambiguous, but was accomplished in this unorthodox manner. The manga took one Japanese cultural assumption (that one must always strive for excellence in whatever one does) and modified it by tying it to another cultural assumption (that the clan must rely on marriage and childbirth to continue). Excellence at shogi would not be enough in itself to reintegrate Kazuo into society, if society were still to shun him because of the hook. Those who flocked around Kazuo the stellar gymnast avoided the handicapped Kazuo. Furukawa was similarly shunned, by Kazuo and the entire class, because of her obesity. She is shown throughout the story as being alone, eavesdropping on conversations rather than participating in them. When she speaks, it’s never to her peers, but to an adult or (through a microphone) to Kazuo. This also provides yet another example of the belief that it is easier for disabled people to relate to each other than for disabled and nondisabled people to relate to each other: The group of disabled people are presumed to have a shared experience that the nondisabled majority cannot understand. Yet, in Japan, where the groups you belong to make up who you are, even belonging to a group of other disabled people is normal behavior. As long as Kazuo belonged to a group—even a group of two—with a shared experience, he was accepted into Japanese society.

This in-group dynamic is also illustrated in a sequence from “Hadashi no Gen” (Barefoot Gen), a semiautobiographical story by Nakazawa Keiji about surviving the atomic bombing of Hiroshima, Japan, in 1945. Gen, the title character, was in grade school when the United States bombed Hiroshima; he and his pregnant mother are the only members of his family to survive the blast, although both were mildly affected by radiation poisoning. They leave Hiroshima for the fishing village of Eba to begin life again. To earn money, Gen does what nobody else is willing to do: He becomes an attendant to Yoshida Seiji, who was also caught in the blast. His family will have nothing to do with him, for fear of "catching" radiation sickness; added to the isolation is the fact that Seiji, a promising artist before the war, lost the use of his hands in the blast. He thus despairs of ever being able to paint again, and he takes it out on Gen.

This is another part of the pattern in Japanese pop culture depictions of people with disabilities: that a physical disability manifests itself in a corrupted spirit as well (rage, callousness, depression). If the disabled person cannot rise above this himself, he must do so with the help of other members of the group. In the story, Gen's friendship and cheerful demeanor in the face of Seiji's abuse help to change his outlook; Seiji resolves to continue painting, even if he must hold the brush between his teeth.

What happens when one chooses to accept one's disability? This happens to two different young women in a series of stories by Wada Shinji: "My Friend Frankenstein," in which Dr. Frankenstein's creation wanders nineteenth-century Germany befriending and helping women and children. The monster first meets Mia, a young noblewoman who was ostracized as a child because of a large birthmark on the back of her neck; accordingly, she developed a cold and cruel personality reflecting the coldness and cruelty directed toward her. Through her friendship with the monster (whom she perceives as being tormented because of his appearance just as she was), she stops trying to cover up the birthmark, saying that she must accept herself before anyone else can accept her—including the man she will eventually marry. (As was the case with Kazuo and the hook, Mia—although a German character—acts on assumptions shared by the comic's Japanese audience.)

On the other hand is Hilda, a pretty young deaf-mute who also forms a bond of friendship with the monster. Both are captured and put to work as servants for the greedy and corrupt nobleman Herr Kurzhardt. Hilda is actually worked to death by Kurzhardt, which sends the monster, whom Mia renamed Silas, into a homicidal rage, as he massacres the nobleman and his equally corrupt guests at a dinner party.

Hilda violates the expectation that a disabled person is dissatisfied with life with a disability; she has adjusted to life with a kind and caring disposition. However, there is no way in which her disability can be either hidden or compensated for. For failing to fit in with the "group" of characters with disabilities, Hilda must die by the end of the episode—poignantly, of course, and in a manner that brings to the eye of the reader the tears that Hilda never sheds. This is another mark of her difference: the fact that she doesn't cry at all during the story, not for sorrow or for joy, sets her apart in a lachrymose medium where tears are often used as proof of a character's compassionate spirit. In this case, the spirit was there but the tears were not, and this was, in a sense, an additional disability.

These examples, and a few others, were drawn from the author's private collection of Japanese comics, of various genres, assembled over some 30 years. However, the simple fact that a disabled character is featured in perhaps 10 out of more than 2,000 short stories or series episodes—less than one-half of 1 percent—reflects the segmentation of the pop culture version of Japanese society in which those with disabilities can, at best, participate in society by joining a distinct and separate group.

—Patrick Drazen

See also Experience of Disability: Japan.

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CASE MANAGEMENT

Case management is a process of care planning and coordination of the services and resources used by people with disability and their families. Primary functions of case management include assessment, development of a care plan, securing access to services, and monitoring to ensure service timeliness, comprehensiveness, and quality over time. Many types of care professionals provide case management, including social workers, nurses, rehabilitation counselors, mental health providers, and physical and occupational therapists. Case managers are employed in many settings, including vocational rehabilitation providers, health insurance plans, government agencies, mental health centers, social service providers, workers' compensation carriers, health care organizations, and private practice. Family members and consumers themselves also act as formally designated case managers within particular programs.

While case management has been a cornerstone of community-based care since the late 1960s, its structure and functions have evolved in response to broader changes in health care and disability policy. Emphasis on cost containment has promoted professionalized models aimed at service rationing, while the independent living movement has advanced consumer direction of case management programs. Many, and often competing, objectives are embedded in case management programs, and research repeatedly demonstrates that expectations for them exceed their accomplishments. Case management nonetheless remains an important mechanism for coordinating fragmented service systems and ensuring access to needed services over time.

For people with developmental disabilities and persistent mental illness, case management originated in the United States in the community-based care movement of the late 1960s. As mandated in federal and state legislation, case managers were responsible for developing and implementing individualized care plans in coordination with interdisciplinary teams of service providers. Their primary objectives were to ensure that disabled people received care that was accessible, comprehensive, and continuous to enable them to live in the least restrictive environment as independently as possible. In some states, parents received training to become case managers for their own children, and overall the emphasis of case management programs was on developing independent living skills and self-direction.

Inflation in the costs of both health care and workers compensation in the 1970s led to case management's adoption within vocational rehabilitation services. Rehabilitation nurses and counselors became case managers coordinating medical and vocational services. Here, as in mental health and long-term care more generally, policy goals of increasing service access came into conflict with those of rationing care and decreasing expenses. These translated into role conflict for case managers, especially those more therapeutically oriented. The next decade saw cuts in federal and state support for mental health and rehabilitation accompanied by Medicaid Home and Community-Based Services (HCBS) waiver programs and other demonstrations of integrated delivery systems with case management at their core. Case management remains central to HCBS waiver programs throughout the United States.

Throughout this time, a variety of models of case management developed, with differential degrees of specialization, control over service resources, emphasis on medical versus social services, and extent of consumer direction. Starting in the mid-1970s, the independent living movement pushed for case management conducted by disabled individuals themselves to the greatest extent possible. Developed in concert with personal assistance services (PAS), in this approach professional case managers train consumers to acquire, monitor, and evaluate services, based on a consumer-directed care plan. Ideally, professional case managers serve only until the consumer is able to assume the role, at which point the former assumes more of a "consultant" position. In practice, however, professional case managers often still retain dominance in determining care plans and authorizing payments. Criticism of this has promoted "cash and counseling" demonstrations (similar to programs found in West European countries), where disabled consumers receive a cash benefit to negotiate for services with as much or little case manager involvement as they desire.

The ascendance of managed care and integrated health care systems since the mid-1990s has led to the employment of case managers who follow patients with chronic illness and newly acquired disabilities from their initial medical treatment onward. At the same time, insurance carriers, home health agencies, and other private providers have developed an industry of "disability case management" focused on returning disabled employees to work. Responding to the increased role and skills required of case managers in these areas, organizations providing case management have pushed for it to be recognized as a professional credential. The Commission for Case Management Certification (CCMC), incorporated in 1995, administers requirements for certifying case managers, while a related organization, the Case Management Society of America (CMSA), promotes professional development of case managers in diverse service areas.

In part a legacy of the divergent policy currents shaping case management's agenda, there are inherent conflicts built into the role. In particular, it is antithetical to expect case managers to advocate for consumers' access to services while also being gatekeepers to service resources. Related to this are the dilemmas of attempting to increase client autonomy through a professionally dominated position, as connoted even by the terms *case* and *management*.

Similar trends and issues are apparent in applications of case management in Canada, Europe, Scandinavia, and elsewhere throughout the world. In the United Kingdom, *care management* was the cornerstone of the community care policy 1989 White Paper, which relied on workers in local authority social services to coordinate care for disabled and older people. Program critics focused on the conflicts involved in asking care managers (as they are termed there) to curtail expenditures while also serving those at risk, or in attempting to ally simultaneously with families, consumers, and service providers. A 1996 act allowed the disabled to employ their own care managers using money that otherwise would have gone to social service authorities.

Attempts to evaluate the effectiveness of service programs have also been beset by the inherent ambiguity and complexity of case management. In long-term care as well as mental health care, random assignment demonstration programs have demonstrated limited results of professional case management in facilitating cost-effective community-based care. Meta-analysis of two decades of mental health case management programs found them yielding small to moderate improvements in service outcomes. Equally modest findings emerged from Project NetWork, a demonstration conducted by the Social Security Administration to evaluate case management as a means to promote employment among people receiving Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) assistance. Small increases in net earnings for participants did not reduce their reliance on SSI or SSDI long term, and the program increased net costs in public funds.

Case management remains ubiquitous in services for people with physical, developmental, and mental disability. While there are many variants of the role of case manager, it is possible to identify a continuum of approaches. At one end, case management involves professional control over care planning, referrals, and coordination of specialized services. The case manager depends on extant services and is charged with fiscal oversight and cost containment. At the other end, case management is consumer driven. The case manager consults with and trains individuals and families to obtain, coordinate, and evaluate services of all types, including those for all family members. These different roles reflect various modes of allocating service dollars as well as divergent service philosophies. The philosophy of consumer-direction drawn from the independent living movement is increasingly being applied to case management for disabled people of all ages. This refocuses such programs on the process of disablement and shifts their objectives from lowering health care costs and reducing institutional care to the maintenance of social participation and personal autonomy.

As a "Band-Aid" approach patching services together one consumer at a time, case management by itself cannot achieve broader coordination of the service systems used by disabled people. Service gaps and fragmentation, divisions between social and medical care, and inadequate financing are redoubtable problems barely touched by case management approaches. At the same time, any broader attempt at service integration will be inadequate unless it also works at the level of the individual. Because of this, and because of its ability to transform itself to the variable climate of service system design, case management will remain a central fixture of disability policy.

—Ann E. P. Dill

See also Independent Living; Social Work.

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CEREBELLAR ATAXIA

In one of the earliest descriptions of the cerebellum, Galen (AD second century) speculated that it was the source of the spinal cord and motor nerves, and with a portion called the cerebellar vermis acting as a valve to control the flow of animal spirits from the ventricles. Views of cerebellar function changed through later centuries and have included control of memory and intellect, involuntary actions such as heartbeat or breathing (Willis, seventeenth century), and even sexuality (Gall, nineteenth century). In the nineteenth and twentieth centuries, animal lesion experiments and careful observations of humans with cerebellar damage indicated that the cerebellum did indeed have a significant role in movement control, though the nature of that role was (and still is) debated. Opinions about cerebellar function ranged from a tonic influence on movement (Rolando, nineteenth century; Luciani, late nineteenth century; Holmes, twentieth century), to a coordinator of movements produced by other motor structures (Flourens, nineteenth century; Babinski, early twentieth century), to the principle regulator of postural muscle tone (Sherrington, early twentieth century). In this period, scientists also thought that the cerebellum had a unitary function, with no localization of control for different body parts or types of movement.

The modern view is that different cerebellar regions play an integral role in the control of different behaviors including voluntary limb movements, eye movements, balance, and locomotion. This view is based on the anatomy of cerebellar connections as well as studies of neural recording and the effects of cerebellar damage. It is also clear that the cerebellum exerts control over the flexibility of these behaviors; the cerebellum is very important for learning to adjust motor behaviors to new situations.

The most striking and debilitating effect of damage to the cerebellum is ataxia, which comes from the Greek words *a*, meaning "without," and *taxis*, meaning "order." Originally, it was a general term for incoordination and was applied to a number of different medical disorders including heartbeat and bodily movements. It is now typically used to mean the incoordination of movement following damage to the cerebellum.

Cerebellar ataxia can result from damage to the cerebellum itself, or pathways to and from the cerebellum. This is typically caused by stroke, degenerative disease, or tumor. If there is damage to only one side of the cerebellum, the resultant symptoms manifest on the *same* side of the body as the damage (e.g., right cerebellar damage causes right-sided ataxia). There are many signs of ataxia, and different individuals can have some or all of them, depending on the location of damage. Since ataxia is a very general term that globally incorporates any incoordination, it is often used in reference to a movement of a specific body part (e.g., arm ataxia) or type of movement (e.g., gait [walking] ataxia). There are many common manifestations of ataxia. *Dysmetria,* for example, is the inability to make a movement of the appropriate distance, with under- or overshooting the desired target. People with cerebellar damage tend to overshoot when they move rapidly and undershoot movements when they move more slowly, wishing to be accurate. Overshooting can be a significant problem that leads to breakage of objects or even personal injury. *Dysdiadochokinesia* is an inability to make rapid, alternation movements of a limb, and it appears to reflect abnormal control of opposing muscles. *Asynergia* refers to an inability to combine the movements of individual joints of the body into a coordinated multijointed movement. This leads to movements looking clumsy and abnormal. People with cerebellar damage may also show *hypotonia* or abnormally decreased muscle tone (e.g., floppier motions). Often hypotonia is either present only during the early phase of cerebellar disease or may not be present at all.

Damage to the cerebellum can cause a variety of other problems, including abnormal eye movements such as overshooting of eye movements, or *nystagmus,* which is an involuntary and rhythmic beating movement of the eye. Another common finding is *action* or *intention tremor* during limb movements, which is an involuntary oscillation occurring during movement and disappearing when the limb is at rest. Cerebellar damage can also cause a speech disturbance called *dysarthria,* where words become slurred and more difficult to understand. This tends to be a major problem and frustration for individuals with cerebellar damage, as it makes communication (particularly on the phone) more difficult. In addition, other people often assume that people with speech abnormalities have impaired intelligence, which is not the case in people with cerebellar damage.

Possibly the most common and disabling impairments of cerebellar damage are *balance deficits* and *gait ataxia.* Balance abnormalities are characterized by increased postural sway, either excessive or diminished responses to perturbations, poor control of equilibrium during motions of other body parts, and abnormal oscillations of the trunk (*titubation*). Gait ataxia, or walking incoordination, is often described as a "drunken gait," with distinctive features including variable foot placement, irregular foot trajectories, a widened stance, a veering path of movement, and poor coordination of the joints of the legs. Thus, walking tends to look clumsy and unstable. Some people with gait ataxia report that they have been accused of being intoxicated, based on their slurred speech and walking abnormalities. This can lead to social embarrassment and inconvenience because they must explain (sometimes in great detail) what their condition is and that they are, indeed, not intoxicated. Some people report carrying a cane or keeping it in the car with them, even if they do not need it for walking, just to make it clearer to other people that they have a neurological disorder and are not intoxicated.

People with ataxia can have mild to severe motor disorders in these areas but can live long and full lives. However, more often than not, the ataxia impinges on their job, home life, and recreation. Many people find that their job is harder to do with ataxia. Ataxic hand movements make handwriting illegible, causing difficulties with typing on the computer. For people with more physically demanding jobs, the balance disorder and walking ataxia can affect their work. Often people find that they have to modify their job or require new training in another area in order to continue working. Speech dysarthria can make talking on the phone at work or home more difficult. Sometimes people are frustrated enough to stop answering the phone and instead to let their spouse or partner do it for them. At home, modifications such as installation of handrails and grab bars usually make walking ataxia quite manageable. Recreational activities also can be modified to allow people with ataxia more participation.

There are few treatments for cerebellar ataxia at this time. There are no known medications that consistently improve the symptoms of ataxia across diagnoses or slow the progression of degenerative diseases. The main treatments are therefore rehabilitation training, including physical, occupational, and speech therapy. It is not known if there are ways to optimize rehabilitation training, particularly given that the cerebellum is involved in not only movement coordination but also the learning of new movements. Regardless of how robust practice effects are, even nonspecific effects of exercise including increasing aerobic capacity and strength are important and can improve movements of people with cerebellar ataxia.

—Amy J. Bastian

See also Neurological Impairments and Nervous Disorders.

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CEREBRAL PALSY

Resulting from a lesion in the brain that is static, cerebral palsy is characterized by consequent motor impairments, which do not progress over time. So briefly summarized, cerebral palsy (CP) is nevertheless a condition with a long history and an extraordinary culture.

Earliest records suggest people with CP from ancient Egypt, whence a stele depicts a young man with the inturned and atrophic feet strongly suggestive of spastic diplegia. The Bible also makes frequent references to "lame" figures, some of whom may have had CP, given their temporal associations. For example, Acts 3:2 and 3:7–8, written by the physician Luke, describe a beggar "who had been a cripple from birth" and who, when the Apostle Peter "grasped him by the right hand and pulled him up," "at once his feet and ankles grew strong; he sprang up, stood on his feet, and started to walk."

Throughout the Middle Ages, many examples of children crippled since birth are found in the listings of saints' miracles; these describe the divine cures of those who frequently defied medical intervention. One case from early-fourteenth-century Umbria, Italy, tells of a boy, Ceptus, who had learned to walk by ambulating on the sides of his feet because his ankles and feet had been twisted from birth. When he was about 10 years old, doctors having failed to heal him, Ceptus went on pilgrimage to the tomb of Saint Clare of Montefalco. There he laid upon the tomb and suddenly rose up throwing off his crutches; he walked normally into the waiting arms of the excited parishioners with the church bells pealing in the background. In the early fifteenth century, the painter Raphael (1483–1520) depicted a beggar with sufficient verisimilitude to suggest that he had observed such figures with equinus deformities in Renaissance Italy. Medicine struggled against these miracles.

The early textbooks dealing with the diseases of children, Metlinger's 1497 *Regimen for young children* and Felix Wurz's text, translated into English in 1656 as *The Children's Book,* describe cases of lame children, but without sufficient details to make reasonable retrospective diagnoses. In 1827, the Frenchman J.-B. Cazauvielh described the case of a palsied individual with a partially atrophic brain on autopsy in the *Archives générales de médecine.* Coincidentally, the noted French pathologist Jean Cruveilhier published an anatomic plate of a brain, strongly suggestive of an in utero ischemic event. In 1828, Maurice Delpech, studying poliomyelitis, developed the tendo-achilles lengthening surgery for the equinus deformity, also associated with CP.

It was nearly 16 years later, however, that William John Little, a British orthopedist who had polio and an equinus deformity himself, delivered a series of lectures at the Royal Orthopedic Hospital (1843), which appeared in the *Lancet.* He described the aggregate clinical features of CP. By 1889, in Philadelphia, Sir William Osler published a small tome depicting a series of CP cases. Osler focused on the pathology and neurological findings of the patients he saw. In effect, this approach characterized the medical view of CP for the next century. Osler coined the term *cerebral palsy* to collectivize the cases. Much of his evidence seemed to corroborate Little's conclusion that CP is a direct result of birth trauma. Scientists from Little's time through the 1940s continued to characterize different cerebral lesions to associate with CP. Only the celebrated psychiatrist Sigmund Freud challenged this theory in 1897, suggesting that perinatal difficulties were not the cause but the marker of intrauterine insults. It was not until 1986 that Nelson and Ellenberg successfully challenged this concept, well over a century after Little advanced it.

In the history of medicine and CP, development of therapies and etiologic hypotheses has been slow but steady. Unlike epidemic conditions such as poliomyelitis, CP's "background" nature has not galvanized the public imagination to reallocate research and care dollars in the same way. However, with the creation of the field of pediatrics in the late nineteenth century, CP was included in the canon of children's ailments that pediatricians had to know. While CP affects both children and the adults they become, its scientific and clinical advocates have since often been pediatricians.

CP is caused by events that occur before, during, or after birth. There are many possible causes, including inherited genes, fetal exposure to chemicals like mercury or to infections like rubella, strokes in newborns, and interruption of oxygen to the fetal brain (asphyxia). The incidence of CP in developed countries is approximately 2 percent and does not appear to be changing with "improved" technological care for newborns. In the United States today, there are more than 500,000 people with CP.

Rather than a single condition, CP is actually a constellation of conditions. They are unified in having disabilities of chronic movement and/or posture. A person with CP has muscles that can either be too loose (hypotonic CP) or rigid (spastic), or they can have reduced control of these muscles, including impaired coordination (athetoid) or balance (ataxic). Their condition may include a combination of these effects (dystonic). Only one's legs (diplegic or paraplegic), one side (arm and leg; hemiplegic), or all four limbs (tetra- or quadriplegic) may be affected. As the conditions are variable, an individual with CP can have manifestations anywhere along a spectrum from mild awkwardness to profound impairments of walking, fine motor control, and other voluntary movements. As CP is not a progressive condition, it entails long-term impairments including contractures and other musculoskeletal deformations.

CP may be associated with seizures and altered hearing, vision, or other senses. There is a roughly 66 percent association with mental retardation, although CP itself does not affect cognitive function itself. It is important to recognize that, as a technical condition, CP need have none of those associations. Many people with CP have normal or supernormal IQs.

Despite this modern understanding, for many years, people with CP were lumped together with others into a general clinical and social category of "idiots," often resulting in institutionalization. Work by reformers and physicians such as Séguin, Bourneville, Crothers, and Phelps shifted both the diagnostic and therapeutic perception of those with CP. Medical care of children with CP had a significant impact on the development of the field of medical rehabilitation and child neurology, particularly in the United States. Today, such care is often multidisciplinary and resource intensive, including medications, surgeries, assistive devices, and physical, occupational, and speech-language therapies. The application of this sociomedical therapeutic model in other cultures often suggests its limitations. Increasingly, people with CP have been changing the perception of the condition as well.

In literature and art, CP has been an uncommon motif until the latter half of the twentieth century, when authors such as Christopher Nolan and Christy Brown helped propel CP into lay consciousness outside of the spheres of charity and institutionalization. The development of electronic and other media has helped bring together personal experiences of those with CP, as have growing sports leagues and cultural organizations. From Egyptian images and the rhetorical power of medieval miracles, people with CP have had a significant if slowly cumulative influence on the culture around them. They continue to have a great deal to teach socially, medically, and culturally.

—Walton O. Schalick III

See also Desire Magloire Bourneville; Bronson Crothers; Edouard Onesimus Séguin.

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CHANGELING

Changeling are most commonly said to be beings exchanged for a human child by fairies, trolls, demons, devils, or witches and are common in world folklore and mythology. They also appear in the lives of saints, treatises on witchcraft, Shakespeare and other literature, and theological and philosophical works. The word *changeling* derives from *cambiones,* from the late medieval Latin *cambio,* an unusual transformation of matter; also *killcrop,* from the German *kielkropf*; and the German terms *wechselkind* (exchange child) and *wechselbag* (exchange brat). While most examples of changelings conform to the idea of a child exchanged by other-worldly beings, many early modern and modern usages came to denote "those with changeable wills" and in some cases, intellectual disability, notably in John Locke's *Essay Concerning Human Understanding.*

Germanic legends and those of countries surrounding the Alps typically describe the changeling as having a "thick head and staring eyes who would do nothing but eat and drink," most later accounts deriving from the brothers Grimm tale "The Elves." Recent scholarship has questioned the folkloric roots of this story and indeed the whole changeling myth, identifying the roots of the myth with elite medieval theologians such as William of Auvergne, who questioned that such beings existed, though contemporaries saw them as evidence of the devil's work.

British literature tends toward much broader descriptions of changelings, with little reference to the features generally found in the Germanic legends.

There is some evidence that the nature of the changeling was in part determined by common regional disease patterns. Scottish changeling stories frequently refer to infants simply wasting away in a form of "consumptive disease." A Welsh source notes a reputed changeling "who was deformed, his legs being so short that his body seemed only inches from the ground when he walked" but goes on to note "that he was very sharp." Many modern interpretations of these legends endorse the view that these were children with various disabilities or congenital diseases. The standard psychological interpretation is that this was a means of coping with the birth of a disabled child, though this has been questioned by recent scholarship.

Cretinism, whose physical characteristics roughly match those of the typical Germanic changeling, was endemic in certain regions of the Alps due to mineral deficiencies in the water. Goiters are commonly associated with cretinism, which would account for the common German term for changeling, *killcrop*, from *kielkropf*, meaning "crop in the throat." This has contributed to the common association of changelings with intellectual disability.

The modern association with intellectual disability has dominated much of the contemporary literature on the subject. The most often cited example of the association of intellectual disability and the changeling is in relation to Martin Luther's alleged comments on changelings as "having no souls" and recommending they be disposed of. Others have made the direct association between the changeling legend and infanticide and abuse of people with intellectual disabilities. In both cases, these interpretations have been questioned both for their historical accuracy and their imposition of modern psychological notions onto historical reality.

—Tim Stainton

See also Cretinism; Folk Belief.

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CHARITY

The word *charity* is a Christian term derived from the Latin *caritas,* which signifies the disinterested love of one's fellow human beings, *agapè* in Greek, as opposed to the love that is desire, *eros*. The meaning of the word was often realized over the course of centuries by alms to the poor and destitute, with the condescension that this entails and the absence of social analysis that it hides. The use of the term should be rigorously exclusive, if we do not wish to make a caricature of what charity has produced in history. To situate the genesis of charity and then its avatars, we should first speak of the word *love*, which is, in a sense, its basis.

The Hebrew Bible (the Christian Old Testament) speaks a great deal of love. The word means a host of different things: We say that we love certain foods, that we love our friends and family, and that we love to travel. The Hebrews knew all these meanings, but they elaborated a notion of the love of God, that is, the love that is God and the love that we owe God, which goes well beyond current secular significations of the word. This conception is exemplified in Israel's affirmation that God displays a concern for, an unfailing fidelity to, his people and that he maintains with Israel a dialogue of tenderness but also of reprimand, which makes him the ideal of the Father. It is rather the people who, from time to time, distance themselves from Yahweh, preferring the cult of idols.

Deuteronomy tirelessly recalls that the love of God for Israel is unearned, for example, 7:7, to cite one text among innumerable others. This perfect love of God for his people, that is, disinterested, gratuitous in the sense of unearned, faithful, tender and firm, is realized, tentatively but equally and progressively, in a relation and personal dialogue with him. This evolution in the realization of God's love is chiefly observable in the texts of the Psalms, which are principally ascribed to the decade of 580 BCE, the period after the Exile. This tradition of love is also found in the New

Testament. The affirmation of the fullness of God's fatherhood dominates, since Jesus presents himself as issuing directly from the intimacy of God and as the gift of God, given to all men. Jesus, in the course of his short career, through gestures and statements reveals himself as this love incarnate, and his crucifixion its culmination and supreme proof.

This biblical background must be borne in mind to understand the exact sense of charity. In the current Christian vocabulary, the words *love* and *charity* are often used interchangeably. God is love in the sense of charity, *caritas*, which designates as much the love from God as the love that humans should bear toward one another. It is in fact essentially the fraternal consequences of the love of God to which the word charity refers. If God loves us and we should love him, we must give witness to this, first, by loving one another. We remember that Christ said that two commandments are equivalent: to love God with all our hearts and to love our neighbors as ourselves and as they are loved by God.

Here Christ is clearly following in the great spiritual tradition of the prophets who preceded him. Reference could be made to a great number of texts, in particular Mark 12:30-31 and the parallel passages in the other Gospels. Thus, waiting for the end of time and bearing faithful witness to the Gospels, the essential activity of the disciples of Jesus is charity. It is preferentially addressed to the poorest, to the most destitute, those who suffer most, for they are in the greatest need and are, indeed, the image of Christ on the cross. This is the context in which we will be tried on Judgment Day.

Matthew's Gospel established the six "acts of mercy": provide food, provide drink, receive the stranger, cloth the naked, visit the sick, and visit the imprisoned. In the course of the 10 centuries of the Middle Ages, iconographical representations of these acts of charity would flourish, and at the same time they were constantly driven home in homilies. It is here that alms become the principal form of charity toward fellow humankind and its movement from the rich to the poor.

The risk of narrowing the evangelical commandment and the symbolic thrust of the Gospel of Matthew to these acts of mercy is evident, and the very word *mercy* is indicative of this contraction. We should not believe, as it too often the case, that the medieval period reduced the commandment to be charitable to the gift of food and lodging to the poor and to strangers. Spiritual leaders such as Francis of Assisi, Saint Dominic, and Saint Bernard show otherwise. The scorn currently directed toward the Middle Ages is unmotivated. On the other hand, we must understand the deep signification, despite the ambiguous evidence, of alms during this period. As Saint John himself said, we do not see God and so must give him proof of our faith through the concrete works named by Matthew. The touchstone of salvation will be acts of mercy.

It must be emphasized that the rich, or those who possessed property (the bishops, monasteries, and parishes as well as the lords and later the bourgeoisie), were obliged to devote a substantial portion of their goods to the relief of the poor and the sick. Foundations dedicated to the indigent and vagrant flourished for centuries; this is the origin of the leper houses all across Europe, organized like real towns or monasteries. This was also the origin of the hospices, what we might call care centers and hospitals (an early name was Hôtel-Dieu); the latter were institutions specifically established to provide care. These were the first institutions to be "medicalized," if this anachronism is allowed in reference to facilities of this period. We see, then, that acts of mercy entailed considerably more than the donation of a few coins or clothes. Alms represented a great system of social organization, just as it was a system for the circulation of wealth.

As an example with regard to the infirm (for in the Middle Ages there was no conception of handicap or disability), it should be noted that charity generated multiple establishments that provided lodging as well as some specialized institutions. The hospices were not specialized and admitted all the poor. Generally speaking, for the entire period from the fourth to the fifteenth centuries, the infirm were also poor. To be infirm meant not to be able to meet one's needs and the needs of one's family through work. Being infirm meant being reduced to beggary. There were few infirm in seigneurial families, given the demography of the times, and they remained more or less hidden in castles and manor houses, when they did not die young. Thus, infirmity was synonymous with poverty, and charity, in the form of the provision of lodgings, was the principal social response to their situation.

We should, however, note the Quinze-Vingts for the blind, founded in France by Louis IX, Saint Louis. The name means "fifteen score," or 300, and indicates that the royal foundation was dedicated to the reception of this number of individuals who had lost or never had sight. It was a building in Paris where 300 blind people found room and board but were not confined. By day, they would go begging like the others in the streets, because they still had to pay a basic fee to the institution. The Quinze-Vingts had a long history, which will not be summarized here, until its present incarnation as a hospital specializing in ophthalmology.

Starting with this institution-building potential of the principle of charity, its history can be traced up to its end, when charity was replaced by public aid in the eighteenth century, during the Enlightenment. In fact, when charity did eventually generate social institutions, these were above all in what can be called "short relationships." By this is meant that it is one individual who addresses another individual or a group of individuals, without any intermediary of a public authority. Even Saint Louis, founder of the Quinze-Vingts, acted as an individual in providing comfort for 300 blind people and thus participating in his own salvation. Even when supported by royal funds, the foundation was not an obligation of the state. In the eighteenth century and in particular during the French Revolution, the state's duty to see to the needs of the indigent and the infirm would be affirmed. But this initiates another regime other than that of charity: public assistance. Thus, the state, especially in Europe, began to provide a social insurance so that those in need did not have to rely totally on charity or their families.

Charity, as we here understand it, comes to a close at this forking of the way. It should be added, however, that a third system for the relief of poverty and infirmity would emerge at the end of the nineteenth century: solidarity, itself made possible by the insurance system, based on the principle of contributions by each worker or each member of the association and then a redistribution to each according to certain rules.

Charity has been the object of much negative comment, and many of the slogans of disabled people have been of the type, "We don't want charity–we want our rights." History does not move backward and does not repeat itself. As a consequence, the system of charity, in its capacity as a system that addressees social problems, is behind us. Yet charity as a personal act remains active and often comes to fill the gaps left by insurance and assistance programs. With the substantial unemployment that all developed societies now know, a considerable portion of citizens are marginalized, even finding themselves victims of a process of social exclusion. The safety nets formed by insurance or social protection systems no longer work for them. They are again left to the good will of private persons who finance charitable works, foundations, or hostels.

Thus, we see forms of aid reappearing that seem to belong to the past. It should be noted, however, that there is no dedicated system that addresses itself exclusively to human risks or human misfortune. In European systems of social security, in many of the elements of aid, just as in similar types of aid from the eighteenth and nineteenth centuries, the traces of charity are numerous. Should we rise up against this state of affairs? Certainly, disabled people no longer tolerate the condescending charity that relieves those who practice it from the greater duties of solidarity. Demands for civic rights, nondiscrimination, and equality of opportunity are now primary. Historically, the situation is more complex than a simple opposition between charity and rights, since it is also from charity that the demand for rights was born. But, as noted, history does not repeat itself.

—Henri-Jacques Stiker

See also History of Disability: Medical Care in Renaissance Europe; Religion.

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▣ CHILD ABUSE

Child abuse, be it physical, sexual, or emotional, at its essence involves the exploitation of a vulnerable person by another person who by virtue of age, development, or social rank has power over the victim. Child abuse can happen to any child, but disabled children are particularly at risk because of their physical or mental limitations and because of their increased dependence on caretakers.

While child abuse is an age-old problem, it was "discovered" and packaged as a medical problem in the last half of the twentieth century. Beginning in the 1960s and 1970s, physicians began to recognize child abuse as a distinct social problem with important medical and psychological features. The description of the battered child syndrome in 1962, for instance, identified a constellation of symptoms caused by abusive injury that doctors had not previously recognized. It was no accident that doctors in particular, and society in general, were awakened to child abuse during a period of heightened social awareness. The social activism of the 1960s and 1970s primed Americans to the needs of many oppressed and victimized groups. Doctors and other members of the helping professions felt called to advocate for children. With the decline of many once-deadly infectious diseases, pediatricians shifted their attention to issues of development and prevention; child abuse seemed a natural topic for their interest.

The medical recognition of child sexual abuse followed the discovery of child physical abuse. By the 1970s, physicians involved in child physical abuse broadened their focus to include victims of sexual as well as physical violence. They asked fellow doctors to be alert to the signs and symptoms of sexual abuse in their young patients and used their influence to protect these children. Child physical and sexual abuse increasingly entered the public discourse. Researchers explored who was at risk and how best to identify child abuse and treat it. National surveys of abuse, conducted in the 1980s and 1990s, demonstrated that disabled children were at increased risk of abuse.

The relationship between child abuse and disability can be viewed from multiple perspectives. Why are disabled children at increased risk of both physical and sexual abuse, and do certain types of disability make a child particularly vulnerable? What unique identification and treatment challenges exist in abused children with disabilities? How do physical and sexual abuse of children contribute to long-term disabling conditions? Can the answers to these questions help shape effective prevention, identification, and treatment programs?

RISK OF CHILD ABUSE IN CHILDREN WITH DISABILITIES

The true prevalence of child abuse in children with disabilities is unknown and will always be difficult to determine with accuracy, in part because definitions of abuse vary, as do definitions of disability. Nevertheless, researchers have estimated that the incidence of maltreatment in children with disabilities is between 1.7 and 3.4 times greater than in children without disabilities. Child protective services workers believe that in almost half of child abuse cases involving children with disabilities, the disability either led to or contributed to the abuse. In addition, children with disabilities tend to experience longer durations of maltreatment. Possessing multiple disabilities also increases a child's chances of physical and sexual abuse and is associated with longer durations of abuse.

These statistics have prompted researchers to ask why disabled children are more likely to be abused. Do particular disabilities place children at higher risk? Are there unique features of the perpetrators or the environment of abuse that makes these children more vulnerable? Neglect appears to be the most common form of child maltreatment in disabled children, followed by physical and then sexual abuse. Emotional and behavioral disorders place children at the highest risk of abuse and neglect. A number of factors (personal, medical, familial, and societal) influence a disabled child's risk of abuse. Communication disorders, for instance, may hamper a child's ability to disclose abuse effectively. Power inequities between a child and caregiver are more exaggerated in disabled children and may make a child more vulnerable to abuse. Some researchers have proposed that the added stress of caring for a child with disability, increased social isolation for the caregiver, and lack of respite care for the caregiver may place some children at higher risk for abuse. The increased dependence that disabled children may feel on their caretakers may prevent or inhibit them from reporting the abuse. Issues of power and control may be more exaggerated for children living in institutional settings. And social factors, such as the stigmatized nature of abuse in our culture and the dehumanization of some disabling conditions, make abuse less likely to be addressed and add to its impenetrable nature.

VULNERABILITY TO ABUSE

Various authors have offered explanations for the increased risk of abuse in children with disabilities. Some adopt a "frustration model" of abuse, suggesting that social and familial stressors, parental inadequacies, and characteristics of both the child and his or her disability result in the abuse. Others focus on the extra vulnerability of disabled children: their increased dependency on others, their relative lack of control over their lives, a lack of knowledge about how to respond to sexual advances, their social isolation, an increased desire to please, communication difficulties, and the relative immaturity of many disabled children. Clearly, the nature of each child's disability affects his or her risk for abuse. The learning disabled child will have different types of vulnerabilities than a child who is deaf or blind. How and to what extent these different factors affect a child's risk of being abused and the child's response to the abuse remain to be rigorously explored. Some researchers have pointed out that the stigma around disability can foster abuse: If a disabled child is somehow perceived as less human than an able-bodied child, then the abuse will be viewed as less problematic.

DISABILITY AS A CONSEQUENCE OF CHILD ABUSE

In addition to disabled children being at increased risk of abuse, physical and sexual abuse can contribute to or cause a variety of disabling medical and psychiatric problems. These problems may be the immediate results of the abuse or they may have a more complex etiology that takes years to be fully elaborated. Identifying past or ongoing child abuse and recognizing that it may contribute to or compound the disability can be an important part of protecting the abused child from further abuse, and ultimately treating the child.

The results of physical abuse of children occur on a spectrum. Abusive head injury in children, especially shaken baby syndrome, can cause neurological devastation and even death. The survivors of shaken baby syndrome are being studied currently to better understand the spectrum of behavioral and developmental consequences of nonlethal shaking. To some extent, the type and forcefulness of the physical abuse determine the severity of the developmental outcome. Some children with intentional burns, for instance, may have problems with fine and gross motor skills, other burn victims may have posttraumatic stress disorder as their major outcome of their abuse, and still others may have minimal adverse results.

The neuropsychological consequences of abuse, whether physical, sexual, or neglect, are currently being investigated. In addition to the physical harm inflicted, the stress of abuse appears to alter the brain's ability to react to later stressors, thus "rewiring" the brain. These changes in brain chemistry may be particularly important in early childhood when brain development is rapidly occurring.

Many researchers have looked at the mental health consequences of child abuse. Psychiatrists have recognized that survivors of child physical and sexual abuse are disproportionately represented in the mental health population. In addition, survivors of abuse are more likely to have chronic somatic complaints such as various chronic pain syndromes. Although these problems have been more studied in adult survivors of abuse, abused children may develop somatic complaints or mentally disabling conditions.

POLICIES AND PRACTICES

The abuse of any child does not occur in a vacuum; the familial, social, and medical milieu must be considered to protect children from further abuse and optimize their recovery from the abuse. The unique problems of each disabled child pose methodological challenges to those who study the abuse/disability relationship. Nevertheless, research in this area is important, not only because these children are at increased risk of abuse but also because conclusions made about nondisabled abused children cannot necessarily be extrapolated to disabled children. Finally, increasing society's awareness of this problem will help stop ongoing abuse and can lead to effective prevention.

—H. Hughes Evans

See also Childhood, Youth, and Adolescence; Children with Disabilities, Rights of; Crime and Delinquency.

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CHILD CARE

In modern societies where most parents work outside the home, families often have trouble finding affordable, quality child care. The parents of children with disabilities have historically faced even greater hurdles, since almost no formal child care services accepted disabled children during the nineteenth and much of the twentieth centuries. Accordingly, many families have found no other alternative but to place their disabled children in full-time institutions. With the rise of the deinstitutionalization and disability rights movements in the 1960s and 1970s, disabled children in Western Europe, the United States, Canada, and Japan have increasingly gained access to child care, albeit often through segregated programs. In industrializing and developing nations, however, child care for those with disabilities remains deeply problematic.

In the United States, the limited supply of child care overall is the result of its public-private organization (a pattern typical of much social provision in the United States). Formal child care originated in charitable day nurseries in the mid-nineteenth century and did not become a matter of public concern until World War II, when the federal government funded centers for the children of defense workers. This arrangement, however, lasted "for the duration only," and direct federal funding for child care did not again become available until the 1960s, when it was linked to efforts to move public aid recipients into the labor force. In the meantime, the government encouraged the growth of private child care (either voluntary or commercial) through tax breaks to providers and parents paying full fees. Federal subsidies for child care for poor and low-income families declined in the 1980s under the administration of President Ronald Reagan but rose again with passage of President Bill Clinton's "welfare reform" plan in 1996; current funding is, however, still inadequate. Because of resistance to setting federal standards and weak regulation in many states, the quality of both public and private services is uneven. By contrast, in many other advanced industrial societies, the state has played a more active role in organizing, funding, and regulating child care. Particularly since World War II, France, Sweden, Denmark, and parts of Italy and Canada have developed model services that are affordable, high in quality, and universally available.

INSTITUTIONAL CARE

Prior to the development of institutions for disabled people in the early to mid-nineteenth century, most disabled children were cared for at home by extended families and communities. Some children with disabilities found basic care amid the larger population of dependents in poorhouses, asylums, and orphanages. But the mid-nineteenth-century rise of state and private institutions (along with state schools for disabled children) in many West European nations, the United States, and Canada marked the real beginning of segregated care. These institutions, inspired by growing populations of urban poor, the pathologization of disability, and eugenicists' fears of "racial degeneracy" and "feeblemindedness," were designed to separate disabled people from the broader population, often permanently. While state schools for the deaf and blind and programs for crippled children, unlike those for the feebleminded, did not aim at lifelong segregation, they did require the removal of disabled children from their families and communities. These schools thereby reinforced the assumption that children with disabilities could not be properly cared for and educated at home.

The institutional model—and the primitive care it offered—increasingly gained sway, to the point that parents found keeping their disabled children at home logistically challenging and socially unacceptable. In 1851, the United States had 77 residential institutions for children; by 1910 there were 1,151, and by 1933 there were 1,613. Parents who needed care for children with disabilities, especially if they were working class or lived in urban areas without extended families, increasingly found institutionalization their only option. Day nurseries refused to accept sick or disabled children, and orphanages routinely sent feebleminded children to state institutions. Many doctors pressured parents to relinquish disabled children to the state just after birth. In the 1950s, one doctor told a father: "It will sap [your wife's] life, and seriously injure yours. It will create a home atmosphere that will be impossible for future children."

In the 1950s and 1960s, family members and politicians throughout Western Europe, Canada, and the United States began to advocate for the deinstitutionalization of people with disabilities. In particular, activists were emboldened by reports exposing the mistreatment and long-term emotional and intellectual harm suffered by institutionalized disabled children. In Illinois, young inmates were sometimes punished for infractions by being locked alone in "quiet rooms" for weeks or bound spread-eagled for days. The idea of "normalization"—that disabled people should be able to live at home with their families and be integrated into the broader community—and the burgeoning disability rights and independent living movements also played critical roles in spurring deinstitutionalization. The push toward community-based living was aided by a growing realization that it was cheaper than institutionalization. By the late 1970s, so many disabled children were living at home that many state institutions closed for lack of clientele.

Despite the success of the deinstitutionalization and disability rights movements in Western Europe and North America, the institutional model of care for disabled children remains prevalent globally. In the early to mid-twentieth century, industrializing nations such as China and the Soviet Union established state institutions to care for abandoned children, disabled and able-bodied alike. Today, little has changed in these countries. Deinstitutionalization and disability rights movements capable of challenging the deadly conditions in these institutions and the social prejudices underlying them have not emerged. Facing extreme prejudice and almost no social and financial support, parents of such infants routinely abandon their progeny at institutional doorsteps. In Russia, despite a 1990 law mandating social integration of institutionalized, disabled children and promising disabled people full civil, political, and economic rights, Human Rights Watch (2003) reported, "Infants classified as disabled are segregated in 'lying-down' rooms, where they are changed and fed, but bereft of stimulation and essential medical care. Those who are officially diagnosed as 'imbeciles' or 'idiots' at age four are condemned to life in little more than a warehouse, where they may be restrained in cloth sacks, tethered by a limb to furniture, denied stimulation, training, and education. Some lie half-naked in their own filth, and are neglected, sometimes to the point of death." By removing disabled children from the community, this segregation reinforces the social attitudes making such ill-treatment possible.

CHILD CARE IN THE DEINSTITUTIONALIZED ERA

In Western Europe, Canada, and the United States, deinstitutionalization has had mixed, even paradoxical, effects on the care of disabled children. In the United

States and Great Britain, deinstitutionalization and family support programs have enabled families to care for children with disabilities at home. These initiatives, however, have not fully addressed parents' problems in finding acceptable child care, nor do they address the segregated care that is available. Although programs dedicated to children with disabilities—respite care, early intervention, residential schools, and specialized day care services—cost more than integrated programs (even those that bring in experts and additional staff), segregated services remain the norm. Such programs provide invaluable aid and training for disabled children and their families, but they lack sufficient spaces. In addition, few run for a full day or workweek and respite care hours are limited by month and year, leaving parents scrambling for additional coverage. Children with disabilities are also overrepresented in group homes and foster care, where they make up 20-25 percent of populations (as compared to only 5–10 percent of children overall). These expensive programs help reinforce the notion that disabled people do not belong in the broader community and add to the profit margins of the private companies that have largely replaced public institutions.

Programs integrating disabled and able-bodied children, such as Head Start in the United States (which requires that 10 percent of enrolled children have disabilities) and some church, public school, and family day care facilities, have made significant strides. Most parents desire integrated programs for children with disabilities, and many studies have demonstrated that they teach tolerance to all children and serve disabled children better. Yet, for much of the 1970s and 1980s, these programs were rare and underfunded in comparison to their segregated counterparts. Operators feared that they could not adequately serve disabled children and that children with disabilities would dramatically increase costs; some were uncomfortable with the principle of integration itself.

In the United States, the Americans with Disabilities Act of 1990 (ADA) has significantly improved parents' chances of finding quality child care for children with disabilities—especially in integrated programs. The ADA specifically covers child care services (both family and center based) and bars them from rejecting children with disabilities unless they present "a direct threat to the health and safety of others" or require "a fundamental alteration in the center's program." The Department of Justice has mandated that centers cannot charge parents for disability-related services (e.g., administering medicine, monitoring diabetes, or helping with toileting), operators must admit older children who use diapers and children with HIV/AIDS, and programs must integrate children (including those with cognitive disabilities) into age-appropriate classrooms.

The ADA has opened up many more child care options to families with disabled children, but problems remain. More than 45 percent of mothers of disabled infants do not return to the paid labor force because they cannot find appropriate child care. Children with disabilities often require care into their teens, when finding care is particularly challenging. Centers do not have to accept a disabled child if it would force them to hire another worker, and operators may dismiss children for being disruptive or needing individualized attention, definitions that many parents feel can be manipulated. Parents can challenge operators' rejections through mediation, but not all families are aware of this right.

Parents' continuing inability to find appropriate child care reduces their incomes, a critical issue given the extra medical expenses often associated with disabled children. These mothers are particularly likely to have lowered incomes due to intermittent participation in the labor force. In desperate situations, lack of child care may lead parents to reinstitutionalize their children. One mother told a congressional committee:

> There is no such thing as day care available to my daughter [who has tuberous sclerosis]. It does not matter who pays for it or what the cost is, it simply does not exist. . . . Lack of day care was the deciding factor in my decision to place my daughter [in an institution]. I could not continue to disrupt my daughter with constant changes and I refused to lose a third job over day care. (quoted in Fink 1988:1)

Other industrialized nations such as Sweden, Italy, and Canada have pioneered inclusive child care programs. Building on such countries' long history of providing social services, these programs emphasize restructuring environments to reflect the needs of all children rather than just integrating disabled children. Sweden, which established universal child care in the 1970s, emphasizes that the needs of children with disabilities "are primarily to be met in regular child care and not by singling them out for special treatment. High overall quality in the preschool or leisure-time centre is viewed as the best kind of support for many of these children." Inclusion is seen as key to both teaching able-bodied children tolerance and ensuring that disabled people experience "normalization" from a young age. Italy, in 1977, mandated that children with disabilities be integrated into child care. Teachers hired to support children with disabilities work with all children to ensure integration and avoid singling out disabled children. Most Canadian provinces support some inclusive programs; Alberta's Integrated Day Care Program pays all extra costs associated with disabled children (including full-time special needs coordinators who focus solely on integration) and provides mobile teams for special training. Not all parents of disabled children in industrialized countries are able to find spots in inclusive programs, however; in Germany and the Netherlands, for example, segregated care persists.

UNEVEN DEVELOPMENTS

The 85 percent of the world's disabled children living in developing countries encounter a complicated mix of integrated and increasingly segregated child care. The institutional model of care once common in industrialized countries is rare in the Third World, with only 5 percent of children with disabilities (mostly children of the urban elite) in institutions. In villages and small towns, the extended family system often plays a critical role in helping care for disabled children and easing their incorporation into the broader community. In the past 20 years, the rise of community-based rehabilitation programs has enabled disabled children to receive specialized education and training at home and taught their communities to be more tolerant.

Yet many children with disabilities in developing countries have historically encountered extreme prejudice and segregation in care—an isolation that is now increasing. Certain cultures have long interpreted disability as a curse, contagion, or evidence of past sins, resulting in the loss of all support from the extended family and social isolation. In countries from Thailand to Uganda, investigators have found disabled children who had never been allowed outside their home for fear of family shame. These children generally receive only the most basic level of care and no training or education.

Poverty, urbanization and industrialization, HIV/AIDS, and the structural adjustment politics of the International Monetary Fund and World Bank also lead to limited, isolating care for children with disabilities. Labor migrants with disabled children face a double disadvantage, especially in urban areas: Not only have they lost the support of extended family and community, but their countries lack the extensive social services provided to disabled people in industrialized nations. Consequently, mothers going to work often have to leave disabled children with older siblings or even lock them inside their homes. With structural adjustment programs increasing basic living costs, more parents must migrate to find work and mothers are compelled to work even longer hours outside the home. The HIV/AIDS epidemic in sub-Saharan Africa has also created millions of orphans, often infected themselves and facing severe discrimination. Few receive any formal care; only 35,000 of the 800,000 AIDS orphans in Kenya, for instance, can be accommodated in orphanages, leaving most of the rest to wander the streets and work in odd jobs or prostitution.

—Sarah Rose with Sonya Michel

See also Caregiving; Childhood, Youth, and Adolescence; Family; Family, International.

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CHILDHOOD, YOUTH, AND ADOLESCENCE

It is a truism for parents: The birth of a child is a transformative experience. Priorities, perspectives, and plans change. The power of the child to transform adults is almost boundless. Like a bioemotional philosopher’s stone, the child transmutes an adult into a parent. This change often compromises primal urges, such as self-preservation, changing them into a stronger urge of self-sacrifice for the child. Certainly, there is a measure of biological imperative here, the propagation of one’s genes, making the self-sacrifice in fact a kind of self-preservation and a hoped-for immortality, but the motivations are also cultural and psychological.

This truism is even more applicable for the child with a disability. Such children have an incredible power to transform the world and the people around them. For example, children with seizures, limps, and sensory impairments were carried hundreds of miles by their parents to be cured at medieval saints’ shrines. Children with disabilities at medical institutions in nineteenth-century Europe altered the development of a wide spectrum of medical professions as well as the distribution of government budgets and private organizations. In mid- to late-twentieth-century America, the children of the March of Dimes drives and muscular dystrophy telethons inspired extraordinary numbers of people to charitable action. Similarly, the experience of disability in childhood has radically altered the personal development of world leaders, artists, and writers, as well as ordinary people. While international and national debates have raged across time about how to “respond” at a systemic level to children with disabilities, their individual and collective impact on humankind has been profound and irrefutable.

The interface of the child and of disability exists at multiple levels. These include (1) children with disabilities themselves, (2) the families of children with disabilities, (3) children in families with other children with disabilities or with parents with disabilities, (4) societywide care systems for such children, and (5) social perceptions of children with disabilities and the impact of that perception on adults with and without disabilities. These patterns have played out across time and culture with remarkable variation and similarity. What follows is a brief suggestion of the many examples of the role of children and disabilities in our societies.

DEFINITIONS

In the West, the definition of a child has traditionally been a human who is younger than 14 years old, although adulthood is now moving internationally to 18 years old. Around the globe and across time, this definition has varied. In premodern, rural Japan, boys who were 15 and girls 13 were considered adults; it is now 20 for both. In Samoa, cultural changes have altered both the age of adulthood and its cultural identifiers over the course of the twentieth century. In sub-Saharan Africa, shifting definitions of child and adult have challenged researchers for years.

From antiquity into the early modern period in the West, the life cycle of humankind was characterized by the Ages of Life, which varied in number from 3 to 12; with 7 being the most common. These ages were variable by time period and geography, but generally broke down as Infancy and Childhood, which covered the period up to about 14 years old; followed by Adolescence, up to 21, 28, 30, or 35; then Youth, to 45 or 50; Senectitude; Old Age; and Death. Importantly, disability was inherent in at least the first stage, infancy, usually judged to be less than two or three years old. It was characterized by inadequacy of the limbs for walking and inability to produce articulate speech. In the Middle Ages, the mimicry by old age of childhood's disabilities was a frequent topos in literature.

Today, in industrialized countries, a variety of ages may represent the boundary between adult and child—21, 20, 18, or 16—based on the bestowal of certain societal privileges such as voting, military service, driver's licenses, or drinking ages. Biological shifts have often represented that transition, such as the age when a female bears her own child. The age of consent to marry, in such cultures as it is necessary, has varied dramatically; gender too, significantly alters the status of child versus adult. While legal definitions vary by country and governmental body, familial or wider cultural expectations vary more widely and personally. Is the 30-year-old who lives with her parents still a child? Is the 12-year-old runaway fending for himself on the streets an adult? The meaning of "child" is highly dependent on context.

The terms of childhood are important to the understanding of disability too. The Latin word *infans* meant "unable to speak." Over time, it also took on the meaning "unspeakable." Similarly, the word *monster*, so often associated with children with congenital malformations, derives from the Latin *monstrere,* which means to show or demonstrate. In English, *youth* and *adolescence* are near synonyms with *child*. Yet youth has the added resonance of lost youth as opposed to senescence. Thus, *youth* carries an intrinsic hint of disability to come. The Renaissance and early modern fascination with the fountain of youth, for example, speaks of the inherent disability in youth's absence. Similarly, adolescence, a comparatively modern term that existed in Latin from the verb meaning to grow up, carries in its current incarnation a kind of disability itself; in this sense it is often perceived as the social maladjustment in the transition from child to adult; the disabilities of reduced danger aversion and experimentalism provoke many functional consequences. Adolescence in fact is often considered a state of frank social disability. This entry, however, will consider the child and childhood as the central focus.

THE CHILD ACROSS TIME

Philippe Ariès, a twentieth-century French demographer and social historian, proposed that the concept of childhood started in the late sixteenth and seventeenth centuries. He argued that the utility of a separate stage of human experience—the child's—emerged in the upper classes, gradually growing into a focus of study by the twentieth century. But the chronological thrust of this thesis has been vigorously denied by subsequent historians. It is impossible to ignore the potential danger seen in children during the Middle Ages, for example, when Pseudo-Albertus Magnus, writing *De secretis mulierum* in the thirteenth century, implored his readers in the preface of his "serious" work to prevent any child or anyone of childlike disposition from reading it. Knowledge in the misguided hands of the cognitively limited was hazardous. On the other hand, the extraordinarily positive influence of the child was undeniable, as when the birth of an heir to a throne sparked celebration among a populace, or in the profound growth in influence of the *baby* Jesus in medieval Catholicism. Children provoked adult reactions in a variety of ways.

For a family with a disabled newborn, those reactions started at home. During antiquity and the Middle Ages, the abandonment of unwanted infants did occur. Medieval theologians suggested it was possible that the number of affected infants was such that a man might unknowingly sleep with his previously abandoned daughter in a brothel. However, abandonment was not common in either ancient or medieval cultures, at least to the level of exposure and death, even for the child with a disability. Because of their intrinsic emotional and rhetorical power, children, either with or without disabilities, have often been social, metaphoric lightening rods.

The child with a disability could also be a source of inspiration, or of warning. In 1449, the burgers of a German village mutilated and blinded the children of criminals to act as a warning for other adults not to steal. This was an extrapolation of punishments of maiming and blinding the thief, stemming from Hannibal and before through medieval kings such as Charlemagne and Saint Louis to the Arabic cultures of today. A similar episode is recounted in the twelfth-century *Roman de Rou* during a Norman peasant revolt. The emotive power of a disabled child was such that in some medieval cities, poor parents were accused of blinding and mutilating their children to provoke more alms. This may not have worked well. A blind man from the Hôpital des Quinze-Vingts, founded in thirteenth-century Paris, told the story of a "little boy" who helped him beg. Passers-by maltreated the boy, filling the begging bowl with mud, knocking it from his hands, or giving him stones instead of coins. They even took the rock on which he sat while begging.

The able-bodied child also saw in disability a sense of "otherness." Their reactions could also be a danger to the disabled because of their mischievousness. William Coe, a yeoman who was a boy in Suffolk ca. 1680, remembered leading a blind beggar into a body of water as a joke. At the same time, early modern, like modern, children played games that broke the bonds of expected (or normal) posture, imitating disabilities—like hopping on one leg or spinning to get dizzy. Today's "Marco Polo," "Blind Man's Bluff," and three-legged races continue that theme of the child and the disabled.

Despite Ariès's thesis, a fairly consistent concern for children and for their distinctive nature from adults has existed in Western history. What is evident, however, is that during the seventeenth and eighteenth centuries, a shift in how we consider children in the West took place. Previously, children were seen philosophically as inherently sinful. Pierre Bayle, a Dutch Calvinist at the end of the seventeenth century, felt children's native sins were added to by their "blindly" believing whatever they were told.

Especially under the aegis of Jean-Jacques Rousseau and John Locke, children were reconfigured as innocent, only corrupting under the influence of adults. The ramifications of this shift have been profound. In Locke's *Second Treatise on Government,* he argued that during the imperfect state of childhood, one holds one's children in custody from God. For Locke, disability was also at the interface of connecting the child and the adult. A man blinded by smallpox could forget his childhood's memories of what colors look like. Consequently, the continuity between child and adult could be severed by any kind of memory loss. Education was a critical component in preserving children and the continuity of being into adulthood. This argument was enhanced dramatically by the French philosopher Jean-Jacques Rousseau. He minimized the importance of book learning and recommended that a child's emotions should be educated before his reason. He placed a special emphasis on learning by experience.

A close linkage between children and the disabled was also made in the eighteenth century. Locke suggested that children and "idiots" do not have the least apprehension of innate truths, thus equating the two groups. The subsequent fascination with the child was a staple for Enlightenment philosophers and scientists as they tried to understand humankind's role in the natural world. Describing the role of language in the development of the child led to a string of sensational "discoveries" of feral children, the so-called wolf-children, into the twentieth century. Jean Itard and Arnold Gesell observed and experimented with children raised without social interaction with other humans. These children's social isolation crippled their physiological ability to think and communicate, and vice versa. This research altered the understanding of child and language development. The "nature versus nurture" question continually turned on understanding children. Similarly, Charles Darwin's impact on eugenics was usually mediated through offspring and child-bearing, thus provoking discussions, laws, and actions of euthanasia, sterilization, and institutionalization.

Nevertheless, medical concern for children as a specialty probably reached a critical mass during the Enlightenment. In France, at least, in 1772, Gilibert was calling for specialists in pediatric care, especially for children with chronic ailments. Such arguments undoubtedly led to the founding of the world's first pediatric hospital in Paris, L'Hôpital des Enfants Malades, in 1802. That focus was soon echoed in the Germanic countries and throughout Europe. Such institutional support eventually provoked the specialization of physicians in children's diseases and sparked a similar rise in the United States by the later part of the nineteenth century. One of the ideological drivers for separate institutions was to protect innocent children from the corrosive effects of adults also hospitalized.

Arguably, a significant change in the nature of disability and childhood came, in the United States at least, during the Progressive Era and the growth of industrial-capitalism. With rising working-class employment in urban settings attracting youths and a rise in modest disposable income for these employees, a significant youth culture of independence provoked concern among the middle class at the dawn of the past century. Coupled with a declining age of menarche and a rising age of marriage, these changes sparked progressive reforms for child labor and welfare, including robust requirements for school attendance (rising from 6.7 percent of adolescents in 1890 to more than 50 percent by 1930). These changes increased the functional requirements for children with disabilities, but they did not offer solutions for the ensuing social challenges. At this same time (ca. 1900), children were also converted from objects of "utility," that is, laborers on farms or factories, to objects of "sentiment," that is, into so-called consumer goods. In effect, the middle-class child's relative value had become worthless by the middle of the nineteenth century. Similarly, child labor laws made the lower-class child less "valuable" by the early twentieth century. Child insurance policies became more complex social devices as a consequence. Finally, a sequence of international wars provoked an escalating concern for the physical "fitness" of U.S. and European male youths. The public welfare seemed inextricably linked with the health and able-bodiedness of its adolescents, and by extension, its younger children. Children with disabilities thus became a perceived national threat.

One result of such mingled social concerns was the rise of eugenics and its situation within official and unofficial policy. In the United States, celebrated cases such as that of Harry Haiselden, MD, a Chicago surgeon in the 1910s who practiced and promoted the "euthanasia" of newborns with disabilities, sparked both sympathy and debate. Laws allowing the sterilization of both girls and boys with disabilities synergized with concerns to safeguard future generations from the "burden" of their own disabled offspring. While such efforts continued well into the second half of the twentieth century in the United States, they found their apotheosis under the Nazi regime in 1930s Germany and the institution of the Aktion T4. Under this official program, children and then adults with disabilities were selectively killed both in hospitals and in special centers. Even after Hitler officially ended the program a period of so-called Wild Euthanasia continued into the 1940s. In addition, experiments on children with disabilities using tuberculosis vaccines touted the idea that these children were not the objects of minimizing suffering, but rather of obviating the "ballast-existence" for the public. In the United States, echoic experiments occurred with institutionalized children, such as those at Willowbrook.

While elimination of children with disabilities became one mechanism to reduce disabilities in future generations, specialists discovered new disabilities to describe and prevent. Childhood development was critical in the early mental health movement and dynamic psychiatry of the 1900s–1920s in the United States. The experiences of childhood became the cause of many mental disabilities, as perceived by psychologists and psychotherapists. One's life as a child could impair one's life as an adult, putting the two in tension and, at times, at war. The application of preventive measures in childhood—a kind of mental health "prophylaxis"—could be seen as early forms of disability prevention, beyond the venues of the eugenicist. Lawrence K. Frank argued that society had become "mentally disordered," thus disabling the entire U.S. social body because of the "sickness" of adolescent/youth culture. Certainly, some of the social anxiety came from fears of technology and the inadequacy of the family to absorb them without conflict.

DEVELOPMENT AND DEPENDENCE

The duality of dependence of the child with a disability—dependent as a child and dependent as a person with a disability—at once intensified and negated a child's disability. For the caregiver, the dual dependence can add more “work” for the adult; for society, the dependence can be nullified. The child is already dependent and so is less apparent than a newly disabled and dependent adult. At times, the child’s disability and its developmental potential can even invert the disability. Society frequently turns disabled children into heroes, as in Great Britain during World War I or in the United States during World War II. The hybrid relationship of disabled veterans, infantilized by society, and the heroicized congenitally disabled child was evident in England during World War I. The close identity of disabled children and soldiers has played itself over and again, as, for example, in the United States of the 1960s when veterans with amputated limbs were taught to ski; children with amputations learned at the same time, the two groups idolizing each other.

The issue of normality was especially central in childhood and adolescent culture as it came to be typified in the early twentieth century in the United States. There, Viennese psychoanalyst Alfred Adler’s notion of the inferiority complex was quickly absorbed and disseminated. Similarly, the “defects” of adolescents could become a target of national concern during wartime recruiting efforts. Approximately 25 percent of U.S. military recruits ages 18–19 years were evaluated as being physically or mentally defective after the Great Depression. Like concerns were expressed in Great Britain, France, and Germany.

Fears over normal development extended beyond the militaristic. The effect of parenting on the chronically ill child with a disability in the 1940s was considered a possible venue for degendering. If not raised “properly,” a parent’s anxiety could rob a boy of his manhood or a girl of her femininity. The nexus of the parent, the child, and disability could thus cross the bounds not only of (in)dependence but also of gender identification and sexual behavior because of, for example, coddling. Thus, a curious multilevel interdependence between able-bodied children, disabled children, able-bodied adults, disabled adults, and society at large has existed for many years. This was also seen in the early modern relationship between some noble children and the court dwarf, who could be delegated as nurse, companion, or tutor to the child. Paintings of the dwarf and child together evoke multiple levels of sociocultural comparison. From the late nineteenth century, there was a progressive, at-once practical and symbolic comodification of the child’s body, particularly with respect to life insurance, which by the mid-twentieth century had begun to wane in favor of a pricelessness of the child, irrespective of its able-bodied state.

In 1930, a citywide survey of New York City concluded that the issue of disabilities was significantly one of childhood as so many children had disabilities and so many adults had disabilities that started in childhood. Responding to such concerns and others, by 1950 most advanced industrial societies had introduced comprehensive family allowance systems (the United States was a notable exception). France was the pioneer and also the most generous with almost 5 percent of its national income in 1961 allocated for children.

With the growing valuation of the child with(out) disabilities has come a shift in causation. Where until the mid-twentieth century in the United States a child’s disability was often blamed on his or her parents, over the past 50 years the blame has shifted to the child itself. Unlike the medieval image, neither parental poverty nor moral inequity is the cause of familial harm, but rather the presence of the disabled child. Scholars and researchers have assigned to the child blame for difficulties faced by the family and by society at large: divorce, social isolation, geographic immobility, national or state debt. The mechanisms invoked have ranged from anger to grief, denial to guilt, marital incohesion to social withdrawal and a host of other social and emotional processes. A 1981 article created a new “medical” condition, parentaplegia, to characterize the impact of the disabled child on its parents.

Simultaneously, by the 1980s, historians of Western childhood raised an alarm about the loss of notions of childhood. They observed that 12- and 13-year-olds were among the highest-paid fashion models, that from 1950 to 1979 crime by children had increased more than 100 times, that children’s clothing was now adultlike, and that children’s sports such as Little League now had world championships, with adultlike umpiring. The distinctions between the child and the adult were blurring. Children were at once harming and being harmed by the nature of modernity. The veracity of these concerns has yet to be proven, but it is clear that as in other centuries, our perception of the reciprocal impact of children and society is heightened.

The impact of a child with a disability is also evident prior to conception. It was a common medieval belief that the Devil could substitute a dysmorphic child for a "normal" child if the parents were sinful. By the late Middle Ages, the mother's body was often the source of disabling forces upon the fetus. Like an umbrella, the liver protected weeping humors falling in the abdomen from reaching a child implanted on the right side. Thus, a child on the right side of the womb was likely to be a boy and well formed; on the left side, the child was more likely to be a girl and deformed. Claude Quillet, much admired by Nicolas Andry, the founder of orthopedics, wrote *Callipaedia* (1656), a treatise on how to produce beautiful children during pregnancy. This work extols many positive actions, but it also invokes the fear of causing physical deformities in inchoate children if husband and wife are intimate during the mother's menses. Such cautions were quite old, dating back to antiquity at least, and readily generated fears of harming infants/creating disabilities even before a child was conceived.

On the other hand, the fetus can disable the mother. Today, in sub-Saharan Africa, a disproportion between the birthing fetus' head and the mother's pelvic outlet can cause fetal death and fistulae (pathologic connections) between the anus, rectum, uterus, and vagina. The result is an unchecked flow of urine or feces through the vagina and severe social and medical disability.

Finally, the absence of a child can be a disability. The inability to conceive (whether because of the mother, the father, or both) has often been blamed on the potential mother, perceived as a disability for those seeking heirs throughout time. The social consequence has been ostracism, divorce, or death, as suggested by Henry VIII and Anne Boleyn. In the twenty-first-century United States, it is quite common for women to refer to their "biological clock," which includes not only the approach of menopause and the inability to procreate but also the increasing likelihood of birth defects and Down syndrome after age 35. Such concerns were common in history as well.

CHILDREN'S CONDITIONS

Starting from the newborn period, children are subjected to environmental events that can result in impairments with disabling consequences. From malnutrition to infections to trauma and child abuse, infants acquire traumatic brain injuries, spinal cord injuries, and skeletal defects. From metabolic disorders to genetic defects, children are also born with conditions that can restrict their development.

In the United States, the incidence of children with physical disabilities is about 6.5 percent; in central Asia, the rate is reported as approximately 10 percent, though all such statistics are highly dependent on definitions, cultural context, and sample sizes. The most common conditions associated with American childhood disability are respiratory diseases and mental impairments; in Vietnam movement disorders are the most prevalent, accounting for about a quarter of childhood disability. Considering conditions demographically, the older a child is the likelier it is to have a disability; nevertheless, in some developing countries, more than one-half of disabilities are acquired congenitally. There is also a higher incidence among boys and children from low-income and single-parent families. The functional impact on society is considerable. Thus, disability among U.S. children provokes some 66 million days of restricted activity each year, of which more than a third are lost school days. Medically, this combination, in our medicalized society, creates each year nearly 26 million physician contacts and 5 million hospital days.

These numbers suggest some of the ways that childhood disability has been pathologized at a social level. Yet the pathology has been even more metaphoric. The notion that children become a type of disability for their parents (e.g., a social handicap, limiting adult-adult interactions; a financial impediment) was generalized to the image of adolescent culture being an infectious disease or pathology to disseminate to the "body politic" in the 1940s of the United States. Similarly, the growing perception of the "harm" of the child with a disability on its family has grown in Western culture over the past 50 years. In other parts of the world, stigmatization can be profound. More than 80 percent of parents with disabled infants in

Zimbabwe receive no assistance from their nuclear or extended families; they most frequently cite stigma as the cause—that the disability becomes a bad omen for the family in general and so must be ritually expunged or else eliminated from the family unit.

Among the unique features of children are some of the disabilities associated with them. Children may have conditions peculiar to their age provoking their disability, such as Osgood-Shlatter disease, an inflammation of the adolescent knee of typically short duration. But in other conditions, such as juvenile rheumatoid arthritis, or congenital conditions, such as cerebral palsy, the symptoms may begin in childhood but last a lifetime. In still different settings, a condition may start symptomatically postnatally, such as cystic fibrosis (CF), and last throughout childhood with an early death. CF has thus traditionally been considered a child's disease. But now increasingly people with the condition are living into adulthood with a lengthening life expectancy. Such shifts provoke sociological changes in health care distribution and professional identity, as insurance companies alter their life-expectancy tables for a given diagnosis and internists are forced to learn more about CF as those with the condition transfer their care from their pediatricians. Still other conditions have become associated with childhood, as scoliosis and adolescence, because of medical screening and professional identification. Certainly, this kind of perception can change over time with cultural shifts.

Development, the change of the child as it ages, is a key Western concept underlying the experience of children and disabilities. The Latin term, *infans,* above spoke to the infant's inherent dependence on adults, but that dependence ultimately gives way through growth to independence—the disability evolves into ability. But for disabled children, evolving ability and disability over the life course changes the meaning of their disability. Thus, the differing life stages of children can alter the experience of disability, both because of changes within their own body and psyche and because of the shifting perception of the infant, child, youth, or adolescent by society around them. The infant with cerebral palsy has different expectations of self and culture than does the nearly adult adolescent with cerebral palsy. Particularly in adolescence, transitioning from childhood to adulthood with disabilities can present unusual challenges.

Such chronological variation can also be useful or instructive. A recurrent motif in the story of children with disabilities is that many, born with disabling conditions, often do not realize that they have an "abnormal" condition until they leave the home and interact with other families. Congenitally deaf children commonly experience the sense that other families are behaving oddly, compared to their own, when they first visit a friend's home and see them talking orally. These experiences highlight the social component of disabilities, which can be mitigated or obliterated by cultural adaptation. At a community level, Martha's Vineyard, an island in Massachusetts, culturally developed widespread sign language use because of a high prevalence of hereditary deafness in the nineteenth century.

Today in the West, most children with chronic health conditions survive to adulthood. Simultaneously, rates of disability among younger Americans have increased dramatically during the past 40 years, mainly through the rapid growth of a few common conditions (obesity, asthma, and mental health conditions). The growth of these disabilities among young people has tremendous implications for quality of life of these individuals as they mature, as well as for national health and related expenditures. Consequently, where positive and negative eugenic policies were the norm previously, contemporary societies struggle with different means of prevention as well as decreasing the social component of disabilities through education, access, and support.

In Western medical models, caregiving often extends outside the family. For children with disabilities, while the family still remains the core caregiver, assistance is also given by many health professions, from nursing to social work to the therapies to pediatrics to pediatric rehabilitation, as well as educators. Two common factors that distinguish child care from adult care are child development and education. Children since before antiquity have been recognized as having anticipatable stages in their growth and capabilities, both physical and cognitive. But since the nineteenth century, educators, clinicians, and investigators have established "normal" patterns and relative stages of growth and development, from height/weight charts to tables of expected abilities at each age. The implications of development for the child with a disability include naturally changing/improving facility with both physical and cognitive tasks. Thus, infants with exacerbations of asthma are more dependent on others for monitoring and keeping their airway clear and stable; adolescents with attention deficit disorder have greater self-awareness and cognitive/physical coping skills to care for themselves. And through all these changes, teachers and school systems must respond to the growing needs of the child.

On the other hand, the developing child experiences shifts in both physical and emotional balance. Thus, the infant's head-to-body-size ratio is almost one-third, but the adult's is almost one-tenth; the infant with a static myopathy, a condition affecting muscle strength, has to use different strategies to keep his or her head up than the adolescent with the same condition. Similarly, the adolescent has very different emotional motivations than the infant for keeping his or her head up. Consequently, children with disabilities are biologically a "moving target" for their family, for their medical team, and for those giving longitudinal assistance. The developing nature of their biological substrate provides both basic hopes for improving function over time and specific challenges for adaptive strategies, which distinguishes them from adults.

The inherent "plasticity" of the child's body also affects reaction to potentially disabling conditions. Children's ability to recover most or all of their function from a broken bone is radically better than that of nonagenarians. Immunologic and hematologic systems also frequently give hope for notable recovery or improvement beyond that of an adult with a similar impairment. On the other hand, a child's ability to establish a "higher" quality of life long term with a spinal cord injury than an adult who acquired that injury during adulthood may have more to do with psychological and cultural plasticity.

CHILDREN WITH DISABILITIES IN SOCIETY AND CULTURE

Unlike adults, children already exist in a state of long-term dependence on (or cooperation with) others for subsistence. Where nondisabled adults are usually expected to be able to see to their own daily, bodily functions and needs, children, in a developmental fashion, only slowly are able to control their excretory, nutritional, and daily living needs. In most cultures, care for the child, with or without a disability, is expected to be the responsibility of the biological parents or their designees. In this sense, the child with an acquired disability has expected, designated caregivers, another standard difference from the adult situation. A young, single adult might fall back on this model of care, or an adult with a partner might depend on his or her partner for care. In the child's case, examples of abandonment, orphaning, and poverty have necessitated broader social support and care for children when parents are unable to fulfill their commonly expected roles. Thus, in the West, religious institutions for many centuries have offered that support, and in more recent centuries, governmental systems, such as homes, institutes, and hospitals, have filled those roles.

As a consequence of the different expectations of dependence of the nondisabled child and adult, the presence of a significant disability for an adult often includes a form of social stigma akin to infantilization. That an adult would need the long-term care of another adult for excretory or nutritional needs is so like the typical pattern for an infant or young child as to symbolically provoke a comparison to the child.

A child's cultural, developmental dependence is also evident in education. Integrating the child with a disability into an educational system, usually designed for a spectrum of the "normal child," represents one of three recurring settings of broader social integrations and disabilities, the other two being (re)integrating the worker with a disability and reintegrating the soldier with a disability across many societies and time periods. The history and description of "special education" are crucial topics, which are dealt with elsewhere in this encyclopedia, and remain fundamental to the notion of the child with disabilities in our society.

Differences of the child at various developmental stages have also provoked philosophers who consider disabilities. At one extreme of these discussions is Peter Singer. Among others, he has suggested that an infant's lack of long-term and continuous memory affects definition of self. This identity changes as the child acquires a continuous sense of self over time. To inflict suffering on the younger child in hopes of improved quality of life in the older child creates a moral dilemma, which should not always be decided in favor of the older child. Using this logic, Singer has notoriously argued, and some physicians have enacted, a form of euthanasia for infants with severe disabilities in hospitals, based less on the societal politics of the early twentieth century and more on elements of individual's rights. Cognate arguments regarding abortion and children's end-of-life care are also rife. Throughout the West, disability rights activists have vigorously and intellectually reasoned against such arguments. The critical and compelling nature of these debates clearly indicates the power of children and disabilities in contemporary cultures.

But the role of the child and disability is not restricted to philosophy, medicine, and politics. The power of the child to evoke notions of innocence, purity, and vulnerability, especially since the "discovery" of childhood in the seventeenth and eighteenth centuries, has been an active principle in many cultural developments. In art, the child with a disability has most frequently been depicted with a range of provocative, equivocal, or more positive emotions. The bust of an ancient Egyptian princess preserved in Berlin depicts with neutrality a congenital cranial abnormality. The mingled spirituality and quietude of a Roßlan child of the seventeenth century with a possible neural tube defect evokes the sanctity of disability. And the inviting joviality of the club-footed boy in the seventeenth-century painting by Jusepe de Ribera or the fetching shyness of Annibale Carracci's sixteenth-century *Hunchback* cry out the simple humanity of people with disabilities. The power of children and disabilities extends into the creation of artistic movements as well. Primitivism and other movements in art were motivated in part by fascination and envy at the untutored nature of children's attempts at art. Paul Klee, the expressionist painter, noted that art's primal source is discoverable in the work of uncorrupted children and psychotics, making both conditions highly functional for the primitive arts.

In addition, the motif of a child with a disability is extensive in literature. From Charles Dickens's pivotal Tiny Tim in *A Christmas Carol* to the Spanish-Arabic story *The Girl Without Arms,* from Clara Sesseman in Johanna Spyri's *Heidi* to E. B. White's title character in *The Trumpet of the Swan,* children are continually exposed to disability in fear and triumph, isolation and companionship. Scholars have divined a shift over the past 200 years in the thematic tone of disability in children's literature, in English at least. Victorian culture typically took advantage of the immoral stigma of disability to evoke charitable pity and to stimulate moral uniformity. Gradually, more recent authors use disability as a device to highlight similarities across physical difference, critiquing intolerance and social myopia. Even in movies and advertisement, childhood disability is becoming more integrated and mainstream, from the covers of runners' catalogs to Luke Skywalker's amputation in *The Empire Strikes Back* (*Star Wars*), the quintessential adolescent crossing into adulthood.

One can speak of children with disabilities as fragile. But inherently, and paradoxically, they are extremely durable and potent, able to change families, institutions, experiences, and social values in ways adults with disabilities never could. Yet despite their power, children and especially those with disabilities often remain hidden at the level of international policy, analysis, and culture. Confronting this paradox remains a profoundly important task for us all.

—Walton O. Schalick III

See also Early Childhood Intervention; Family; Family, International; Feral Children; *Healthy People 2010;* Infanticide; Jean-Jacques Rousseau.

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CHILDREN OF DISABLED PARENTS

Broadly defined, children of disabled parents include any child from birth to age 18 who is being raised by at least one parent with a disability. In the United States, it is estimated that there are at least 15 to 20 million children of disabled parents and an additional 25 to 30 million adults who were raised by a disabled parent. The implications of being raised by a disabled parent have been the source of numerous studies, public conjectures, and professional scrutiny—all of which touch on the fundamental rights of disabled people to be parents as well as the fundamental rights of children to be raised in an environment conducive to maximal development. Despite the lack of appropriate resources for most disabled parents and their children as well as persistent negative assumptions about these families, the vast majority of children of disabled parents have been shown to have typical development and functioning and often enhanced life perspectives and skills.

The exact numbers of children of disabled parents vary considerably depending on several subjective criteria used to estimate them. Each of these factors not only determines which children are included as "children of disabled parents," but these factors also contribute to the diversity of perceptions and experiences among these children. How significant is the parent's disability? Does the parent's disability routinely affect parenting tasks and responsibilities? Has the parent been disabled during most of the child's upbringing? Does the parent describe himself or herself as having a disability? For example, most Deaf parents, parents with multiple sclerosis, and parents with short stature or parents from several ethnic communities would not self-identify as "having a disability"—yet children from all these parent groups are typically included among "children of disabled parents." Children of disabled parents may also include children raised primarily by a grandparent or other relative with a disability.

As with children from any group of families (e.g., African American families, Catholic families, rural families), there is no single picture to describe children of disabled parents. As in all families, each child's temperament, personality, gender, and birth order as well as the family's ethnicity, and social and economic status are important factors that contribute to childhood experiences and outcomes. However, a number of additional factors are part of each child's experience of being raised by a disabled parent, notably: What is the nature of the parent's disability? Has the child experienced changes or loss of the parent's capacities (e.g., a newly acquired disability or change in functioning)? Does the child also have a disability? If there is a second parent or other primary caregiver, is he or she also disabled? What meaning does the child learn about the parent's disability from the parent, other family members, peers, or the larger society? How isolated from or integrated into the local community is the child's family? What disability-appropriate information, technologies, or resources are available to the disabled parent and the child? How does the parent's disability affect specific age-dependent parenting tasks (e.g., diapering, reading stories to the child, assisting with homework)? Ultimately, however, research has shown the best predictor of outcomes for children of disabled parents to be the same as for children of nondisabled parents: the quality of the relationship between the parent and child.

National data indicate that the majority of children of disabled parents (86 percent) are not disabled. Overall, the number of disabled children of disabled parents is somewhat higher than the number of disabled children of nondisabled parents. The higher figure may be partially due to higher rates of adoption of disabled children by disabled parents, although available data cannot confirm this explanation. However, disabled children of disabled parents are often seen as having the advantage of having a parent who has the experience and can serve as a role model for their disabled child.

Many people assume that being raised by a disabled parent is potentially risky and even damaging to the child—ranging from concerns over the child's physical safety to whether a disabled parent can adequately meet the child's social, emotional, or developmental needs. In his studies of caretaking responsibilities among children of disabled parents, Richard Olsen discusses how these children are often presumed to be victims, with criticism explicitly extended to their disabled parents for even having children in the first place. This negative expectation confirms the widespread social prejudice many parents with disabilities report about their rights or abilities to parent. Such speculations are further fueled by a number of studies that concluded that being raised by a disabled parent invariably leads to significant negative outcomes. Children of disabled parents are thought to be at risk for numerous problems including behavioral problems, psychological impairment, delayed language development, poor self-concept, psychodynamic conflict, developmental delay, and child neglect or child abuse.

Yet many of these studies of children of disabled parents that predict negative outcomes fail to make important clarifications and generally mirror broader societal prejudices about the capabilities of people with disabilities. For example, several studies generalize from a single case study of a child of disabled parents to all children of disabled parents. Often these case studies are drawn from clinical populations and represent the most troubled extremes. Other studies fail to distinguish between different types of parental disabilities or blur the age distinctions of the children. Many studies of children of disabled parents also fail to identify or investigate important contextual factors—particularly, known risk factors such as poverty, a parent's history of abuse in childhood, parental substance abuse, parental depression, or lack of adequate family resources and supports. Without considering these distinctions and contextual factors, problems within the family are invariably attributed to parental disability.

In contrast to studies that presume pathology and ignore important distinctions among these children and their parents, several more recent investigations are characterized by nonpathologizing hypotheses as well as their focus on specific parental disabilities and a specific age range of children. In one of the first major studies to contradict the prevailing negative research hypotheses and suggested outcomes for children of disabled parents, Frances Buck and George Hohmann found that children whose fathers had spinal cord injury displayed normal development in all areas investigated (personal adjustment, sex role identification, body image, health patterns, athletic interests, interpersonal relationships, parent-child relationships, values and attitudes). They concluded that children raised by parents with spinal cord injuries grew to be healthy, well-adjusted adults.

Although investigating different populations of disabled parents and their children, a number of other researchers have similarly adopted a nonpathological framework as well as clarifying important family characteristics. From these studies as a whole, several consistent themes emerge among these families: a notable lack of norms and role models for disabled parents and their children, more fluid and more flexible family roles available to parents and children, barriers to positive family functioning located in external social and environmental obstacles rather than the result of a parent's disability, greater resiliency and problem-solving skills among family members, and a desire for greater public awareness and more informed professional practice. Most of these investigations conclude there is average to better-than-average development and functioning among children of disabled parents and found positive outcomes as well: enhanced coping and problem-solving skills, greater acceptance of difference, and more positive attitudes toward disability.

Despite these positive findings, the pathological supposition that children of disabled parents will be parentified is pervasive and persists among professionals as well as among the general public. *Parentification* is defined as a functional or emotional role reversal in which the child takes on responsibilities normally reserved for the parent or other adult figure. Such children sacrifice their own needs to accommodate the needs of the parent, and long-term and persistent parentification is presumed to lead to developmental delays as well as adult dysfunction. Children of disabled parents are frequently presumed to be parentified, assuming the physical and emotional responsibilities that their disabled parents cannot.

Yet several recent studies question this assumption. Studies by Megan Kirshbaum and her colleagues at Through the Looking Glass found, for example, that disabled parents frequently took on increased responsibilities and risks rather than stress their infants or ask their young children for assistance. Lisa Cohen found that physically disabled parents were often reluctant to ask their older children to do tasks common to children of nondisabled children (e.g., taking out the garbage) if the parent felt it was necessitated by the parent's disability. A national study by Rhoda Olkin and Kelley Abrams documented that adolescents of disabled parents perform the same number of household tasks as teens of nondisabled parents. In his national studies of deaf parents and their hearing children, Paul Preston questioned the inflexible and ethnocentric notions of family functioning used to assess families with deaf or disabled parents, finding such values are frequently normed on Western, Caucasian, middle-class, and able-bodied families. Instead, he and others suggest that some children's responsibilities are normal and appropriate within the disability and Deaf communities, and it is more often negative social expectations and misinterpretations that pathologize these families. Finally, a number of these and other researchers stress that the availability of resources is an important mitigating factor in the degree and type of assistance required within the family.

Additional nonpathologizing and focused studies of adult children of disabled parents complement findings from studies of younger children of disabled parents. First, adult children consistently distinguished between their internal family norms and functioning (which considered the parent's disability as normal) and the persistent stigma and social exclusion directed at the family from outsiders. Second, adult children remained protective of their parents and identified numerous social and environmental barriers as far more problematic than their parent's disability. Third, most adult children described positive outcomes of being raised by disabled parents: greater social awareness, better problem-solving skills, increased comfort with and acceptance of difference, increased adaptability, and generally having better life skills and being more worldly. Fourth, adult children identified similar factors that contributed to more positive life outcomes: the parent's positive self-esteem, the availability of extended family support and community resources, and the presence and support of other adults in addition to their parents. Finally, and most significantly, adult children underscored the most pivotal issue regarding the impact of their parents' disabilities: the quality of the relationship they had with their parent.

One group of children and adult children of disabled parents is notable not only for the number of studies conducted about the group but also for the group's social and organizational visibility. Children raised by culturally Deaf parents are typically raised within a distinct linguistic and cultural community, and these childhood experiences have a lifelong impact whether the child is hearing or deaf. Ninety percent of the children of deaf parents are hearing, and these hearing children frequently develop strong bilingual skills and bicultural identities as both Deaf and hearing. As adults, a majority of these hearing children continue to participate in the Deaf community socially and often professionally (e.g., as interpreters, teachers, counselors). Children of Deaf Adults (CODA) is an international organization of adult hearing children of deaf parents. Founded in 1983, this organization's mission is to promote family awareness and individual growth in hearing children of deaf parents. A complementary organization KODA (Kids of Deaf Adults) is dedicated to deaf parents and their hearing children under age 18. Deaf children of deaf parents are also noteworthy as transmitters of Deaf language and culture among their deaf peers who come from hearing families. Considered core members of the Deaf community and frequently assuming leadership roles within the Deaf community, deaf children of deaf parents outperform deaf children of hearing parents on almost all intellectual, social, and psychological tests. Although this cultural heritage from their childhood experiences is particularly evident among hearing and deaf children of deaf parents, research and anecdotal evidence suggests comparable perspectives also exist among many other children of disabled parents as well.

—Paul Preston

See also Childhood, Youth, and Adolescence; Deaf Culture; Parenting.

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CHILDREN WITH DISABILITIES, RIGHTS OF

In every society, children's inferior roles and limited ability to advocate for themselves render them uniquely vulnerable to deprivation of their rights. That vulnerability is significantly increased for children with disabilities whose heightened dependence on others and need for support exacerbates their inferior role. For children with disabilities, deprivation of rights may take the form of denial of treatment, lack of accessibility to settings and experiences, isolation, neglect, exploitation, and abuse from caregivers. The recent history of Western countries reveals that it was only a few decades ago that a child with disabilities was deprived of the most fundamental rights of citizenship in the form of denied access to public education and to participation in community life. Instead they were assigned to institutional or custodial care and experienced a lifetime of isolation, neglect, and deprivation of opportunities for academic, social, and personal growth. Unfortunately, that situation still exists today in countries around the world reflected in rejection of children with disabilities by family and community and their subjection to discriminatory and abusive practices in orphanages and institutions.

Advocacy efforts by, and on behalf of, adults with disabilities have contributed to a growing awareness of human rights internationally. Awareness of the rights of children and youths with disabilities has also been addressed although not as extensively. The priority for making children's rights the basis for policy development, legislation, and service provision is reinforced by emerging issues in developing and developed countries. Within a global perspective, disability is disproportionately distributed in the developing world. Children in turn account for the largest number of those with disabilities, reflecting the combined consequences of poverty, endemic disease, inadequate health care, poor nutrition, and lack of education. In developed countries, the rights of children with disabilities and chronic conditions are central to debates about societal responsibilities and resource allocation. If the premise of human rights is to serve as the basis for equitable services for all children and to address their unique vulnerabilities, it is essential to define what constitutes the rights of children in general and of children with disabilities in particular.

In 1959, the United Nations published the first Convention on the Rights of the Child. Thirty years later, in 1989, the second UN Convention on the Rights of the Child was published and went into force in 1990. The convention consists of 54 articles with 41 articles specifying the nature and conditions of the rights of children and the remaining 13 articles pertaining to implementation of the convention. Major principles underlying the convention are based on the premise of the child's integrity as a person and inherent right to life and survival, to an identity, to be the first to receive services, to a family environment, to protection and assistance in institutional care, and to protection from exploitation. In a related area, the convention speaks to protection of the family unit as the context of the child as a right of children with particular reference to its caregiving responsibilities.

Of particular relevance to the rights of children with disabilities are the paragraphs of Article 23 that define the responsibilities of member states. Paragraph 1 declares that States Parties recognize "that a mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promotes self reliance and facilitates the child's active participation in the community." Paragraph 2 reads,

> States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the circumstances of the parents or others caring for the child.

Paragraph 3 further specifies that the assistance

> be provided free of charge, whenever possible and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest social integration and individual development, including his or her cultural and spiritual development.

An essential right defined in the convention is the right of children to be heard and to have the legitimacy of their perspectives, interests, and preferences recognized. In most societies, the right of an individual to be heard in a formal sense is not afforded until late adolescence or early adulthood with societal affirmation of maturity, often in conjunction with the right to vote. The right to be heard is likely to be limited for children in general as it is for persons with disabilities. For children with disabilities, that right may essentially abridged. This is particularly problematic in that their ability to express their feelings or wishes is restricted making them vulnerable to neglect and abuse. How to ensure this right for children with disabilities and chronic illnesses is an ethical challenge, in that their physical or mental needs may require medical treatment or therapeutic interventions for which they are unable to provide or withhold consent. Ensuring the means and conditions under which the child can exercise choice to withhold or provide consent for treatment or intervention is an ongoing issue that needs to be addressed.

A central principle in the Convention on the Rights of the Child is access to education for all children including those with disabilities. This principle is recognized and extended to children in the preschool years in a related UN document, the Standard Rules on the Equalization of

Opportunities for Persons with Disabilities published in 1993. It was further elaborated in the Salamanca Statement and Framework for Action in 1994 specifying the provision of special education for children with disabilities or learning difficulties. The Salamanca Statement specifies that the educational approach for children with disabilities should build on an inclusive approach and be child centered in its application. Education for children with disabilities in the preschool years should be defined by goals of fostering development and school readiness. A review of legislation for education of children with disabilities in different countries indicates that there is not a clear position concerning these rights. While the goal of such legislation may be to ensure the rights of children to education, the legislative acts are mainly defined in terms of the provisions, resources, and manner of services to be provided.

The UN Convention on the Rights of the Child, Rule 6 of the UN Standard Rules on the Equalization of Opportunities, and the Salamanca Statement represent universal standards for equalization of opportunity for children and youths. As such, they formalize the child's protection from discrimination, abuse, neglect, and denial of access and the right to care, support, and education. Most of the member states of the United Nations have ratified the convention. It should be recognized that ratification does not mean that the rights of children are in fact fully or even partially upheld in countries that have ratified the convention. However, the convention makes the rights of children explicit, constituting a universal bill of rights that can serve as a framework in the development of national policies, legislation, and practices pertaining to the rights of children. Adherence to the principles of the convention also implies obligation by society to honor the rights of children with the provision of identified needs.

—Rune J. Simeonsson, Eva Bjorck-Akesson, and Joaquim Bairrao

See also Childhood, Youth, and Adolescence; United Nations Disability Convention.

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CHINA

See Disability in Contemporary China; Experience of Disability: China

CHIROPRACTIC CARE

The chiropractic profession was founded in 1895 after magnetic healer Daniel David Palmer adjusted the thoracic vertebra of janitor Harvey Lillard and restored a hearing loss that the unfortunate janitor had suffered. From such modest beginnings, the profession has grown into one of the three major branches of Western medicine; the other two are allopathic medicine and osteopathic medicine. What sets chiropractic apart from its two brethren is that it does not use either surgical or pharmacologic interventions as one of its therapeutics. It focuses, rather, on the spine as intimately involved in helping to maintain health for the human, and it pays special attention to the nervous system as the most significant contributor and coordinator for function and health in the human body. Given this focus, chiropractic uses as its approach the desire to maintain optimal neurophysiological balance in the body, which is accomplished by correcting and reducing structural or biomechanical abnormalities and disrelationships, which have been referred to as "subluxation" and/or "fixation." The main procedure a chiropractic physician uses to provide balance is the spinal joint adjustment, which is usually delivered by hand.

Once a marginalized profession, chiropractic has been increasingly accepted by the public, whose satisfaction with treatment has been found to be rather high. There are now more than 60,000 chiropractors in the United States alone, and there is a growing presence across the globe. Of the complementary and alternative medical (CAM) professions, chiropractors are used more often than any other provider group. Studies have shown that in just a 20-year period the use of chiropractic has tripled, from 3.6 percent of the population in 1980 to 11 percent in 1997. This growth has been accompanied by improvements in education, research, public perception, and public acceptance.

The average chiropractic educational program consists of 4,820 classroom and clinical hours of training. Of these, approximately one-third are spent in basic science education, with the remaining two-thirds spent in clinical science training and internship. The educational program is similar in many regards to medical education, with the chiropractic student spending more time in anatomy and physiology and less in public health. The emphasis in chiropractic education is toward musculoskeletal function and biomechanics as well as manipulative and other manual therapies. Postgraduate training in a number of disciplines is required for relicensure, and the profession offers a number of specialty training programs and residencies (e.g., radiology, orthopedics, neurology, and sports medicine).

Spinal manipulation, or adjustment, is the core clinical procedure used by chiropractors. Many technique systems exist, and discussions about the merits of each comprise an active part of professional discourse. With regard to manipulation, at root it refers to the application of a force (load) to specific body tissues with an intent to create a therapeutic effect. The many systems provide guidance as to the specific methods used to deliver that force (i.e., amplitude, velocity, location, contact on the body, and force direction).

Most people seek chiropractic care for painful complaints of the musculoskeletal system, which is one of the most common causes of disability. Of those who do seek such care, about 60 percent are suffering from low back pain, with the rest suffering from neck pain, headache, and extremity symptoms. Many of these people have chronic problems. More than 80 randomized clinical trials have been conducted using spinal manipulation, with the majority supporting benefit for the treatment of back pain and neck pain as well as headache, all significant causes of disability. Economic analyses have shown cost benefits with chiropractic intervention as well. It is likely that decreased disability can result if chiropractic management is introduced early in the therapeutic process.

—Dana J. Lawrence and William C. Meeker

See also Complementary and Alternative Medicine; Pain.

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CHRISTOFFEL-BLINDENMISSION

Christoffel-Blindenmission (CBM) is an independent aid organization of Christians of various denominations united by the commission to help blind and other disabled people in third world countries, irrespective of nationality, race, sex, or religion. One major field of work is the prevention and curing of blindness, another one the rehabilitation of disabled people. This was already the urgent request of Pastor Ernst Jakob Christoffel. In 1908, he founded the first project—a home in Malatia (Turkey) for blind and otherwise disabled and orphaned children.

In all, this interdenominational agency supports more than 1,000 development projects in 108 countries, most of them in the third world. The projects comprise hospitals with eye departments, mobile eye care services, primary health and rehabilitation facilities, schools, and training centers, besides others. In 2002, approximately 264,000 people with disabilities were part of disability programs that concentrated on schooling and training to promote their inclusion into society and independent living.

In the 1960s, CBM departed from the traditional mission approach of establishing or maintaining its own stations. Instead, CBM saw itself as a provider of services and set itself to the task of enabling the national churches by giving them professional advice and financial assistance and by seconding personnel. Today, CBM cooperates with almost 700 partners (national churches, international missions, local self-help groups, and Christian aid agencies).

The seconded staff, numbering approximately 110 and made up of eye doctors, nurses, special educators, physiotherapists, rehabilitation experts, project managers, and consultants, consider their main task to be that of training national coworkers. This is in line with the theory that by training hundreds, one can help hundreds of thousands of people. Via the partner organizations, almost 9,200 national experts are funded by CBM.

Between 1976 and 1984, independent groups of mission supporters formed in the United States, Canada, and Australia began to handle the administration of incoming donations themselves and supported their own projects. Over the past few years, CBM member associations have also been founded in Austria, Italy, Switzerland, Belgium, the United Kingdom, and New Zealand. All member associations are united under Christian Blind Mission International (CBMI).

In 1999, CBM, other agencies, and the World Health Organization (WHO) initiated VISION 2020: The Right to Sight—a global initiative for the elimination of avoidable blindness by the year 2020. The program will enable all parties and individuals involved in combating blindness to work in a focused and coordinated way.

The worldwide services are largely enabled through donations, bequests, and legacies. In Germany alone, some 100,000 mission friends provided approximately £34.2 million in 2002. CBM has been awarded the seal of approval of the German Central Institute for Social Affairs (DZI). CBM works interdenominationally and has been officially recognized by the WHO. It is among others a member of the Social Service Agency of the German Evangelical Church, the Association of German Development NGOs (VENRO), and the Association of Evangelical Missions (AEM), and it is a partner by agreement with the Association of Protestant Churches and Missions.

—Patrick Devlieger

See also Developing World.

Websites

Christoffel-Blindenmission, http://www.christoffel-blindenmission.de

▣ CHRISTOPH, FRANZ
(1953–1996)

German activist

Franz Christoph, industrial clerk, journalist, and cofounder of the German disability rights movement, was born in Furth im Wald, located in the upper Bavarian Forest. At age 1, Christoph contracted polio, after which he used assistance devices to walk, propelling himself forward with his left leg. At age 8, he came to the Landesanstalt für körperbehinderte Jugendliche (Bavarian Institution for Physically Handicapped Youth) in Munich, from which he escaped at age 14. His mother found him an apprenticeship as an industrial clerk.

Through engagement in the Arbeitskreis für aktive Behindertenhilfe (Working Group for Active Disabled People's Assistance) in Berlin, Christoph discovered his life purpose in 1976: confronting the "disability experts." From then on, he attended scientific conferences and argued with professors over the concept of a "disability standpoint." His premise was that disabled people were oppressed by nondisabled people on the basis of societal norms and values. For him, the issue at stake was the recognition that disabled people had competences of their own. In 1979 in Bremen, Christoph became one of the cofounders of the first German Krüppelgruppe (Cripples' Group), a cross-disability group with emancipatory aims. The members of the so-called cripples' movement, out of which the German disability rights movement evolved, categorically rejected the term *behindert* (handicapped or disabled) opting instead for the old, discriminating description, *Krüppel*, of which the self-chosen use was to make clear the claim to self-representation and self-consciousness. Looking back, however, Christoph regarded this first attempt of reinterpreting disability in positive terms as failed.

As a disability rights activist, Christoph gained wide publicity and suddenly became famous when at an event to celebrate the International Year of the Disabled on June 18, 1981, in Düsseldorf he hit the federal president, Karl Carstens, with his crutches. This public action led to his first book, titled *Krüppelschläge. Gegen die Gewalt der Menschlichkeit* (*Cripple Punches: Against the Power of Humanity*). Christoph also played an important role in the German anti-euthanasia movement. In 1990, he chained himself to his wheelchair at the entrance of a large publishing house to protest against the "deadly zeitgeist" of the contemporary utilitarian euthanasia debate.

After a long stay in Hamburg, Christoph returned to Berlin in the early 1990s and became politically active with the Party of Democratic Socialism (PDS). At the same, time he wrote an extensive manuscript that was published after his death in 1998 under the title *Ich bin (k)ein Felix* (*I am (not) Felix).* His own life formed the background for this character-driven developmental novel. He died on December 28, 1996, in Berlin. Christoph remains in memory not only as an influential activist of the German disability rights movement but also as a storyteller with great quick-wittedness.

—Christian Mürner

See also Advocacy Movements: Germany.

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CHRONICALLY SICK AND DISABLED PERSONS ACT OF 1970 (UNITED KINGDOM)

The Chronically Sick and Disabled Persons Act (CSDPA) was introduced to Parliament as a private members bill aimed at strengthening the provisions in the 1948 National Assistance Act (NAA). The NAA had been introduced after World War II, along with a raft of provisions (e.g., the legislation that established the National Health Service) aimed at eradicating what are known as the five "giant evils": want, disease, ignorance, squalor, and idleness (Timmis 1996). It was the first legislation of its kind. Section 29 of the NAA gave local authorities the power to make arrangements for welfare provisions for certain disabled adults. The duty is vaguely worded, and largely discretionary, whereas the CSDPA attempted to create legally enforceable duties to individual disabled people in relation to a variety of welfare provisions.

The parts of the CSDPA that have had most significance have been Sections 2 and 21. Section 2 is an extensive provision, stating that where a local authority has functions under Section 29 of the NAA, are satisfied that it is necessary to meet a person's needs that it make arrangements for the following matters:

- The provision of practical assistance in the home
- The provision or assistance in obtaining wireless television library or similar recreational facilities
- The provision of lectures, games, outings, or other recreational facilities outside the home
- Assistance in traveling to participate in services provided under Section 29
- Assistance in adaptations in the home
- Facilitating the taking of holidays

- The provision of meals
- The provision of or assistance in obtaining a telephone and any special equipment for using the telephone

It shall be the duty of the authority to make those arrangements in exercise of their functions under Section 29.

While the scope of Section 2 is very broad, and while the decision in *R. v. Gloucestershire CC ex p Barry* (1 CCLR 7, 1997) confirmed that, where a local authority has carried out an assessment of the needs of a disabled person and decided that the provision of services under Section 2 is necessary to meet that person's need, then the authority is under an absolute duty to provide that service, the issue of resources has nevertheless been a major barrier to the full efficacy of this provision. This is because the House of Lords' decision in that case also meant that while recourses are irrelevant to the provision of the service, they can be taken into account when reaching a decision as to whether or not a person's need for services is such that it is necessary to provide the service.

With regard to the other provisions of the CSDPA, Section 21 (as amended) provides that local authorities shall issue badges for display in the cars of disabled people (essentially for the purposes of exemption from parking restrictions, to ensure greater mobility for disabled people). The badge scheme has proved extremely popular, although it has recently been the subject of a review by the Disabled Persons Transport Advisory Committee, which made recommendations aimed at, among other things, clarifying the purpose and use of the badge and tackling abuse of it. Section 21 was more recently amended by the Disability Discrimination Act (2005) to, among other more minor amendments, provide that the holders of foreign disabled persons' badges be afforded the same concessions as holders of domestic "blue badges" in respect of parking concessions. The clause makes provision to formalize existing (nonstatutory) recognition of parking badges issued in the European Union or in certain other European countries (for which there is reciprocal recognition), and to extend this recognition to badges issued in other countries.

The CSDPA also contains provisions relating to access to and facilities at premises for disabled people where those premises are open to the public (Section 4), as well as provision relating to toilets and universities and school buildings. These provisions are somewhat weak, however, and have been largely overtaken by the provisions of the Disability Discrimination Act of 1995.

—Catherine Casserley

See also Disability Discrimination Act of 1995 (United Kingdom).

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CHUAS OF SHAH DAULAH, THE

The shrine of the Muslim saint Shah Daulah (ca. 1581–1676), at Gujrat in the Punjab, used to receive children with microcephaly left by their parents or collected by agents, starting perhaps in the eighteenth century. These children, who were cared for in the informal shrine community, were called *Chuas* ("rats" or "mice") from their appearance. Most had some degree of mental disability. The first published description appeared in 1866 from Wilson Johnston, a British physician. He saw nine Chuas, ages 3 to 40 years.

Later reports generated speculation that the children's heads had been artificially deformed to produce microcephaly, to extract charity from the public. No evidence has been produced to support this hypothesis. In 1902, a senior British psychiatrist examined 12 shrine Chuas and found they were cared for there as well as they would have been at his own government hospital (Ewens 1903). Meanwhile, ethnographers discovered the widespread regional practice of applying clay bowls to infants' heads to shape the broad, open forehead considered desirable. This maternal cosmetic manipulation, which continued through the twentieth century, probably served to sustain suspicions, which still surface intermittently in the mass media. The government of Pakistan took control of the shrine in 1969 and prohibited reception of any additional Chuas.

—Kumur B. Selim

See also Middle East and the Rise of Islam.

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CICERO, MARCUS TULLIUS

(106–43 BCE)

Roman statesman and author

Cicero is a byword for rhetoric. He lived in the troubled times of the failing Roman Republic and in fact was killed as political revenge late in the year 43 BCE, the year following Julius Caesar's assassination. Cicero is important to disability studies because he summarizes the Roman attitude toward rhetoric and disability; that is, it seems always to have been perfectly acceptable to call attention to someone else's physical characteristics. Bodily disfigurement, he states, is always good material for jokes. Robert Garland summarizes Cicero's views in *The Eye of the Beholder* (1995: 74, 76). Indeed, the biographer Plutarch (*Life of Cicero* 1.3–4) tells us that the family name Cicero is based on *cicer,* Latin for "chickpea," because one of Cicero's ancestors had a nose that resembled a chickpea. Far from being embarrassed by the name, Cicero once engraved a chickpea following "Marcus Tullius" instead of spelling out his surname (Plutarch, *Life of Cicero* 1.6). Cicero wrote voluminously; his surviving works can be found in a 28-volume Loeb Classical Library collection.

—M. Lynn Rose

See also History of Disability: Ancient West.

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CITIZENSHIP AND CIVIL RIGHTS

Citizenship may be defined in narrow legal terms as a status recognizing formal, associational membership of a nation-state. This juridical status confers rights to persons who are members of a nation-state and who participate fully in society. It is assumed that there is a high degree of correspondence between the rights and duties of citizenship expressed as a relationship between taxation contributions and entitlements to welfare, health, and educational benefits. What we might call *juridical citizenship* is the possession of civil and political liberties, while *social citizenship* is the enjoyment of the social and economic benefits of membership of a nation-state through residence or birth.

Social citizenship is the central issue in modern interpretations of disability and impairment. The effective enjoyment of the benefits of citizenship is based either on a principle of contribution or benefice. Where the contributory principle is dominant, individuals who do not pay taxes do not in general receive the full range of entitlements. People who do not have employment and hence do not pay taxes tend in practice to be second-class citizens. Whereas the medical model of disability concentrates on the individual limitations of physical impairment, the social model of disability defines disability as the absence of the full array of rights that conventionally flow from social and political participation. Disability in this sense is a lack of citizenship.

Disability typically involves some explicit, or more frequently implicit, form of social exclusion and hence some curtailment of social, political, and economic rights. For example, political rights were limited in Britain because the 1949 Representation of the People Act prevented people resident in institutions with "mental illness" or "learning difficulties" from being included on the electoral list. A subsequent act in 1983 allowed patients to vote but only under narrowly defined conditions. These prejudicial limitations were alleviated somewhat by the 1995 Disability Discrimination Act, but parliamentary legislation still follows the individualistic medical model, which fails to recognize the various ways in which society disables people with impairment by denying their rights and dignity as citizens. It is assumed that impairment prevents people from fulfilling their duties because they cannot fully contribute to society, for example, through work, military service, or parenting.

In the United Kingdom with the creation of the welfare state and the full development of citizenship, it was assumed that the state would recognize not only the right to economic welfare and security but also the right to share fully in the social heritage and to live the life of a civilized being. As an absence of rights, disability implies that individuals are partly excluded from this social heritage and cannot live their lives fully in terms of prevailing social standards. Disability involves the curtailment of social rights because, especially in the contributory model of citizenship, it is assumed that people with impairment cannot participate fully in society. Disability means there is an imbalance between contributions and entitlements, and hence disability raises problems relating to respect, identity, and status. Work earns not just income but respect and status, and therefore impairment typically involves both a loss of social rights and lack of recognition.

In disability studies, there is much controversy about the status and meaning of *impairment* and *disability*. The social model concentrates on the socially constructed nature of disability, treating it as a loss of social rights. The social model has criticized the medical or individual model, which treats disability as a personal tragedy for which professional care and personal adjustment can provide solutions. The social model perceives disability as oppression for which collective action and full entitlement can provide social equality and social participation. Disability politics have in response asserted the need for the redistribution of resources to achieve equal citizenship and recognition of disability as a special social and political category. Whether recognition can result in enforcement will depend on a set of justiciable rights, state support, and political action.

This distinction partly rests on epistemological arguments about the social construction of disability and the distinction between impairment and disablement. Radical constructionism regards the difference between impairment and disability as artificial. What is labeled in society as "disability" is the historical and social product of cultural values and not an incontrovertible fact of nature. Anthropological research shows that disability is culturally variable. Although constructionism has been a powerful perspective in disability studies, there are arguments in favor of retaining a notion of human embodiment to understand the physical limitations of impairment. However, we should not accept a simple dichotomy between the impaired and the able. Impairment is, like health, complex and heterogeneous. It is also a process stretching over the life cycle of the individual, and the majority of the population will, especially in old age, experience some degree of infirmity and impairment. Disability as a loss of rights is in some sense socially constructed, but impairment has real consequences, for example, on mobility. We can capture this common experience of impairment through the notion of human vulnerability.

The vulnerability perspective suggests that, first, we have to attend to impairment as a set of real restrictions on movement and mobility for which modern technology and medical science provide some solutions. Second, we should recognize disability as the curtailment of social rights for which we need political remedies. Finally, impairment is a set of circumstances that affects everybody at some stage in the life cycle, because with increasing age impairment is a consequence of chronicity. In old age, impairment typically combines with unemployment and poverty to produce an erosion of entitlements. The concept of vulnerability indicates the universal character of impairment over the life course. In societies with graying populations, there is a complex interaction between disadvantages associated with aging, chronicity, and impairment that constitute "disability"—a condition of social marginalization resulting from an erosion of rights in societies whose values are grounded in ableism, work, and youthfulness.

In British sociology, the debate about citizenship and social welfare was dominated by the social theories of T. H. Marshall (1893–1982) and Richard Titmuss (1907–1973). According to Marshall, citizenship expanded through three stages: The development of legal rights in the seventeenth century was indicated by habeas corpus, jury system, and rule of law; political rights in the nineteenth century were institutionalized in the parliamentary system, free elections, and the secret ballot box; and social rights in the twentieth century were enshrined in social security and the welfare state. Social citizenship was a status position that ameliorated class inequalities arising from a capitalist market, because the social rights of citizenship involve some level of redistribution of wealth through subsidies and welfare benefits. According to Titmuss, the mass mobilization of the population for warfare during World War II was an important condition for the growth of postwar social rights, but he traced the origins of the National Health Service to the medical inspections of the South African Boer War, which showed that the British working class was generally unfit for combat. The expansion of social rights, especially rights to health care in the twentieth century, was connected with military discipline and combat requirements, because warfare promotes an internal process of social and political criticism. In the United States, the Vietnam War played a part in extending the recognition of social rights, especially for disabled war veterans.

We can detect in these historical examples the important nexus between the able male body, imperialism, nation building, and social rights. Citizenship is primarily an institution in which able-bodied men create a nation-state in which military service is rewarded by social benefits such as housing, education, and a health service. In this sense, the polity is an imaginary fraternity of masculine bodies that are bound together by notions of discipline and duty. It is perhaps ironic that Lord Nelson, who was the archetypal citizen of a nation of free and heroic Englishmen struggling against what they saw as the tyranny of French revolutionary terror, was himself a disabled war veteran.

These sociological perspectives on social citizenship can be regarded as parallel to the economic arguments of John Maynard Keynes (1883–1946), who argued that the economic depressions of the business cycle could be alleviated through demand management, for example, by building the economic infrastructure and developing welfare systems. State intervention in the market place was an instrument of postwar reconstruction. Keynes's analysis of the Depression, the problem of funding the war and rebuilding postwar society, was influential on both sides of the Atlantic. Social Keynesianism contributed to "the postwar consensus," namely, the agreement that the state had to assume some responsibility for developing social welfare programs to alleviate poverty, disability, social deprivation, and economic recession.

Access to health care was an important aspect of the development of citizenship. The Beveridge Report of 1942 envisaged a "welfare state" that was implemented in 1946 by the National Insurance Act and the National Health Act. The latter was designed to secure improvement in the physical and mental health of the people of England and Wales and the prevention, diagnosis, and treatment of illness and disease and to provide or secure the effective provision of services in accordance with the act. The services were to be free of charge. The act to some extent assumed a finite level of sickness and disability, which would be removed by the introduction of a national health service. It did not take into account rising expectations of health and health care and the elasticity of health needs. It did not fully consider the graying of the population and the growth of chronic illness and disability in the elderly. It could not envisage the current inadequacy of pension provisions or the rising costs of medical technology and medical provision. It did not adequately understand the contradictory interests of professional medical care and bureaucratic management of hospitals and clinics.

There are important differences between the liberal legacy of the United States and the European tradition of social citizenship. Alexis de Tocqueville (1805–1859) recognized that the strength of American democracy was a function of the vitality of its local associations, community groups, and churches. Tocqueville noted that a powerful administrative apparatus did not develop in America, and political participation was effective at the local rather than the national level. American federalism has reinforced this tradition of local and regional participation. Self-help and community involvement have been important ingredients of the American response to disability. There are consequently two important issues that shape citizenship in the United States. First, American democracy emphasizes civil and political rather than social and economic rights. Second, whereas in Britain citizenship arose to ameliorate inequalities associated with social class, in American citizenship ameliorates inequalities associated with ethnicity and migration. The result is that historically charity and philanthropy have played a more significant role in the delivery of services in the United States than in Europe and the United Kingdom. Civil activism has been particularly important in the United States in attempts to sustain social security safety nets for vulnerable social groups. Current proposals to privatize Social Security by investing part of the payroll tax receipts in stock and bonds through either the trust fund or individual accounts may increase the precariousness of elderly, disabled, and sick individuals. These privatization strategies would not be economically sufficient to maintain current benefit levels for the disabled.

NEOCONSERVATISM AND WELFARE POLICIES

Despite significant national differences, Western societies experienced a remarkable period of economic growth from 1945 to 1977. The postwar consensus saw the emergence of the right to health care as a universal principle that was assumed to be necessary for economic prosperity and social harmony. Societies such as Germany, Britain, Canada, and the United States moved toward universal coverage of their populations by publicly funded schemes. Even the United States, where collectivist welfare has been resisted, almost half of all spending on health care for the population (or 46.7 percent) is raised from the public purse to fund programs such as Medicare and Medicaid. This period of social consensus with full employment, high levels of economic growth, and relative stability in welfare services came to an end in the 1970s. President Richard Nixon's announcement in 1970 of the existence of a health care crisis was indicative of a new era of fiscal constraint. The postwar welfare system came to an end with the development of neoconservative economic strategies, the social policies of prime ministers Margaret Thatcher's and John Major's conservative governments (1979–1997), and the political dominance of the Republican Party in the United States. The transformation of health care delivery and the collapse of the postwar consensus was brought about by many causes: the OPEC oil crisis (1973–1974) and the increase in energy costs, the decline of corporate profitability, the combination of high inflation and high unemployment, the graying of the population, the simultaneous growth in chronic illness and new communicable diseases such as HIV/AIDS, the rising expectations of health care, the rigidity of health care bureaucracies, and the costs of technological and medical research.

The neoconservative revolution of the 1970s created a political environment in which governments were no longer committed to the universalistic principles of full employment, health care, and welfare benefits. Welfare profligacy, according to neoconservative reformers, was no longer to be funded through deficit budgets. Welfare had to be paid for by responsible, that is, working, citizens. New principles of active citizenship were embraced, namely, welfare for work, private insurance for health care, private education, flexible retirement, and healthy lifestyles. Neoconservatism promoted individualism and responsibility rather than collective involvement. Although social Keynesianism was in decline before the advent of policies of privatization and deregulation, Thatcherism in Britain rolled back the "nanny state" and promoted private initiatives in an enterprise culture, and Reaganomics in the United States established similar principles of fiscal constraint, private provision, and individual responsibility. In the United Kingdom, New Labour or the Third Way strategy encouraged joint ventures between public and private sectors in health care and education. Community enterprise and partnerships between state, business, and the voluntary sector were intended to replace voluntary associations in the delivery of welfare and health services. Similar policies were adopted in Canada where health care expenditure declined by 5 percent between 1991 and 1996.

These policies of cost containment in the 1970s were driven by conservative strategies derived from the philosophical individualism of writers such as F. A. Hayek (1899–1992). Neoconservatism has three important political components: Individuals should take responsibility for their own health (e.g., by not smoking), rights talk has obscured the importance of duty, and welfare benefits should be dependent on work. These policies have negative consequences for disabled people, because impairment often precludes people from full-time employment. Neoconservative philosophy implies that disease, for example, sexually transmitted disease, is often the result of irresponsible individual lifestyle and irrational behavior. However, the increasing prevalence of disability in Western societies is a result of the epidemiological revolution associated with the graying of populations. Disabilities associated with chronic illness and aging, or those that result from industrial accidents, are not amenable to policies derived from neoconservative individualism, because they are not attributable to irrational behavior and inappropriate lifestyles.

The underlying problem of welfare state systems is that the emphasis on individual contributions and the work ethic rather than needs and social solidarity inevitably curtails the social rights of people with impairments. The curtailment of social rights leads to marginalization and low respect. The social democratic model provides a high level of service and support, but it also produces a passive and dependent community. The liberal model provides a residual welfare state, but it paradoxically enhances the social conditions that result in social activism. The provision of welfare services depends significantly on the contribution of the family to the welfare state, and the burden on women is particularly important. The economic constraints of the contributory model of citizenship have been reinforced by the prevalence of the medical model of disease and the concomitant reluctance to recognize the social and political roots of disability.

IDENTITY POLITICS, NATURAL TALENTS, AND FAIRNESS

T. H. Marshall understandably assumed that British society was socially and culturally homogeneous. His influential theory of citizenship did not as a result address a range of problems that have subsequently become salient in contemporary politics, namely, the issues of identity, difference, and diversity. Citizenship confers status and identity to members of a political community, and as modern societies have become more diverse with the growth of labor migration, the flow of refugees, and the increase in asylum seekers questions of identity or "identity politics" have become central to contemporary citizenship. The traditional issues of economic citizenship—safety at work, full employment, access to union membership, the right to strike, retirement and security of pension rights—continue to be important aspects of social policy, but new issues concerning cultural identity now shape what has been called "cultural citizenship." Disability politics belongs to a wider category of representation that political scientists have called "ascriptive identity groups" that organize around characteristics such as race or age that individuals cannot freely choose. Political identification by ascription creates important problems of representation. For example, people with learning difficulties may not want to accept the label that creates the basis of ascription.

Disability has also become an issue in identity politics and cultural citizenship, because the disability movement has questioned the taken-for-granted assumptions about equality and participation that historically underpinned Marshallian citizenship. Critics of the social rights model argue that universal assumptions and expectations about equality cannot be delivered by modern states, and furthermore these assumptions cannot address the special needs of particular social groups. We need a differentiated not a uniform definition of citizenship. Achieving standardized equality of outcomes or opportunities may be neither feasible nor desirable, and hence fairness of treatment rather than equality of outcome may be more relevant to differentiated citizenship.

Although this argument has been directed primarily toward the inclusion of ethnic minorities, it applies with equal force to the politics of disability. Political philosophers such as John Rawls and Ronald Dworkin have argued that equality of opportunity makes sense only if people start life with the same or similar resources and chances. Societies are fair if people's fate is determined by their choices rather than their circumstances. Theories of equal opportunity have primarily concentrated on the arbitrary nature of gender and race in determining people's life chances. More recently, attention has turned to the role of "natural talents" in the distribution of social rewards. Very talented athletes should be rewarded for their skills and training by winning competitions; the same arguments might apply to the social competition for wages and other economic rewards. But what is a natural talent? Demographic research shows that the members of higher socioeconomic groups have longer life expectancy, lower morbidity, and lower infant mortality than lower socioeconomic groups. Generally speaking, richer people are taller people, because diet and genetic legacy play an important part in height. Therefore, what appear to be natural talents are often socially produced.

The "natural lottery" is unfair if we assume that all human beings have equal moral worth. Citizenship mitigates the social consequences of the arbitrary lottery of nature; it exists to ensure that some level of equality can be achieved, for example, through some redistribution of resources through collective sharing of wealth. However, what are the grounds on which we can justify the claim that all human beings are morally equal? Philosophers have traditionally claimed that equal moral worth has to be justified either by religious arguments (we are all equal in the eyes of God) or by reference to natural law (we are equal in terms of an ideal notion of Nature) or by a theory of social contract (we were all equal in a state of nature before the existence of social inequalities). These three principles of justification have an arbitrary element—what happens if you do not believe in God, in Nature, or in the original state of nature? The argument about human vulnerability suggests a possible solution. We are all equal in the sense that we are all vulnerable over the life course in terms of the arbitrary contingencies of human existence. Society should be organized to protect those individuals whose lives are the most precarious in order to achieve some fair distribution of resources.

Although political philosophy has recognized the importance of fairness as a principle of democracy, conventional theories of citizenship have failed to address adequately the issues of impairment, disability, and social rights. We have seen that the effective entitlement of citizenship has been historically based on three contributions: work, war, and parenting. In return for economic employment, military service, and family formation, individuals are regarded as active citizens and rewarded accordingly. We can immediately understand the disjunction between disability and social rights, because citizenship implies a set of cultural assumptions about ability and competence. The very word *disability* indicates that able-bodied citizens are not handicapped and can participate readily in work and military service. If employment and career are constitutive of respect, then the exclusion of people with impairment from continuous employment, regular income, and retirement benefits is not only a material hardship, but it also undermines the conditions for self-respect and social recognition. For example, social rights to sexual activity and reproduction are often denied, because disabled people are imagined to be without sexual desires or sexual needs. This negation of sexuality does not protect people from victimization, and disabled women are often the targets of sexual abuse. The conventional view of citizenship assumes an ideology of ablement that excludes people with impairments from social participation.

If we regard employment as de facto a fundamental condition of social participation, then physical impairment often prevents people from participating as effective citizens. The underlying assumptions are that there is a necessary conceptual connection between a right and a duty, and empirically an almost perfect balance between entitlements and contributions. These assumptions are controversial. For example, in ethical discourse we often ascribe a moral status to the human embryo and hence attribute rights to unborn children. Pro-life activists believe that abortion is murder and hence a denial of the rights of the fetus. While children may have rights, it is not clear that they have duties. There are many circumstances in which there does not appear to be a clear connection conceptually or empirically between rights and duties. Because the citizenship rights of nation-states have often failed to support people with impairment, the disability movement has found more effective support under the banner of human rights.

HUMAN RIGHTS AND DISABILITY

Human rights, which are enjoyed by individuals simply as human beings, have expanded with contemporary globalization. The social rights of conventional citizenship have not always served disabled people adequately, and citizenship often appears to favor duties over rights. As a result, human rights have an obvious appeal, because they are not necessarily connected with the contributory model of social citizenship. While the social rights of national citizenship often collide with the individual rights of universal human rights legislation, the individualistic tradition of civil and political rights is increasingly influenced by the social dimension of the International Covenant on Economic, Social and Cultural Rights (CESCR) (a covenant proposed by the Office of the UN High Commissioner for Human Rights, which was ratified by the UN General Assembly). The national framework of disability organizations is also being replaced by international organizations, as the disability movement becomes a global social movement, for example, through the creation of Disabled Peoples' International (DPI) in 1981 with its first world congress in Singapore. The DPI exists as a political grassroots organization to advance debates on the impact of war, inequality, poverty, and industrial exploitation on creating impairments and sustaining disability. In the future, we can expect that the issues of disability and impairment will be addressed, not by social citizenship in the framework of nation-state but by human rights in the framework of global governance.

The social rights model of Marshallian citizenship has also been criticized because it promoted bureaucratic welfare strategies that were not sensitive to cultural differences and as a result employed undemocratic and patronizing methods that normalized conditions that were deemed to be socially deviant. The management of mental abnormality and physical disability through total institutions was famously criticized by sociologists such as Erving Goffman and Howard S. Becker. Social inclusion often meant in practice the normalization and suppression of difference in the interests of social uniformity and social control. The medicalization of disability has often meant that issues of social rights and individual needs could be ignored by treating the impairment rather than attending to the person. In response, alternative strategies of deinstitutionalization were adopted in the 1970s, but decarceration was also criticized when it became merely a cost-cutting exercise. Successful deinstitutionalization requires significant professional and community support, if it is to provide alternative forms of care. These issues surrounding the framework of institutional care expose a more fundamental problem of social inclusion versus personal autonomy.

DEAFNESS, COMMUNITY, AND EXCLUSION

The tensions between social rights, inclusion, and normalization can be illustrated by the history of the treatment of deafness, because it provides us with an important example of the social and political issues that surround impairment. The social struggles over the rights of deaf people illustrate the contradictory processes of inclusion and exclusion that frequently attend impairment. The traditional response to deafness, especially to the prelingual deaf, was to regard it as a personal calamity. Those who were unable to acquire speech were automatically labeled "dumb" or "mute." Before the late eighteenth century, there was little prospect that people with hearing impairment could acquire any education, and their opportunities for employment were severely limited. Hence they were effectively segregated from society. Medical interest in the diseases of the ear began in France in the seventeenth century, and mastoidectomy was developed in the early nineteenth century by James Hinton in London and Rudolf Schwartze in Halle, but the important advances were educational and cultural rather than medical. In 1755, Abbé Charles-Michel de l'Épée founded a school in France to teach sign language whereby students could write down what was communicated to them through a signing interpreter. De l'Épée's interest in sign language was a product of

Enlightenment debates about the historical origin of language, and whether a universal language had existed prior to the differentiation of modern languages. According to de l'Épée, the "mimicry" of the deaf was the root of such a foundational language.

De l'Épée's pedagogy had a dramatic impact on social attitudes toward the deaf. The philosopher Étienne Condillac (1714–1780), exploring the origin of language and the creation of symbols, was interested in the deaf, whom he had regarded as merely "sentient statues," being incapable of thought. However, on seeing de l'Épée's pupils, he became a convert to the beneficial effects of education and the use of sign language. In the United States, Thomas Gallaudet and Laurent Clerc established the Asylum for the Deaf in Hartford, Connecticut, in 1817. The French sign system, which was imported into America by Clerc, was rapidly amalgamated with the indigenous signing conventions, and American Sign Language (ASL) evolved under the influence of deaf people, who came to Hartford during its early years. In 1864, Congress passed a law recognizing the Columbia Institution for the Deaf and the Blind in Washington as a national deaf-mute college, and by 1869 around 41 percent of deaf teachers in the United States were themselves deaf.

The success of ASL meant that deaf people were able to acquire education, but it also reinforced the social solidarity of the deaf as a distinctive community with its own language, educational system, and culture. Sign recognized the difference of the deaf and celebrated their social distinctiveness. However, toward the end of the nineteenth century, there was a new emphasis on assimilation and conformity, and cultural differences were regarded as divisive, unnecessary, and undesirable. The assimilationist strategy was expressed through an emphasis on speech rather than sign, and oralist educators set up "progressive" educational institutions that ignored signing and imposed a curriculum that required speech. The Clarke School for the Deaf in Northampton, Massachusetts, was opened in 1867 to teach speech, and at the Congress of Educators of the Deaf in Milan in 1880, where deaf teachers were excluded from a vote, the use of sign was officially proscribed.

The social effects of this new pedagogy were dramatic. Whereas almost half of all deaf teachers in the United States were deaf in 1850, this proportion declined to one quarter in 1900 and to 12 percent in 1960. The costs of speech education are prohibitive. Deaf people show no "native disposition" to speak and speaking is an ability that must be laboriously and oppressively taught to them. By contrast, they have an immediate propensity for sign, and can achieve considerable fluency by the age of 15 months. The underlying problem is that many people outside the deaf community do not regard sign language as a "proper language," and hence it requires the supplement of speech, or indeed the replacement of sign by speech.

As a consequence of the civil rights movement and the political organization of the deaf themselves, social attitudes began to change in the 1970s. The social and political problem is that while deafness is an impairment of hearing, deafness is transformed into a social disability—a denial of social rights and status. There is a Deaf culture and a Deaf community, whose members include people with a congenital hearing impairment and hearing people who have grown up in the ASL community because they are children of deaf people. This community is held together culturally and socially by a separate and distinctive language and by the experiences of exclusion and stigmatization. In this case study of deafness, we can detect an important illustration of the intersection between bodily impairment, the historical stigma of being a "deaf-mute," and the mobilization of a community to achieve social citizenship. It also illustrates the argument that social inclusion is often achieved at the cost of difference and distinctiveness. One challenge to the National Association of the Deaf (NAD) as an ascriptive identity group was the growing medical use of cochlear implants to provide deaf children with hearing. Because 90 percent of deaf children are born to hearing parents, cochlear implants would undermine the existence of a distinctive deaf community. NAD has accepted the use of such implants while supporting the dignity of deafness and the pride of the deaf community.

LEARNING DISABILITY: COMMUNICATIVE RATIONALITY

This discussion so far has been primarily based on concerns about physical impairment, and hence "learning disability" raises important but different problems and issues. The concept of learning disability includes people with significantly reduced ability to understand new or complex information or to learn new skills and a reduced ability to cope independently (impaired social functioning). These disabilities normally start before adulthood with lasting effects on development. This definition is obviously broad and refers to a heterogeneous population. It has in fact two components—an IQ element and a social-behavioral dimension. An IQ of below 70 does not immediately classify somebody as having a learning disability. People with autism often have high intelligence. The category is further complicated by the fact that people with learning disability often also have physical or sensory impairment. It is estimated that in England there are 210,000 people with severe learning disability and 1.2 million with moderate learning disability or 25 per 1,000 people.

Models of citizenship, like models of economic action, presuppose intelligent and rational agents who are capable of understanding and articulating their own interests and needs. Adult citizens can read about and generally understand their legal entitlements. It is assumed that they are capable of undertaking collective and individual action to express their needs and achieve desired outcomes. The notion of an "active citizen" assumes effective and rational agency, and hence the idea of communicative competence is a presumption about the capacities of a rights-bearing agent. Despite the importance of the concept of communication to any understanding of rationality in critical social theory, the problems, for example, of Alzheimer's disease in the aging process and learning disabilities in the practical competence of citizens discursively engaging in the public domain have not been adequately considered as problems of citizenship.

People with severe or moderate learning disability have difficulties expressing or articulating interests and needs. While the deaf and dumb have sign language, it is difficult to assess how much people with learning difficulties actually understand. Deaf people have been able to establish a range of deaf rights that express their interests, but the mobilization of people with learning disabilities presents severe limitations on their political involvement. More problematically, it is difficult for people without this disability to actually know what are the needs of people with learning disabilities. In the case of learning disability, the role of helpers and carers becomes crucial. People with severe learning disabilities might engage with society by proxy, that is, through the interpretative activities of caregivers who become expert in the interpretation of the communications of people with such disabilities. However, because learning disability is profoundly stigmatized, social psychologists have found that people are reluctant to identify with the label. As a result, the political organization of people with learning disabilities by groups such as People First is itself limited by the stigmatic label.

RIGHTS TO HEALTH OR HEALTH CARE?

Despite improvements in the recognition of the rights of disability and impairment in the twentieth century, we might reasonably argue that social citizenship has failed as a mechanism of recognition and redistribution. This failure of national forms of welfare has created opportunities for the development of global responses, especially through the legal instrument of human rights. The emergence of a global discourse of rights for disability has been indicated by the Declaration on the Rights of Mentally Retarded Persons (United Nations 1971), the Declaration on the Rights of Disabled Persons (United Nations 1975), and the World Programme of Action Concerning Disabled Persons (United Nations 1982). Human rights discourse is a promising arena for the development of rights for disabled persons, because they are not based on a notion that entitlement must be based on duty and contribution, but rather on a concept of human dignity. Disability rights within a human rights context have the disadvantage that they are difficult to enforce. More positively, the individualistic strand of the International Covenant of Civil and Political Rights has been progressively supplemented and expanded by the CESCR. Whereas the social rights of national citizenship were often dependent on an assumption about ablement, human rights are primarily based on a notion of human vulnerability, which we all share, not as workers, but as human beings.

We often refer to the rights of disabled people under the general rubric of "health rights," but these are difficult to define; Article 12 of the CESCR recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Article 12 notes that nation-states must take steps to reduce infant mortality, improve the environment, control epidemics, and make adequate provision of health services. However, there is widespread skepticism that a health right can be defined because the right to health is not a right to be healthy. Because there is an important aspect of genetic inheritance in human illness (e.g., in diabetes, Huntington's disease, or Down syndrome), it is difficult to enforce a health right retrospectively. Illness and disability are in part a function of aging, and hence there are life cycle problems. It is also necessary to distinguish between health and subjective health, and it would be difficult to legislate for subjective health satisfaction. Some authors have attempted to define a right to health by reference to some international consensus on health issues or by reference to the empowerment of individuals. Rights to health care rather than to health offer a more practical strategy that can monitor states that fail to maintain conditions promoting health. Many people may not be able to enjoy healthy lives as a result of the "natural lottery," but human rights provisions can constrain governments to meet certain minimum conditions of health care.

CONCLUSION: CITIZENSHIP, CHRONICITY, AND CARE

Modern theories of rights have placed growing emphasis on the issue of human difference and fairness rather than universalism and equality. Theories of difference are sensitive to the anthropological notion of cultural relativism in which disability is seen to be socially constructed and hence variable between cultures. In this social model, the very notion of disability is culturally specific. The social model of disability and the social constructionist account of illness have provided powerful sociological arguments for the disability movement. However, the problem with cultural relativism in political theory is that it cannot effectively develop an ethic of care and satisfy questions about justice. If we argue that disability is in fact a social or cultural difference rather than a natural condition, how can we provide for justice across these social categories? The recognition of cultural differences does not easily provide a theory that can give a convincing account of the general conditions of justice. There is therefore an ongoing and unresolved question: How can we defend universality of the treatment of human beings as human beings? Against cultural relativism, it can be argued that human beings share a common vulnerability, because they are embodied. The conviction that human embodiment is a fruitful platform for an argument in favor of the universality of human rights via the notions of frailty and vulnerability is grounded in the notion of the ubiquity of human suffering. We are, to quote the brutal maxim of Keynes, all dead in the long run. More elegantly, disability is a generic aspect of human vulnerability, and it is therefore part of the human condition. There is a direct relationship between disability, the recognition of human vulnerability, and the defense of human rights as entitlements of human beings, regardless of their social and cultural differences.

The fundamental question of moral philosophy is, Why should I care for strangers, that is, people who are different from me? One answer is that while we are all different in physical, social, and cultural terms, we are all vulnerable, and therefore exposed to circumstance. Citizenship and human rights, however defective, provide strategies for exercising choice over circumstance.

—Bryan S. Turner

See also Activism; Anthropology; Disabled Peoples' International; Deaf Culture; Globalization; United Nations Declaration on the Rights of Disabled Persons.

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CIVIL RIGHTS BACKLASH

When a population that is presumed powerless—people with disabilities—demonstrates the clout to effect social change, it is not surprising that negative reactions from others, or backlash, is vehement. An example is found in the U.S. context of people with disabilities invoking such legislation as Section 504 of the Rehabilitation Act of 1973, the 1975 Individuals with Disabilities Education Act, and the 1990 Americans with Disabilities Act (ADA). Federal civil rights for people with disabilities are embodied in two laws: Section 504, a statement of only 40 words that provided civil rights protection for people with disabilities in programs and activities receiving federal financial assistance, and the ADA, which extended such protection to the private sector.

Section 504, however, required implementing regulations that would give it "teeth" by providing the specific means to bar disability discrimination in hospitals, in schools, and for other recipients of federal funding. Despite the jubilation after the nationwide demonstrations that played a significant role in the 1977 signing of the regulations, the backlash evident in the first two Section 504 cases (*Southeastern Community College v. Davis* [1979] and *APTA v. Lewis* [1981; D.C. Circ.]) disappointed disability advocates. The U.S. Supreme Court ruled for the college against Frances Davis, a hard-of-hearing practical nurse, deciding that accommodations allowing her to be a student were too expensive and difficult. Citing *Davis,* American Public Transit Association (APTA) attorneys successfully contended that "reasonable accommodations" in public transit to provide accessibility would be too costly and burdensome, while serving few people with disabilities.

Noting that they were losing the Section 504 cases, disability attorneys devised a tactic in *Dopico v. Goldschmidt* (1982; 2nd Circuit). Rather than making the case for retrofitting *old* buses, they successfully argued for the requirement that only *new* buses be accessible, thus countering the backlash regarding undue expense and hardship. *ADAPT v. Skinner* (1989; 3rd Circuit) affirmed the rationale used in *Dopico.* Accessibility would be mandated not for the old, but rather only for newly purchased vehicles and newly constructed or newly altered facilities. Backlash against Section 504 therefore served as a catalyst for disability rights attorneys to argue for an interpretation of "reasonable accommodation" that courts would deem neither too difficult nor too expensive. Such an approach was to be embodied in the language of the ADA.

In the case of education of children with disabilities, backlash has taken two forms: first, fear that nondisabled children are being shortchanged to pay for the education of children with disabilities; second, reluctance to include children with special needs in regular classrooms, especially when schools are being held to strict testing standards. So fervent is the backlash that proposals to dilute standards, or even exclude accountability, for educating children with disabilities is given serious congressional consideration. In response, disability advocates support monitoring individualized education program (IEP) accountability and having money follow the child to appropriate educational venues, rather than providing financial incentives inflating special education programs. Disability rights advocates also propose that schools accommodate diverse learning styles.

Judicial backlash against the ADA is evident in the Supreme Court's narrowing the definition of disability and elevating the new federalism, contrary to congressional intent that reflects the nation's need to expand employment of people with disabilities. Recent rulings have practically eviscerated Title I, the employment title of the ADA. In 1999, the Court ruled in three joined employment cases (*Sutton et al. v. United Air Lines, Inc.; Murphy v. United Parcel Service, Inc.;* and *Albertson, Inc. v. Kirkingburg*) that individuals whose conditions do not substantially limit any life activity and/or are easily correctable are not disabled according to the ADA. Dissenting, Justice John Paul Stevens stated, "The Court's approach would seem to allow an employer to refuse to hire every person who has epilepsy or diabetes that is controlled by medication . . . or every person who functions efficiently with a prosthetic limb" ("Supreme Court Rules" 1999). As Georgetown University Law Center's Chai Feldblum, who helped draft the ADA, observed, "These decisions create the absurd result of a person being disabled enough to be fired from a job, but not disabled enough to challenge the firing" (Justice For All 1999).

Denying that Williams's impairment entitled her to a "reasonable accommodation" in *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams* (2001), the Court continued limiting the definition of disability. As a consequence of this ruling in Toyota's favor, employees in Williams's position face a catch-22 situation. They have to demonstrate how significantly their disabilities affect their daily lives to warrant coverage under the ADA. Yet they also have to show they are qualified for their jobs. By revealing their impairments, people with disabilities risk jeopardizing their employment. Also in *Williams,* the Court seems to have reacted against what Berkeley law professor Linda Hamilton Krieger (2003:3) refers to as the "dramatic shift in the ordinary power relationship between employers and employees" inherent in the ADA: the *requirement* that an employer engage, "with a disabled employee or applicant in a good faith interactive process to find ways to accommodate the employee's disability" as long as no "undue hardship" is imposed on the employer.

In ruling on disability legislation, say disability rights advocates, the Supreme Court is usurping the role of Congress, treating Congress as a lower court rather than as a coequal branch operating by different standards. In *University of Alabama v. Garrett* (2001), the Court found insufficient past history of disability discrimination to abrogate sovereign immunity embodied in the Eleventh Amendment and to justify invoking the equal protection clause of the Fourteenth Amendment. Justice Stephen Breyer pointed out in his dissent that this decision, a major departure from past rulings, revealed a misunderstanding of the role of Congress as opposed to the courts. But despite Justice Breyer's citation of more than 300 examples of disability discrimination, the Court, which treated these examples as anecdotal, ruled that the discrimination was not egregious enough to give Congress the power to override state sovereign immunity.

Without invoking the definition of disability or sovereign immunity, the Supreme Court continued to chip away at the ADA. In *U.S. Airways, Inc. v. Barnett* (2002), the Court ruled that workers with disabilities should not have priority over more senior workers who do not have disabilities. Characterizing "reasonable accommodations" as "special" and "preferential," the Court added credence to the misconception that the ADA gives people with disabilities undeserved advantages over those who are nondisabled. In *Chevron U.S.A., Inc. v. Echazabal* (2002), the Court decided that, under the ADA, an employer can invoke the Equal Employment Opportunity Commission regulations to reject a qualified applicant by claiming that, due to the applicant's disability, the job could be detrimental to his or her health. Disability rights attorneys assert that the ADA allows employers to refuse an applicant *only* when he or she poses a direct threat to the health or welfare of *other individuals* in the workplace; the law's intent is not to support paternalistic attitudes that have been keeping people with disabilities unemployed.

Holding that only compensatory damages, not punitive damages, are available under Section 504 or the ADA's Title II, the Court in *Barnes v. Gorman* (2002) has made it increasingly difficult for people with disabilities to seek appropriate recourse under these laws. Continued threats to the ADA were reflected in the unsuccessful challenges by Texas and Tennessee to the constitutionality of Title II's ban on discrimination against people with disabilities by state or local governments. Although in *Tennessee v. Lane* (2004) the Court upheld the constitutionality of Title II, the narrow character of the 5–4 decision, applicable only to access to courts, caused disability advocates to fear that the protection of Title II is still imperiled.

Among the multiple reasons for the pernicious backlash against civil rights for people with disabilities is the presumption that this population seeks unwarranted considerations in the form of generous benefits, windfall legal settlements, and excessive accommodations, all of which allegedly burden the rest of society. The tendency of the mainstream media to treat disability issues as a consequence *only* of impairment, not discrimination, reinforces these stereotypes. Fear of perceiving disability as part of the human condition to which all are susceptible preserves the myth of disablement as an all-or-nothing experience, properly residing only in a medical—never in a civil rights—context.

—Doris Zames Fleischer and Frieda Zames

See also Americans with Disabilities Act of 1990 (United States); Individualized Education Program; Rehabilitation Act of 1973 (United States).

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▣ CLAPARÈDE, ÉDOUARD

(1873–1940)

Swiss physician and psychologist

Édouard Claparède is a notable personality in the history of psychology and the pedagogical sciences. Born in Geneva, he belonged to a French family that had emigrated after the Revocation of the Edict of Nantes and was admitted to the Geneva bourgeoisie in 1724. A physician and psychologist, he is known as the founder, in 1912, of the Jean-Jacques Rousseau Institute and of a school of pedagogical sciences, as the editor of the journal *Archives de psychologie*, and as president of numerous international psychological congresses. But it is above all his published work that has established his worldwide reputation, translated and reissued numerous times in many different languages (see Further Readings below).

An advocate of experimentation in psychology, functional education, and the application of psychology to pedagogy, he was also a scholar, with liberal, middle-class, and leftist views, who took up many causes, in particular the rights of children, world peace, psychology, and cultural and intellectual exchanges among nations. His ideals and experience are summed up in his last work, a kind of will and testament, *Morale et politique, ou, les vacances de la probité* (*Morality and Politics, or Honesty on Vacation*, 1940).

—Henri-Jacques Stiker

See also Psychology.

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CLASSIFICATION IN PARALYMPIC SPORT

Classification is simply a structure for competition. Not unlike wrestling, boxing, and weightlifting, where athletes are categorized by weight classes, athletes with a disability are grouped in sport classes defined by the degree of function presented by the disability.

Traditionally, athletes belong to six different disability groups in the Paralympic movement: amputee, cerebral palsy, visual impairment, spinal injury, intellectual disability, and a group that includes all those that do not fit into the aforementioned groups (les autres). Some sports are specific only to one disability group.

Classification systems can be categorized into two models, sport specific and general. Sport-specific classification systems evaluate and assess athletes taking into account the specific tasks required to compete in each sport (e.g., passing a ball). Therefore, in sports where sport-specific classification systems are used, an athlete who uses a wheelchair for mobility may compete not only against other wheelchair athletes but also against amputees or those with cerebral palsy, if they have the same or similar functional ability.

General classification systems evaluate and assess athletes taking into account only the type and degree of impairment (e.g., degree of sight or visual impairment). In sports where general classification systems are used, classification is disability specific, meaning competition is only between athletes in the same category, for example, amputees against amputees.

Classification enables athlete performance to be measured by the skill and physical ability of athletes, regardless of training effect and genetic superiority or inferiority.

Athlete sport classes are determined by a variety of processes that may include a physical and technical assessment and observation both in and out of competition. This process is performed by an expert team of officials known as classifiers. Classification systems are continually being modified due to the requirements of the sports and the advances in the methods of measurement.

Sport classes are defined by each sport and form part of the sport rules. Each sport class is denoted by a combination of letter and number (e.g., T42—T meaning track, 40 for amputees and 42 for a single-leg amputee). For team sports, such as wheelchair basketball, players are assigned a point value according to their sport class, and the cumulated points for team members participating at any one time (i.e., the five players on court) must not exceed a set number. This ensures that any player, regardless of the degree of disability, has an integral role to play within the team structure.

Classification is an ongoing process, and athletes may be classified not only once but several times throughout an athlete's career. Athletes with changeable conditions may be reclassified over time into different sport classes depending on whether their condition improves or deteriorates.

The classification processes used by the International Paralympic Committee (IPC) was designed to encourage participation rather than exclusion, to provide equitable competition, to distinguish and encourage high levels of performance, to create a simple yet objective process in which sport classes are unaffected by training, and to encourage integrated rather than disability-specific competition.

—Andy Parkinson

See also Paralympics; Sports and Disability; Sydney Paralympics.

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CLAUDIUS, EMPEROR

(10 BC–AD 54)

Roman emperor

Tiberius Claudius Drusus Nero Germanicus became emperor of Rome in his 50th year. Bringing some stability to the Roman Empire between the disastrous reigns of his notorious predecessor, the emperor Caligula, and his even more notorious successor, Nero, Claudius reigned AD 41–54. Claudius was never considered fit for imperial administrative duties, perhaps because throughout his childhood he "was so troubled by various diseases that he grew dull-witted and had little physical strength" (Suetonius 2), but in the volatile political vacuum following Caligula's assassination he was declared emperor to everyone's surprise, including his own. Suetonius tells us that Claudius "stumbled as he walked owing to the weakness of his knees," and, when stressed or angered, had the mannerisms of "slobbering at the mouth and running at the nose, a stammer, and a persistent nervous tic of the head" (30). Claudius' autobiography is lost, but Robert Graves's twentieth-century fiction immortalizes Claudius' wisdom and kindness; indeed, it is difficult to reconcile Graves's portrait with the less sympathetic record of the historian Tacitus, or with Suetonius' charges of "cruelty and bloodthirstiness" (34). Derek Jacoby further immortalized Claudius' erudite joviality and portrayed his physical characteristics charmingly in the BBC television production *I, Claudius,* based on Graves's novels.

—*M. Lynn Rose*

See also History of Disability: Ancient West.

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CLEVER HANS

Clever Hans was a performing horse who became quite celebrated in the first decade of twentieth-century Berlin (roughly from 1900 to 1909) for demonstrating remarkable intelligence. The feats performed by the horse were eventually exposed as simple behavioral responses to subtle cues provided (perhaps unintentionally) by his handler. Since this episode, behavioral researchers have referred to the "Clever Hans effect" to denote the danger of unintentional cueing of the desired behavior by the questioner if experiments are not carefully designed.

Led by his trainer Wilhelm von Osten (1838–1909), Hans would demonstrate almost "human" intelligence by responding to questions with a variety of hoof taps or other actions. Using this method, Hans amazed both the general public and leading psychologists of the day with his apparent ability to perform arithmetic functions, identify colors, read and spell, and even identify musical tones. In 1909, after a series of carefully designed experiments and close behavioral observations, the psychologist Oskar Pfungst concluded that Clever Hans was, in fact, simply responding to very subtle (and probably unintentional) behavioral cues from his handler. The rigor of Pfungst's trials and the detail of his observation are considered classic early examples of experimental design in behavioral psychology.

—*Philip M. Ferguson*

See also Psychology.

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COLLEGE AND UNIVERSITY EDUCATION

See Education, College and University

COLOMBIA

See Experience of Disability: Colombia

COMMUNICATION

Communication is defined as any act by which one person gives to or receives from another person information about that person's needs, desires, perceptions, knowledge, or affective states. Communication not only allows the exchange of information (transaction) within a specific social and physical context but also permits the fulfillment of social needs (interaction). Through communication, an individual develops and maintains an identity and sense of self, provides connections with other people, and promotes membership or affiliation in social groups.

Human communication is a complex phenomenon that is accomplished through the interactions of various components. It may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or nonlinguistic forms, and may occur through spoken or other modes.

The primary components of communication are cognition and language. Cognition refers to the mental activities or operations involved in processing information and acquiring knowledge about the world. It refers to all the processes by which sensory input is transformed, reduced, elaborated, stored, recovered, and used. Processes such as attention, perception, memory/learning, organization, reasoning, and problem solving are dynamically interrelated in most acts of cognitive processing. There are many competing theoretical descriptions of cognition and its development; however, most agree that cognition and language are intricately related both in their development and use.

Language is a system of symbols that when expressed and understood, transmit thoughts, ideas, desires, emotions, and information. Language includes content, form, and use. Language content or semantics refers to the meaning, topic, or subject matter involved in an utterance. Language form includes the three rules systems of phonology, morphology, and syntax. Phonologic rules govern the sound system of the language, morphologic rules are concerned with the structure of words in a language such as the patterns of word endings that indicate tense or number, and syntactic rules refer to the grammatical arrangement of words and morphemes in a sentence.

Language use or pragmatics refers to a system of rules and knowledge that guide how we use language in social settings. It includes knowledge of how to converse with and what to say to different communication partners and in different contexts, and how to initiate, maintain, or terminate discourse and conversation. For example, the Cooperative Principle assumes that conversational participants cooperate by contributing to the ongoing speech event, while the Politeness Principle maintains that participants behave politely to one another, since people respect each other's face. Pragmatics also refers to the use, purpose, or function that a particular utterance serves.

MODES OF COMMUNICATION

Communication may occur through a variety of different output channels. Therefore, in addition to cognition and language, other areas are crucial depending on the mode of communication selected. For example, if speech is the mode of communication, then both speech and hearing become critical for the giving and receiving of the information. If signing or writing is the preferred mode of communication, then vision and some form of upper extremity mobility are required for the successful exchange of the message.

Speech is perhaps the most common mode through which communication is achieved. Speech is a complex motor process involving the coordination of several physiologic systems—respiration for the air stream, phonation for voice production, resonance for voice quality, and articulation for specific sound formation and intelligibility. During the process of phonation, the airstream generated by the lungs vibrates the vocal cords of the larynx, creating sound. Then the movement of the articulators (tongue, teeth, mouth, and lips) shapes the sound into speech sounds. The sounds are made richer and more complex as they pass around and through the vocal tract (larynx, throat, sinus cavities, and mouth). The size, shape, and flexibility of these structures vary from individual to individual and give us our unique "voice personality." While the spoken word itself carries the linguistic message, the voice also communicates much to the listener and is an important part of the total pattern of self-concept. In voice alone, people differentiate maleness or femaleness, estimate age, and identify happiness or sadness, patience or irritability.

Nonverbal communication influences both how people encode messages and decode them. Nonverbal communication refers to those behaviors that are mutually recognized and socially shared and that have a focus on message meaning. Although nonverbal behaviors are dynamic and situation specific, seven categories of nonverbal codes have been delineated. These codes are distinct, organized means of expression that consist of both symbols and rules for their use. Although each code is presented as a separate class, nonverbal behaviors occur together with each other in patterns. They are naturally integrated with verbal expression, with several of them contributing to a single message or thread of messages. The nonverbal codes include the following:

1. Kinesics—messages sent by the body, including gestures, facial expression, body movement, posture, gaze, and gait
2. Vocalics (i.e., paralinguistic)—vocal cues other than words, including volume, rate, pitch, pausing, and silence
3. Physical appearance—manipulable cues related to the body, including hairstyle, clothing, cosmetics, and fragrance
4. Haptics—contact cues, such as frequency, intensity, and type of touch
5. Proxemics—spatial cues, including interpersonal distance, territoriality, and other spacing relationships
6. Chronemics—the use of time as a message system, including punctuality, amount of time spent with another, and waiting time
7. Artifacts—manipulable objects in the environment that may reflect messages from the designer or user, such as furniture, art, pets, or other possessions

In general, nonverbal communication helps people accomplish various goals. First, nonverbal communication creates impressions. Physical appearance cues contribute greatly to this function, but kinesics, chronemics, and other cues also contribute to how others form perceptions of competence and character. Second, nonverbal communication is used to manage interaction. Facial expression, vocalics, and even proxemics are used to signal turn taking in conversations as well as leave taking. Third, nonverbal communication is a primary means of expressing emotion. Some experts have identified nonverbal expression to be an integral part of the emotional experience. In addition, each cultural community has its own display rules for emotional expression appropriateness. Fourth, nonverbal communication allows people to send relational messages. Affection, power, respect, and dominance are all conveyed through nonverbal cues. Fifth, deception is conveyed and detected via nonverbal cues. Finally, nonverbal communication also is used to send messages of power and persuasion; leadership is conferred on the basis of nonverbal cues.

Several factors influence how nonverbal messages are sent and received. Nonverbal messages are shaped by three primary factors: the culture (with the understanding that cultural differences exist), the relationship, and the situation. Although research has identified some universal facial expressions, culture remains a strong influence on nonverbal communication. Cultural values of specific groups affect space and touch norms. Furthermore, gender roles within a culture will determine, to some degree, dress and even baseline kinesics activity (e.g., eye gaze). As culture provides an overall template for nonverbal communication, the specific relationship also determines important norms for interactants. The type of relationship (e.g., helping, adversarial, work, friendship) and the stage of relationship (e.g., a new friendship vs. a sibling bond) influence what is expected nonverbally between interactants. In addition, each communication situation presents its own parameters for nonverbal behaviors. These could include the physical environment, timing, temporary physical or mental states, or the number of people present.

PROPERTIES OF HUMAN COMMUNICATION

Although human communication is an intricate human trait that is difficult to describe, a number of properties of human communication have been identified and detailed. These properties include the complexity of communication, the systematicity of human communication, the relativity of communication to context, the purpose of communication as social action, and the collaborative nature of communication.

The complexity of communication is apparent when one considers that communication is not predicted by the behaviors of its parts taken separately. Communication is more than just the combining of grammatical and lexical units. It is a multilayered system in which the traditionally defined components of cognition, language, and speech function as an integrated whole to accomplish appropriate and effective communication. In addition, several variables extraneous to language are integral components of the communication process (e.g., cultural beliefs, situational features, audience variables, social constraints, and motivations) and influence its use. In addition, the multifunctional nature of communication (interactional and transactional) is further demonstration of the complexity of human communication.

The systematicity of human communication behaviors has been demonstrated across languages and across cultures. For example, the sequence of actions and the structure of conversations have an order and sytematicity that translate into a set of turn-taking "rules" or principles. There are also broad rules, not restricted to any one language or culture, that govern repair of communication breakdowns, question-answer sequences, and conversational openings and closings.

The concept of contextual relativity suggests that communication can only be interpreted in the social and cultural context in which it occurs. Context refers to more than just the physical environment but includes factors such as past experiences and expectations of the individuals engaged in the interaction. Since context is dynamic and may change from moment to moment, the actual words a person states may be interpreted differently at different times.

Communication is a tool for achieving social action. Even within the most routine everyday interactions, communication is used as a means of getting something done. In negotiating social action, subtle strategies or devices such as laughter, facial expressions, or gestures may be used together with or in place of words themselves.

Effective communication is collaborative in nature. Conversations are not a series of discrete statements that pass from active speaker to a passive listener. Rather, as conversations proceed, participants actively construct and negotiate meaning in a coordinated and joint manner.

A COMMUNICATION BILL OF RIGHTS

The National Joint Committee for the Communication Needs of Persons with Severe Disabilities promotes research, demonstration, and educational efforts directed to helping persons with severe disabilities communicate effectively. The committee consists of members from the American Speech-Language and Hearing Association, American Association on Mental Retardation, American Occupational Therapy Association, American Physical Therapy Association, Council for Exceptional Children with Communication Disorders, Association for Persons with Severe Handicaps, and the United States Society for Augmentative and Alternative Communication. The interdisciplinary composition of this committee reflects the importance of communication in all spheres of human functioning and across traditional boundaries. The shared commitment to promoting effective communication by persons with severe disabilities thus provides a common ground on which the disciplines represented by the member organizations can unite in their efforts to improve the quality of life of such persons.

The National Joint Committee for the Communication Needs of Persons with Severe Disabilities developed, in 1992, the Communication Bill of Rights, which states that all people with a disability of any extent or severity have a basic right to communication during their daily activities and across the lifespan. Each person has the right to (1) request desired objects, actions, events, and people; (2) refuse undesired objects, actions, or events; (3) express personal preferences and feelings; (4) be offered choices and alternatives; (5) reject offered choices and request and receive another person's attention and interaction; (6) ask for and receive information about changes in routine and environment; (7) receive intervention to improve communication skills; (8) receive a response to any communication, whether or not the responder can fulfill the request; (9) have access to augmentative and alternative communication (AAC) and other assistive technology (AT) services and devices at all times; (10) have AAC and other AT devices that function properly at all times; (11) be in environments that promote one's communication as a full partner with other people, including peers; (12) be spoken to with respect and courtesy; (13) be spoken to directly and not be spoken for or talked about in the third person while present; and (14) have clear, meaningful, and culturally and linguistically appropriate communications.

—Leora R. Cherney

See also Accessibility; Assistive Technology; Communication: Law and Policy.

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COMMUNICATION: LAW AND POLICY

Communication is an important component of human experience. Throughout history and across geopolitical boundaries, communication laws and policies have shaped the ability of people with disabilities to participate in society. Legislation and policy have been used both to discriminate against and to increase opportunities for people with disabilities. Technology continues to provide new tools and methods for communication, allowing individuals to interact more effectively while prompting additions and changes to existing communication laws.

HISTORY

Before the Enlightenment, philosophy and unwritten social policy often excluded individuals with communication disabilities. Plato and Aristotle believed that speech was audible thought. People with communication disabilities were often considered incapable of thought or learning and were not viewed as intelligent human beings. During the Middle Ages, participation in religious and civic life was often denied to people with communication disabilities. The notion that communication, intelligence, and humanity were interdependent remained prevalent well into the sixteenth century, when academics began to challenge earlier philosophical ideas. In the twentieth century, many countries passed legislation that specifically addresses the need for governments, businesses, and institutions to communicate effectively with citizens regardless of disability.

COMMUNICATION LAW

The Americans with Disabilities Act (ADA) of 1990 and the Disability Discrimination Act (DDA) of 1995 require public entities and businesses to provide effective communication to individuals with disabilities. The ADA covers the United States and the DDA covers the United Kingdom; many similar laws exist in other countries. Methods to ensure effective communication are wide in scope and may require the use of auxiliary aids and services. Braille and large-print publications may be forms of effective communication for a visually impaired person trying to access written information. A transaction involving a deaf person may require the provision of an American Sign Language interpreter. A person with a mobility impairment might have difficulty operating an ATM machine and may require the services of a bank employee to complete a transaction. The entity providing the service is responsible for costs incurred in providing auxiliary aids or services, and the form of communication used needs to be appropriate to the context and needs of the person with a disability.

In the United States, additional provisions regulating communication are found in Title IV of the ADA. Title IV mandated that nationwide telecommunication systems be accessible to persons with speech or hearing disabilities. Telecom carriers in each state were required by the Federal Communications Commission (FCC) to provide telecommunication relay services by July 26, 1993. The Telecommunications Relay Service (TRS) allows a person using a text telephone or nonvoice device to converse with someone using a voice telephone; an operator acts as a neutral relay between the two parties. On March 1, 2001, the FCC expanded the TRS to include service in Spanish, and speech-to-speech (STS) relay. Using STS relay, a person with a speech disability can have his or her voice relayed to the other person on the phone by a trained communications assistant. Services such as STS are also available in Australia and Sweden, and many TRS services are available through the Internet for individuals who do not own specialized telephony equipment.

The Telecommunications Act of 1996, also enforced by the FCC, added provisions to the Communications Act of 1934 to increase communications access for people with disabilities. These provisions, contained in Section 255 of the amended Communications Act, require manufactures and providers of telecommunications equipment and services to ensure accessibility to persons with disabilities. Telecommunications devices need to have accessible input and output systems, and documentation about telecommunications equipment and services must be available in accessible formats. Operator, directory assistance, and emergency services must be accessible to persons with disabilities. The Telecommunications Act of 1996 additionally mandated the phase-in of captioning requirements; the timeline requires the captioning of all English-language broadcasts by 2006 and of Spanish-language broadcasts by 2010, with some exceptions for small broadcasters, public access television, and certain live broadcasts and commercials. In July 2000, the FCC adopted rules requiring video description in a portion of television broadcasts, but the rule was overturned by a federal court in November 2002.

SIGN LANGUAGE AND DEAF EDUCATION

People who are deaf often communicate using different forms of sign language. Sign language is still not universally accepted as a language, even though American Sign Language (ASL) and many other sign languages are linguistically complete forms of communication. It is a common misconception that ASL shares the grammatical structure and vocabulary of spoken English. While some sign languages are closely related to spoken languages, many have a unique grammar that cannot be translated in a sign-to-word manner. Though there are many signed languages in practice throughout the world, ASL has its origins in the deaf communities of France and Italy.

Abbé Charles-Michel de l'Épée, a French priest, is credited with the establishment of the first sign language school for the deaf in 1775. The sign language he taught was a formalized sign system he had developed based on his observations of the communication of the local Deaf community in Paris. His sign systems form the basis for ASL and other similar sign languages practiced today. Thomas Hopkins Gallaudet, an American Congregational minister, studied sign language in Paris beginning in 1816. He returned to the United States with Laurent Clerc, a deaf sign language instructor, and established the first educational programs for the deaf in the nation. By 1900, more than 50 schools for the deaf operated in the United States.

Educational policy makers have advocated for two methods of deaf education, *manualism* and *oralism*. Manualism was used in the original residential deaf education schools, and it emphasized the use of sign language in the classroom. Advocates of oralism encouraged the exclusive use of oral communication skills. Oralists opposed the use of sign languages and encouraged students to use lipreading and speech as primary communication methods. Oralists believed that teaching sign language would limit student ability for speechreading and oral communication. Alexander Graham Bell, inventor of the telephone and instructor of deaf students, was a prominent advocate of oralism, and among others had a large influence in the increasing use of oralist methods in deaf education throughout the late nineteenth and early twentieth centuries. These trends continued until the 1970s and have deprived many individuals of an adequate education in sign language. Scholars today are generally critical of oralism, and encourage sign language education in the manualist tradition. While lipreading and oral communication are still taught to deaf students as useful skills, sign language as a primary form of communication is again a standard aspect of deaf education.

TECHNOLOGY AND COMMUNICATION

Technology is changing some of the primary ways in which people communicate, and recent legislation and policy have attempted to address some of the changes resulting from new technologies. E-mail has become an instant and low-cost means of communicating across the globe. Instant messaging systems are increasingly used by the Deaf community and have become a popular form of interaction for young people. Many public and private organizations publish reports and other information using electronic versions instead of print. As the Internet has become a dominant source of information at home and in the workplace, a variety of entities have proposed and enacted laws and policies governing the accessibility of electronic resources. Both the United States and the United Kingdom have laws that require the accessibility of most public websites, though the scope of these laws is still being determined by the court system. Section 508, a recent example from the United States, was signed by President Bill Clinton on August 7, 2000, and establishes regulations governing the accessibility of the electronic and information technology used within the federal government.

The United States included specific requirements for information technology accessibility through an amendment to Section 508 of the Rehabilitation Act of 1973. Section 508 requires that any electronic and information technology developed, procured, maintained, or used by the federal government be accessible to people with disabilities. As the government continues to increase its use of technology for internal systems and public services, compliance with the law helps ensure effective communication with federal workers and to the public they serve. While Section 508 covers only federal agencies, the requirements for effective communication within the ADA and DDA are increasingly being interpreted to cover electronic communication. Many businesses and institutions are establishing policies to ensure that web pages and other electronic and information technology used internally or by the public are accessible to individuals with disabilities. Communication laws and policies today provide more opportunities for individuals with disabilities than in previous times, and technology continues to introduce new forms of communication. It is likely that current laws and policies will require frequent revision as the modes and methods in which individuals communicate continue to change.

—Nathan White

See also Accessible Internet; Americans with Disabilities Act of 1990 (United States); Assistive Technology; Communication; Disability Discrimination Act of 1995 (United Kingdom); Information Technology.

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National Institute on Deafness and Other Communication Disorders, http://www.nidcd.nih.gov/

COMMUNITY LIVING AND GROUP HOMES

Community living and group homes refer to the Western-based philosophy and movement that holds that people with disabilities should have opportunities to reside in community-based homes. This movement seeks to promote community-integrated living, primarily for people with intellectual disabilities and mental illness, by moving them from large institutions into smaller (fewer than 15 residents), community-based home settings. These settings respond to the desire of people with disabilities to participate in community life. There is increasing research evidence that community living can enable them to exert control over their lives and improve their quality of life. Providing opportunities for community living may also be less expensive than institutional care.

Group homes typically bring together individuals who do not previously know one another into a collective, homelike residence. The residence may be an apartment or a freestanding home and is located within a residential neighborhood. Many models of group homes exist. Sometimes there are live-in care providers; others times there are shift workers, who may or may not be continuously present in the home. Likewise, sometimes the residents have primary responsibility for household matters such as cleaning, cooking, and grocery shopping; other times staff carry such responsibility. As a result of these and other factors, some group homes retain an institutional atmosphere, while others create a more resident-driven, homelike atmosphere. In general, group homes provide less restrictive environments for residents thereby increasing their satisfaction with their living arrangement. They accord residents with disabilities greater opportunities to exercise choice over day-to-day matters and increase their skills and adaptive behaviors. Group homes enable their residents to enjoy greater engagement in and/or responsibility for domestic and personal activities. They have a more active, normalized, and less regulated lifestyle in the community.

HISTORY

Historically, people with disabilities have been cared for by their families and have not had a long life expectancy. Starting in the seventeenth century in England and its colonies, people with disabilities began to be placed in separate facilities with other "social undesirables." By the mid-nineteenth century, state-run large residential care facilities were built or former tuberculosis hospitals and other facilities were adapted to house people with disabilities. Although intended to provide services, opportunities, and resources for living and protection from an unsupportive society, these facilities often were characterized by limited life choices for residents. They frequently experienced a low level of quality of life, abuse, and neglect. Staff showed a general lack of interest in returning residents to their communities.

By the mid-1950s, critiques of institutional care, the availability of new psychotropic medications, advocacy groups, and the international disability right movement were taking root. As a result, there was growing support for changes in the residential care of people with disabilities. Interest increased in reducing reliance on residential institutions and promoting community-based supports. In the early 1960s in the United States, President John F. Kennedy gave the first major presidential address devoted to society's treatment of people with emotional and cognitive disabilities. In ensuing legislation, his administration called for and obtained stronger community supports including community mental health centers, university centers for excellence in research and treatment for people with cognitive disabilities, state planning councils for innovative disability policies and programs, and state protection and advocacy agencies for people with disabilities. These new organizations began in the 1960s and have helped provide support for the development of group homes and community living.

Today, there is great variation among community-based living arrangements. Over time, the trend has been to reduce the numbers of people living together.

Today, there are often fewer than 6 people with disabilities who live together in group homes, although some settings continue to contain 7 to 15 individuals in one home. Some of these community living arrangements involve simple, intermittent staff oversight, whereas others involve almost complete control by and continual presence of nonresidential staff.

CHALLENGES

A serious shortage of community-based options persists, with great disparities in resources within and across countries. Although worldwide the majority of children and many adults with intellectual disabilities live in family homes, many people in Western countries with disabilities now reside in community living arrangements. As the struggle to attain inclusive communities continues, opposition has sprung largely from many communities' attitudes commonly referred to as "not in my backyard" (NIMBY) or a lack of acceptance for integrated housing options. These attitudes often lead to the development of local zoning and land use restrictions that create significant barriers to the creation of new community living residences. Overcoming these restrictions and promoting more positive attitudes toward people with disabilities are currently major activities in the quest to promote inclusive communities. In addition, research continues to question whether the current structure of group homes is able to significantly improve the quality of life of people with disabilities. Low staff pay and high staff turnover rates are among those factors that may thwart people with disabilities' ability to exert greater control over their everyday lives and improve their life satisfaction. Last, the current service system often wrongly associates a need for high levels of support with restrictive environments, thereby leaving many people with significant support needs seldom considered for community living opportunities.

—*Katherine E. McDonald*

See also Advocacy; Housing: Law and Policy; Independent Living; Normalization.

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COMMUNITY-BASED REHABILITATION

Generally speaking, rehabilitation involves the restoration of independence and agency in persons with sensory, psychiatric, physical, and/or cognitive disabilities. *Community-based rehabilitation* is broadly defined as rehabilitation efforts occurring outside medical or institutional contexts. Community contexts of practice can include, but are not limited to, advocacy-based organizations, not-for-profit residential programs, drop-in centers, community health and mental health centers, religious settings, public parks and other outdoor venues, employment settings, and homes of people with disabilities. Community-based rehabilitation programs can focus on just about any disability including autism, intellectual disabilities, learning disabilities, deafness, drug addiction, schizophrenia, depression, traumatic brain injuries, and spinal cord injuries. Community-based rehabilitation allows counselors to vary the contexts of practice based on the specific needs and backgrounds of persons with disabilities. Doing so increases the likelihood that rehabilitation services will be culturally and contextually anchored and therefore relevant to the persons receiving services. Grassroots community leaders, advocates, and professionally trained individuals from a wide range of disciplines can practice community-based rehabilitation. These include occupational therapists, physical therapists, rehabilitation counselors, developmental therapists, community psychologists, social workers, nurses, public health professionals, and physicians specializing in physical medicine or rehabilitation.

In the United States, the community-based rehabilitation movement derived from the deinstitutionalization and community mental health initiatives of the late 1960s and early 1970s. For many years, rehabilitation had almost exclusively occurred in hospital and clinical settings. Early community-based initiatives followed the medical model of treatment. Although in theory they embraced concepts of community participation, in practice many used professionally developed strategies that failed to include the voices of community members in program planning and implementation. In response to a growing dissatisfaction with community-based services among persons with disabilities and rehabilitation counselors, a community development model was proposed in the late 1980s and early 1990s. The community-based rehabilitation movement then began to shift from a treatment/deficit model that served to isolate and stigmatize persons with disabilities to one that promoted societal integration and the improvement of the everyday lives of individuals with disabilities. With this shift, community-based rehabilitation emphasized a strength-based model of social inclusion, political equality, and the translation of clinical and technological knowledge into relevant health care information and self-help skills.

Today, the practice of community-based rehabilitation varies along a continuum ranging from institutional, medical treatment approaches to community-integrated, participatory approaches. Medical treatment may involve biomechanical approaches to rehabilitation, including manipulating the body or teaching and assisting patients with movement and daily living skills. Medical approaches are criticized by disability rights activists and other scholars, researchers, and practitioners who support a more consumer-centered or participatory approach to rehabilitation. They argue that treatment-based rehabilitation approaches are similar to clinic-based approaches that promote the isolation and stigmatization of persons with disabilities; the only difference being that rehabilitation occurs with fewer resources and within community contexts. They argue that medical approaches assume that persons who provide treatment are experts. Recipients of services, or patients, are dependent on experts to direct the course of therapy, which promotes feelings of helplessness. Conversely, proponents of the medical approach to rehabilitation argue that some persons with disabilities are too severely disabled to direct the course of their treatment. Also, a lack of adequate resources prevents implementation of more consumer-driven rehabilitation services.

Alternatively, participatory community-based rehabilitation service approaches emphasize empowering consumers to function more independently. They encourage people with disabilities to advocate for their rights as citizens who are consumers of health care. Participatory approaches work to reduce professional-client power hierarchies by engaging consumers as leaders and treatment providers. Participants are encouraged to organize to develop, implement, and evaluate empowerment-oriented community-based services, not only for each other but also for the larger health care and social communities in which they interact. According to William Boyce and Catherine Lysack, true participation involves a process of personal as well as social transformation in which decision making takes place in the hands of the consumer group and social conditions are thereby affected or changed. This approach is typically associated with social action projects that emphasize the achievement of local, consumer-driven goals. The central tenet of this approach to rehabilitation is that it begins with the problems and needs of community members, rather than with the professional's conceptualization of those problems.

Professionals using participatory approaches to community-based rehabilitation become active knowers and members of the communities they work within. They fulfill these roles by becoming community organizers, meeting facilitators, educators, peer trainers, community advocates, activists, or resource persons for technical or material aid. This involves allowing the consumers to dictate the essential elements of the therapy process. The necessary requirements for legitimate empowerment within the therapeutic relationship are flexibility in establishing the variety of possible roles assumed by both service providers and consumers and the relinquishing of power by service providers to consumers when establishing those roles.

A growing number of integrative, community-based approaches to rehabilitation have developed based on the reconceptualization of persons with disabilities as citizens instead of patients. These approaches seek to combine education, training, practice, and advocacy efforts. One well-known example of an integrative approach to community-based rehabilitation is supported employment. Since the early 1980s, supported employment programs have enabled thousands of people with disabilities to become employed in their communities. Prior to supported employment, persons with significant disabilities who wanted to work were often placed in sheltered workshops. There they earned only pennies an hour in piecework wages. Supported employment programs promote a more integrated and higher quality of life by helping persons with disabilities pursue job opportunities in traditional work environments at pay equal to that of nondisabled persons.

Job specialists work with consumers, exploring their vocational aspirations and supporting them in their efforts to find jobs. Once consumers have a job, they receive on-the-job training and support. Eventually, support is faded out and consumers work independently. Job specialists in supported employment programs work to remove the barriers persons with disabilities face in obtaining employment. Job specialists work to remove the consumers' internal barriers by increasing their feelings of self-efficacy and self-esteem. Persons with disabilities experience a lifetime of oppression and marginalization that often leads them to believe that they are incapable of gaining meaningful employment. Job specialists also work to reduce external barriers to employment by advocating for their consumers as capable contributors to society. In addition to the benefits to consumers and to businesses, who receive dedicated and capable employees at reasonable pay rates, supported employment programs benefit society by reducing the stigma associated with having a disability. Promoting real-life interactions between disabled and nondisabled individuals can lower stigma and build positive relationships. Today, supported employment programs have been established in many other countries including Peru, England, Scotland, France, Ireland, Norway, South Africa, Japan, and Australia.

Internationally, the community-based rehabilitation movement began with two World Health Organization initiatives of the 1970s and 1980s: (1) the primary health care (PHC) campaign Health for All by the Year 2000, introduced in 1978, and (2) the community-based rehabilitation movement that emerged, in part, from the PHC campaign. Generally, the PHC campaign focused on efforts to raise the level of health in the world by increasing access to health care in developing nations. The community-based rehabilitation movement reflected an international recognition that rehabilitation is a key aspect of the campaign for global health. Rehabilitation has to take into account the cultural contexts of participating nations. Today, the World Health Organization helps improve access to rehabilitation services in underdeveloped countries by delivering simple, low-tech, community-based rehabilitation services.

An example of an international community-based rehabilitation program is Jamaica's 3-D Project. 3-D stands for Dedicated to the Development of Persons with Disabilities. 3-D provides home training programs, counseling, educational placements, and job placement or employment development to persons with disabilities in Jamaica. Another example is Guyana's Hopeful Steps. This program works to combat the marginalization of persons with disabilities by educating communities about their needs and abilities. Hopeful Steps also provides individuals with disabilities and their families training and support in becoming integrated and contributing members of society.

Supported employment, Jamaica's 3-D Project, and Guyana's Hopeful Steps programs share common philosophies. Their participatory approaches to community-based rehabilitation are based on the idea that all persons with disabilities deserve opportunities to participate and benefit from society equal to those enjoyed by persons without disabilities. In addition, they work to correct society's misperceptions about persons with disabilities by demonstrating that persons with disabilities are capable of not just participating in society but contributing to it. A philosophy of social justice and respect for basic human rights drives the international movement of community-based rehabilitation to advocate for the rights of persons with disabilities. The community-based rehabilitation movement is helping to change our basic conceptualization of disability from an individual deficit model to a diversity model, where persons with disabilities are no longer considered as categorically different than nondisabled persons. Instead, persons with disabilities are beginning to be viewed as disabled, not by internal deficits as much as by environmental and culturally determined limitations. Working to remove these limitations holds the promise for "curing" disabilities.

—Renee R. Taylor and Curtis J. Jones

See also Developing World; Job Training; Rehabilitation Counseling; Supported Employment; Vocational Rehabilitation.

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COMORBIDITY

Comorbidity is a disease or condition that is present in a patient in addition to the principal disease or condition. For example, suppose the principal reason a person visits a doctor, goes to a hospital, or has rehabilitation is because of an acute condition such as stroke; if the person also has diabetes, hypertension, congestive heart failure, or other conditions, these are called comorbidities.

A synonym for comorbidity is secondary diagnosis; the condition responsible for a visit, hospital admission, or rehabilitation is called the principal diagnosis. Comorbidities are important to consider for people with disabilities because they can influence greatly a person's need for health care, the treatments or interventions that are best, the cost of care, and the person's ability to function in the world.

Comorbidities, as well as principal diagnoses, usually are labeled with numerical codes. There are about 19,000 different codes in the International Classification of Diseases (ICD), which is coordinated by the World Health Organization. Each ICD code indicates the *existence* of a disease; it does not indicate the *extent* (severity) of the disease. Comorbidities can be more or less severe. Occasionally, the code itself indicates that the disease is very severe, for example, having the plague, since many people die from plague. In most cases, however, the same diagnosis code is used for patients no matter what their severity level. For example, suppose a rehabilitation patient has congestive heart failure as a comorbidity. The heart failure can be mild and not interfere with the patient's care or activity level, or it can be severe, leaving the patient weak and unable to do almost any activity, making the rehabilitation care process more complicated and the cost of care much higher.

Rehabilitation and other care processes of persons with disabilities are affected by functional status, as measured, for example, by the Functional Independence Measure (FIM) as well as type of impairment, such as stroke, traumatic brain injury, or spinal cord injury. Because medical acuity and comorbidities can also affect care processes, resource use, and ability to function in community settings, the Centers for Medicare and Medicaid Services has grouped comorbidities together into four tiers—three tiers for different levels of comorbidity severity and a fourth tier for no comorbidities—that are designed to represent more or less medical acuity. In analyses to date, however, these diagnosis-driven tiered approaches do not explain differences in rehabilitation care processes and resource use. Recent research suggests that comorbidity descriptors should incorporate levels of abnormality of various relevant signs and symptoms, such as those in the Comprehensive Severity Index (CSI®), to explain variation in needed rehabilitation care processes, resource use, and community function.

—*Susan D. Horn*

See also Disease; International Classification of Functioning, Disability, and Health (ICF/ICIDH).

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COMPETENCE

A person's *competence*, or *decision-making capacity*, is his or her ability to make and communicate a decision to consent to medical treatment. As such, competence is a threshold issue that is central to the determination of consent and reflective of the law's concern with individual autonomy. A person's decision regarding medical treatment must be respected when the person is competent to make that decision. Conversely, if a person is not competent to give informed consent, it will be necessary to employ an alternative decision-making process before the issue of whether treatment should be provided can be determined.

The test for competence is legal and not medical. While many health and medical tests are used in the determination of capacity (e.g., the Mini-Mental Status Examination or the MacArthur Competence Assessment Test), it should always be recalled that the ultimate issue is whether the person has competence according to the law. Therefore, a person should not automatically be presumed incompetent because he or she has a disability or mental illness. Rather, incompetence must be determined by examining whether a person's illness or disability affects the ability to make a decision to the point where the person should be treated as incompetent. Similarly, a person should not be treated as incompetent because the person makes a decision that is unusual or out-of-step with community expectations. Unusual or irrational behavior may mandate an investigation into a person's competence, but it is not synonymous with incapacity.

PRESUMPTIONS OF COMPETENCE

The common law begins by presuming that adults (those people who have reached the age of majority) are competent. The law also presumes that minors are incompetent (although in some jurisdictions the age of competence to consent to medical treatment has been lowered). Both presumptions can be rebutted by applying the test of competence to the person.

The Test for Competence

The legal test for competency is surprisingly similar across jurisdictions in the United States, United Kingdom, Australia, New Zealand, and Canada. Support can be found in all these jurisdictions for a functional capacity test that examines the patient's ability to receive, understand, and process treatment information. For example, in the English case of *Re C (Adult: Refusal of Medical Treatment)* (1 WLR 290 [1994]), a patient who had schizophrenia refused to consent to an amputation of a gangrenous leg. The judge found that patient was competent to refuse because he was able to

1. comprehend and retain treatment information,
2. believe that information, and
3. weigh the information and reach a decision.

A similar formulation was adopted in the American case of *Matter of Schiller* (372 A 2d 360, 367 [NJ, 1977]) where the court stated the test for capacity as follows:

> Does the patient have sufficient mind to reasonably understand the condition, the nature and effect of the proposed treatment, attendant risks in pursuing the treatment, and not pursuing the treatment?

Some jurisdictions have enshrined the test in legislation. For example, in the Australian state of Queensland, the Powers of Attorney Act of 1998 defines *capacity* as

a. understanding the nature and effect of decision about the matter; and
b. freely and voluntarily making decisions about the matter; and
c. communicating the decisions in some way.

In England, Australia, and New Zealand, the application of the functional competency test to children is referred to as the "*Gillick* competence" test, in honor of the case that stated that a child was competent to consent when that child was able to understand benefits and risks of proposed treatments (*Gillick v. West Norfolk AHA,* AC 112 [1986]). Courts in the United States and Canada apply an almost identical standard but refer to the test as the "mature minor" doctrine.

The Functional Competence Test

Step 1: Comprehending and Retaining Treatment Information

A person must be able to comprehend and retain treatment information to be competent. This reflects a concern with the patient's level of understanding. There are two main issues in this context.

The first relates to the issue of what sort of information must be comprehended by the patient. There are differing opinions as to whether the information needs to consist of basic treatment information or whether it should include more detailed information in line with the doctrine of informed consent. Generally speaking, British commentators and courts have only required the patient to understand very basic information about the broad nature and purpose of treatment for the patient to be treated as competent. Constrastingly, American courts and commentators have required that the patient not only understand the broad nature and effects of treatment but also benefits and risk of the treatment, of alternative treatments, and of no treatment.

The second issue concerns the type of understanding that is required of the person. Some commentators require the person to demonstrate an actual understanding of the treatment information, while others require the person to have a general ability to understand the treatment being offered. The reasons for adopting an "actual understanding" standard is that it focuses in a practical way on the treatment problem faced by the person. On the other hand, the actual-understanding approach is open to abuse in that it may allow a medical professional to withhold information and then claim that the person does not understand what is being proposed. An "ability to understand" approach prevents this abuse from happening because it is not dependent on the person possessing specific understanding of the treatment being offered. In practice, it appears that the courts look at both factors, and the Canadian Law Reform Commission has suggested that either standard can be employed.

Step 2: Believing Treatment Information

This step requires a person to be able to believe the treatment information, or, if the person does not believe the information, that nonbelief must not be caused by delusion brought on by mental illness or disability. For example, in *Tennessee v. Northern* (563 SW 2d 197 [1978]), the patient was found incompetent because she could not believe that she had gangrene. Contrast that with the case of *Re C* (mentioned above) where the patient did believe that he had gangrene, but he just preferred to die with two feet instead of live with one, and was consequently found to be competent.

Step 3: Weighing Factors and Evidencing a Choice

Patients must be able to effectively reason and communicate a choice. There are three main issues in this context. The first relates to an inability to communicate. In the New Jersey case of *Matter of Conroy* (486 A 2d 1209, 1241 [1985]), it was said that a patient may be incompetent because he or she lacks the ability to communicate a decision. For example, in the New Zealand case of *Auckland Area Health Board v. Attorney-General* (1 NZLR 235 [1993]), a patient with a "locked-in" syndrome was found incompetent because of his complete lack of ability to interact with the outside world. Of course, every effort should be made to find a way of communicating with the disabled person, and it may be possible for communication systems, such as letter boards or electronic devices, to bridge the communication gap.

The second major issue here concerns the person's ability to reason. This refers to the subjective reasoning process of the person and not whether the patient's decision would be considered objectively reasonable by other people. Once again, the concern is with whether the person's reasoning is being affected by a misperception of reality or delusion. Determining this is not an easy task as some personal and religious beliefs are not easily distinguishable from delusions. Staunch has argued that religious beliefs are distinguishable from delusions because they are nonrational rather than irrational. Grisso and Appelbaum have stated that it is also useful to see whether the religious belief predates the treatment decision, whether it is held by others, and whether the person has behaved consistently with those decisions in the past.

INQUIRIES INTO COMPETENCE AND RISK-RELATED TESTING

It has been argued by some judges, such as Lord Donaldson MR of Britain, and commentators, such as Buchanan and Brock, that there should be a greater level of competence required of people when they make high-risk decisions. Others, such as Grisso and Appelbaum, have stated that it is not greater competence that is required but rather greater evidence of competence. Arguably, this is because a person either has competence to make a decision or the person does not. Nevertheless, there is the danger that the requirement for greater evidence in higher-risk cases may discriminate against people who make unusual decisions. Only they will be subjected to greater levels of scrutiny. Someone who complies with treatment options in line with medical opinion will be less likely to trigger an assessment of competence. On the other hand, the requirement that competence be disproved in adults mitigates against discrimination because the onus is placed on doctors to rebut the presumption in favor of the person being competent to decide.

—*Cameron Stewart*

See also Consent to Treatment; Decision Making; Patients' Rights; Refusal of Life-Sustaining Treatment.

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COMPLEMENTARY AND ALTERNATIVE MEDICINE

Disability in modern Western societies is often seen as the terrain of orthodox biomedicine. Biomedicine is primarily centered on individual interventions using drugs and surgery to correct malfunctions following breakdown of specific parts of the body. On this conception, the body is typically conceived as a machine differentiated from the mind and spirit. Many mainstream official notions of disability in the past, including that of the World Health Organization, have been based on medical definitions focused on the functional limitations of individuals with impairments, such as those who are unable to walk or are partially sighted. The corollary of this approach is that, with the growing development of modern medicine, there is felt to be a rising need for medically led rehabilitation. The medical model, though, has been challenged as the social dimensions of disability have been more fully exposed, not least by drawing attention to socially defined concepts of normality and discriminatory social constraints on participation. As will be seen in this entry, however, biomedical conceptions of disability have also now been increasingly challenged both generically and in specific instances following the recent expansion of interest in complementary and alternative medicine in the West.

Complementary and alternative medicine is the term used in this context to describe approaches ranging from acupuncture and aromatherapy to herbalism and homoeopathy that are not part of mainstream Western medicine. These are typically used in a manner that is complementary, or opposed, to orthodox medical practices. Such approaches are sometimes referred to as holistic or traditional medicine, although these do not cover all forms of complementary and alternative medicine. While some classical systems such as ayurvedic medicine and traditional Chinese medicine are centered on bringing together the mind, body, and spirit, it is difficult to see how the work of, say, osteopaths who focus on treating bad backs is holistic, particularly when compared to their more eclectic counterparts. Equally, not all complementary and alternative medicine can be seen as traditional, as the cases of chiropractic, which was founded in the late nineteenth century, and biofeedback, which was established even more recently, amply testify. Complementary and alternative medicine is therefore defined as those practices that are politically marginal in comparison to the medical mainstream—as they are not usually a central part of the medical curriculum or extensively funded from official research funding agencies. As such, the approaches that constitute the orthodoxy of one age can readily become the unorthodoxy of another and vice versa.

In this sense, the concept of complementary and alternative medicine arose only once the medical profession had emerged in the West in the late nineteenth and early twentieth centuries. Before this time, there was a relatively undifferentiated field, in which those with disabilities in the seventeenth and eighteenth centuries were free to choose whomever they wished to consult in the health care marketplace. Importantly, the range of practitioners on offer included not only the precursors of contemporary doctors but also groups such as bonesetters and healers—with the public also having the opportunity to take the various pills and preparations for sale on a self-help basis. In addition, sufferers were able to make use of what was typically a stronger cradle of neighborliness and community support in a culture in which the human condition was viewed more holistically, with greater stress on personal constitution in maintaining health. With the rise of modern medicine and the development of the medical profession underwritten by the state, though, all this was to change; as greater unity emerged around biomedicine and the orthodox health care division of labor proliferated, those involved in practicing complementary and alternative medicine were increasingly marginalized as the mid-twentieth century arrived.

However, although the practice of complementary and alternative medicine had diminished in scale in the West by this time, it was buoyed in the 1960s and 1970s by the medical counterculture that came to the fore. This was part of the more general countercultural trend against materialistic values, involving among other things, revolutionary changes in fashion and rising interest in meditation and mysticism. In the medical area, there was growing awareness of the limits to medicine—underpinned by the widespread belief that modern biomedicine had reached a watershed in which it was becoming increasingly counterproductive—in a climate given to debunking the notion of scientific progress. A related challenge to professional authority was also launched that was aimed at overcoming the depersonalization and disempowerment of the patient endemic in biomedicine and allowing consumers to take more control over their own health. This was associated with the development of self-help, where a number of campaigning groups were emerging that lobbied on behalf of the disabled and other health consumers in such areas as cancer and HIV. In the wake of the counterculture, in which there was a particular fascination with Eastern philosophies, public interest in complementary and alternative medicine gained a new impetus.

In this respect, the numbers of users of complementary and alternative medicine in Europe and North America expanded to between one-fifth and two-fifths of the population, although the main therapies employed and the extent of their use vary considerably by country. The majority of this growth involves self-help usage. However, there has also been an associated expansion of practitioners of complementary and alternative medicine. In Britain, for example, these have increased from 30,000 to 60,000 in the past 20 years—a figure that is currently paralleled by the number of chiropractors alone in the United States. Growing numbers of orthodox practitioners including doctors, nurses, physiotherapists, and other health professionals have also employed complementary and alternative medicine as popular and political demand for such therapies has expanded. However, in the hands of doctors—with some notable exceptions—complementary and alternative medicine has tended to be applied in quite a restricted manner. Thus, in the case of acupuncture it has mainly been used by the medical profession for pain and addictions rather than as a panacea as in classical Chinese medicine. It has also largely been medically justified with reference to neurophysiological theories about endorphins as opposed to the traditional principles of balancing the polar forces of yin and yang along meridians.

One reason for this typical pattern in the West of using therapies such as acupuncture in more of a complementary rather than alternative mode is that it is not in the interests of the medical profession to do otherwise in situations where they risk legitimating unorthodox competitors, given the threat this poses to their income, status, and power. Another explanation for the broader reticence of doctors about using complementary and alternative medicine, though, may be their desire to protect the well-being of patients in light of the present limits on the evidence base in this area. Despite the ideology of a safe, “natural” approach to health care frequently espoused by complementary and alternative therapists, there are hazards posed to disabled and other users ranging from punctured lungs in the case of acupuncture to potentially fatal overdosing from herbal remedies. There are also major gaps in the evidence that has been provided for such therapies in terms of randomized control studies. This in part is because complementary and alternative therapies have not attracted the same level of investment from governments and the pharmaceutical companies as have more orthodox remedies.

This, however, is a controversial area. Orthodox medicine plainly has its own problems in terms of safety—as starkly illustrated by the devastating and disabling effects of thalidomide in the 1960s and more recently the growing number of potentially fatal infections contracted by patients in hospitals. In addition, there is much debate about how to assess the efficacy of complementary and alternative medicine. While large-scale randomized controlled trials are rare in this field, many areas of conventional medicine have not yet been subjected to such scrutiny in a thoroughgoing manner for ethical and other reasons.

There are also significant methodological questions about whether the randomized controlled trial is the best way to evaluate complementary and alternative therapies, especially when they are employed holistically. Where treatments associated with complementary and alternative medicine are targeted toward individuals rather than standard conditions as in orthodox biomedicine, their practitioners often argue that other methods of assessment are more appropriate. In this respect, rather than trying to eliminate the placebo effect through the randomized controlled trial methodology, it is frequently claimed that it should be more fully employed in complementary and alternative therapies. This makes other methods such as case studies and consumer satisfaction surveys all the more attractive as evaluative tools.

When looked at in these terms, there is a growing and ever more substantial evidence base for certain types of complementary and alternative medicine in relation to various specific forms of disability—as well as in health care more generally. Part of this evidence base is actually derived from the many small-scale controlled trials of complementary and alternative medicine that have been conducted as compared to placebos and more conventional approaches. Some of these have produced encouraging results, as, for example, in relation to the use of spinal manipulation and acupuncture in the relief of chronic pain. However, from the viewpoint of orthodox research methodologies the numbers of participants have usually been too restricted to make firm judgments about the likely efficacy of particular therapies. In such cases, systematic reviews of trial data can be very helpful, provided that clear criteria for inclusion and exclusion linked to the quality of the studies are employed and there are enough credible trials on which to build the meta-analysis. In the field of herbal medicine, for instance, such systematic reviews have recently suggested that St. John's wort can provide symptomatic relief in cases of moderate depression and peppermint can do likewise in the treatment of irritable bowel disease.

Once we look beyond this form of randomized controlled trial evidence on a more eclectic basis, though, the data set on complementary and alternative medicine becomes even richer. A plethora of individual case studies indicate the positive qualitative outcomes that can be obtained from such therapies, including in relation to different types of disability. The use of complementary and alternative medicine also tends to produce high levels of consumer satisfaction. Of course, the subjective views elicited in such research should not simply be treated at face value, as there are a variety of methodological pitfalls in interpreting such results. Nonetheless, they do at least suggest that unorthodox therapies could help to fill the vacuum created in areas where orthodoxy has little to offer, such as in a number of chronic conditions. In this regard, it is important to acknowledge that complementary and alternative medicine contains many diverse approaches, not all of which are equally well founded. A recent government report in the United Kingdom, for example, suggested that research evidence was currently much stronger for such therapies as herbalism, homoeopathy, and osteopathy than those such as crystal therapy, iridology, and radionics. This underlines how vital it is that the evidence for specific forms of complementary and alternative medicine is carefully and critically scrutinized before claims about its curative or palliative powers are accepted.

However, even where it is felt that complementary and alternative medicine can bring benefit to the disabled and others in the West, there are major organizational challenges to address. One issue is how accessible such therapies are to consumers within state-financed health provision and insurance programs, given that they are still primarily concentrated in the private sector. In this respect, it should not be assumed that complementary and alternative therapies can simply be slotted in as cheaper versions of orthodox medical provision; even when they appear to be more effective they are not necessarily less costly as they can be more labor-intensive than biomedical practices despite the technology that is often involved. This clearly raises equal-opportunities questions in relation to the disabled and other users of such therapies.

Another organizational issue concerns the extent to which complementary and alternative medicine is appropriately regulated in terms of protecting the interests of health consumers, including those with disabilities. In this respect, the remedies themselves and practitioners of these therapies are now increasingly subject to regulation, but the parameters of this are not always well balanced. For instance, despite growing trends toward professionalization, the practice of complementary and alternative medicine in the West is too exclusively concentrated in some countries in the hands of doctors and allied health professionals. In other countries, it is too loosely assigned to anyone who wishes to be engaged in the field—in systems largely based on voluntary regulatory arrangements to which not all practitioners are legally bound.

Finally, it should be noted that complementary and alternative medicine in the West does not simply challenge biomedicine in terms of best practice. In its most radical forms, it also challenges some of the wider assumptions underpinning medical orthodoxy, paralleling the increasing questioning of the medical concept of disability noted at the outset of this entry. Many of those currently involved in practicing complementary and alternative medicine, for example, no longer see consumers in medicalized terms as patients, but rather as more active participants in their own well-being. Given its links to the counterculture, the self-help aspect of this area is therefore not now seen just as an appendage to medicine but also as challenging the power of the medical profession. While biomedicine is currently dominant, the approaches that are now categorized as complementary and alternative medicine could at some stage in the future become more fully incorporated as the basis of a new orthodoxy. Whatever happens, though, it is vital at present that we strive for a greater accommodation between orthodox and complementary and alternative medicine so that those in need of assistance—including the disabled—can draw on the most useful and well-evaluated support from the viewpoint of potential cures, palliative care, and health maintenance.

—Mike Saks

See also Acupuncture; Chiropractic Care; Medicine.

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Research Council for Complementary Medicine, www.rccm.org.uk

COMPUTER SOFTWARE ACCESSIBILITY

The short definition of *computer software accessibility* is as follows: Properties of a computer program or system that allow for the widest possible range of users to access the software system's functionality. To define the term more fully, we should look into the definition of each term in the phrase.

Computer software refers to the programs and instructions that specify calculations and direct computer hardware operations. Software comes in two main forms: system software, which controls the basic functions of the computer system (such as the basic input/output system and resource management), and application software, which perform higher-level tasks, such as word processing and productivity software. Software can range from a single program running on a single machine to a distributed system that runs on multiple machines and communicates over a network.

Accessibility in general refers to an item's properties that allow for the greatest range of use by users with the widest range of abilities and disabilities. Therefore, accessibility can refer to the level of access to a resource by a user, regardless of ability level. Accessibility can range from relatively *high accessibility,* which allows for little to no modification or concession to gain access or use, to relatively low accessibility, which allows only for specific users to gain access and use the product's features.

Therefore, *computer software accessibility* refers to the degree to which a computer program or computer system's properties allow it to be used by the widest variety of users with abilities and disabilities. This also entails accessibility of software that can reside on a single computer, or software systems that run on multiple machines to perform a task.

Accessibility of computer software running on multiple computers can involve accessibility from a number of fronts. An example of this can be an enterprise software package that has database components running on various machines, logic on other machines, and user input handled on yet other machines. The accessibility of the database components can be measured by the ease of use for a database professional with a disability, while the accessibility of the user interface can affect novices using the system for the first time, or experts who are trained in the software package.

Accessibility of software can be affected by a number of factors. First, the architecture of the software may or may not take into account programming standards that allow for third-party systems or devices to extract information from the target software. Much like a computer monitor is able to extract graphic information about software, other output devices have the ability to extract information only if the software programmer specifies it to do so. This includes access by assistive technology, such as text-to-speech systems, tactile feedback systems, and other systems that allow for non-video representation of the software.

Second, the user's control over the software settings is directly affected by the amount of control the software programmer allows the user to have over the specified software. Examples of this include access to change the software system's font sizes, ability to change color and contrast settings in the software, or ability to specify output mode. Changes can be made directly by the user via features in the software itself, or indirectly via the operating system in which the software is running.

An *accessible* software system entails a relatively *high* level of accessibility. Accessible software adapts to a user's needs or preferences without reducing functionality or access to the system. An example of an accessible software system would allow a hearing-impaired individual to transform audio output in software to a textual/visual representation, or allow a visually impaired individual to choose to use audio capabilities to access data from the same system, or allow a person with a physical disability to use other input devices to function with the software system, other than limiting functionality to keyboard or mouse-only use. Accessibility of software is important to ensure that a wide spectrum of people can use the same technology with little to no modification.

In the larger scope, accessible information technology (AIT) encompasses not only computer software but also computer hardware, including desktop computers, laptops and notebooks, and computer peripherals. Accessible environments are the result of having accessible information technology implemented in a setting.

—Bob Alvarez

See also Accessible Internet; Computer Technology.

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COMPUTER TECHNOLOGY

Computer technology is an ever-changing and evolving technology. While the personal computer may be the most common association with computers and computer technology, computer technology has integrated across devices as diverse as copy machines, cell phones, and other communication devices. The integration of computers with power wheelchairs, electronic aids to daily living, telephones, and communication devices has given people with disabilities the potential to control more of their environment than ever before. For a person with a disability, a computer can provide opportunities for communication, education, banking, shopping, or employment that may not otherwise be possible. However, to make use of the advantages offered by computers and their integration with other systems and devices, a person must be able to access the computer.

ACCESS

When considering access to a computer, one must investigate both input and output methods. Input methods to the computer commonly include a standard keyboard and mouse, while output is generally associated with a liquid crystal display (LCD) monitor, speakers, and a printer. Without any adaptations to the system, a person with a disability may have trouble entering data, controlling the mouse, or reading text from the monitor. Those who may have difficulty using standard input and output methods include people with visual impairments, hearing impairments, cognitive impairments, and motor difficulties.

For those who are unable to use a standard keyboard or mouse to input data, alternative keyboards and mouse emulators are available. These alternatives are generally plugged into the standard keyboard or mouse ports on the computer and may be used exclusively or in addition to the standard keyboard and mouse.

ADAPTATIONS TO COMPUTER INPUT

For an individual with a motor impairment who has difficulty accessing the standard size or location of keyboard keys, a smaller- or larger-size keyboard may be useful. Smaller keyboards may be beneficial for those with limited range, such as individuals using a mouthstick or people with weakness in their upper extremities. Larger keys may benefit those who must use a larger surface area such as their thumb, a pointing device, or their entire fist to access each key, rather than one finger. People with visual impairments may benefit from simply larger key labels affixed to a standard keyboard, without changing the size of the keys themselves. A concept keyboard that allows for programming individual keys with pictures versus standard characters, or limiting the number of keys to work in conjunction with a specific software program, may be beneficial for a person with a cognitive impairment.

Although many keyboards have been developed as an alternative for using a standard QWERTY keyboard, manual text entry is not always an option. An alternative to manual text entry that has become widespread commercially is voice recognition. Voice recognition software allows a person with clear diction and strong breath support to dictate commands to a computer, via the use of a calibrated microphone. Voice recognition programs require extensive training by the user, for the creation of voice files that will be assigned to each individual user. Although voice recognition programs have become much more accurate and reliable over time, the level of cognition and dedication required can be a disadvantage for some individuals.

Another alternative is the use of indirect means of manual text entry. These include single or multiple switches and scanning or coded input such as Morse code. Each provides a means of accessing multiple keys. To access keys through switches and scanning, an individual needs to time the activation of a switch to a highlighted or speech feedback scan. The scan singles out each key or set-of-keys option as it moves along at a calibrated, timed pace. With Morse code, the activation of the correct sequence of switch hits allows one to enter text as if using a standard keyboard. The benefit of scanning and coded input is the flexibility offered in terms of access site. A person who is unable to use his or her hands may be able to activate a switch placed near the person's head. Drawbacks to using scanning input are its slow means of text entry and timing of switch activations to the scan. A drawback to coded input is often the cognitive load required in learning the designated key combinations to use the system efficiently.

One method of switch access that is currently in the research-and-development stage is the use of direct brain interface and switch closure. This method is designed to allow a person to select a desired target strictly by concentrating and imagining selecting the target. The signals generated by the person's brain are captured and translated to a switch closure, which in effect acts as if the user activated the switch manually.

Most computer interfaces are based on a graphical user interface (GUI), in which a mouse is used to access icons, windows, and menus. Using the mouse can often present difficulties for a person with a disability. Alternatives to the standard mouse can range from a simple device such as a trackball to a more advanced solution such as a touch screen or an eye gaze system.

An ergonomically shaped mouse, a joystick, or a trackball or track pad are simple alternatives to the standard mouse for an individual with a motor impairment. For example, a person who experiences hand tremors might find rolling the ball of a trackball easier than controlling a hand-held mouse to move the cursor to the desired location. For a person who is unable to use his or her hands, a mouse operated by moving the person's head may be an option. Head-mouse systems range from infrared technology by way of a reflected dot worn on the glasses or forehead to ultrasound technology with location sensors to a camera that translates movement of the head into cursor movement.

For a person with limited vision, software that enlarges the pointer/cursor in conjunction with enlarging the icons, characters, and windows on the display makes using a pointing device possible. For an individual with no vision, keyboard equivalents in conjunction with a screen reader are often used to access the computer.

One of the latest advances in computer-aided assistive technologies is the use of eye gaze technology. An eye gaze system allows an individual to make selections on a computer screen or communication device through the use of eye movement. A camera mounted near the user's eye tracks eye movement through the use of infrared technology. The system allows the user to direct the mouse cursor across the screen through eye movement. Through the use of a separate switch or a dwell-click of the cursor, the user is able to activate desired targets. It should be noted that eye gaze technology is in its early stages, and most systems require repeated calibrating to ensure accuracy for each individual.

ADAPTATIONS TO COMPUTER OUTPUT

Just as there is more than one way of entering data into a computer, there are several means of presenting data to the user. The most common source is generally through a standard LCD monitor. For people with visual impairments, additional auditory output such as indicator alarms, tones, or synthetic speech can be beneficial. The use of high-contrast colors or screen magnification is also commonly used by people for whom standard 12-pt. font or standard screen colors are not appropriate.

For blind users or people for whom screen magnification is insufficient, screen readers are another option. Software programs are available that will read text aloud to the user, navigating through text boxes as well as graphics. Often the user is able to control the speed, pitch, and volume of the output, as well as fast forward or move back to a specific location in the text.

A standard computer printer is the most common source of hard-copy output from a computer. However, for those who are unable to read copy from a standard printer, Braille printers provide blind users with an opportunity to read text that has been converted to Braille and printed out on hard copy.

Refreshable Braille displays provide blind users with the option of reading on-screen text that has been converted to Braille characters through the use of vibrating pins in the shape of individual Braille cells. Refreshable Braille displays allow users to read longer passages of text without using any paper.

For a person with a hearing impairment, visual output in the form of blinking indicator alarms or text messages provide alternative feedback to sound or speech feedback. Newer technologies involve text captioning of spoken and or auditory information presented on a website or DVD.

Adaptations to computer input and/or output can make accessing and using a computer possible when standard available options are insufficient. Computer technology in relation to disability encompasses these alternatives by which an individual is able to access a computer. While many technologies are readily or commercially available, others are still in the research-and-development phase.

—Kathy Hooyenga and Dana Mavros

See also Accessible Internet; Assistive Technology; Augmentative Communication; Computer Software Accessibility; Information Technology.

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CONFINEMENT

Western communities explain and legitimize the confinement of persons with supposed "impairments" through medicalized notions of treatment and care. Bodies deemed impaired are confined for their "own good" and for their "best health." Guided by biomedical logics of beneficence, Western common sense claims that bodily impairment necessitates confinement.

What this popular position overlooks—or, perhaps, actively obscures—is that when social communities confine those they mark as impaired, they create a major source of disability oppression. Confinement either directly causes, or indirectly reinforces, all five major forms of disability oppression: marginalization, powerlessness, exploitation, cultural imperialism, and violence. First, confinement, or the ever-present threat of confinement, removes and marginalizes those categorized as impaired from active integration with the community. Second, confinement leaves the impaired powerless to follow their own will or meaningfully contribute to community life. Third, confinement exploits the impaired by making them the raw material for a vast therapeutic industry. Fourth, confinement creates, symbolizes, and shores up a culturally rigid binary between the able-bodied and the disabled. This binary generates an able-bodied cultural norm that imperially looms over the disabled in an ever-present position of privilege and desire. And, finally, confinement provides the ideal space for violence. Through the exclusion and seclusion of confinement, the impaired may be, and often are, the victims of physical, sexual, and psychological abuse, not to mention sterilization and extermination through eugenic policies and ideologies.

Popular common sense not only overlooks these oppressive realities of confinement, but also covers over the historical dimensions of confinement practices. The popular perspective—which, working through a biomedical lens, sees confinement as necessary and beneficent for those marked as impaired—too readily neglects the historical roots and social imperatives of confinement. Also, it does not acknowledge the historically and socially constructed dimensions of the terms *impaired* and *disabled*. Furthermore, it does not acknowledge how confinement helped bring about and shore up these notions of impairment and disablement. It fails, in short, to acknowledge how confinement practices, which emerged in the industrial era, have been a major source of disablement.

In Western feudal society, the impaired were not confined, primarily because the distinction between the impaired and the nonimpaired was much less marked. Most of the population lived on rural manors. Chronic difficulties due to injuries and communicable diseases (such as tuberculosis) meant that many people were impaired (as we understand the term today) in some way. Whether they were impaired or not, most people spent their lives very close to home because feudalism meant little or no travel. In addition, the impaired and able-bodied worked alongside each other, and feudal work was not commodified into classes of paid and nonpaid activities. It is true that work was gendered (home-work for women; field-work for men), but it was not hierarchically arranged by an outside value system that paid for some work but not others. Work was work and it had to be done. Family and community members, regardless of bodily difference, pitched in as best they could. Since no one traveled much and everyone worked side by side, there was much less difference in experience between the impaired and nonimpaired. Thus, the distinction between the two was not marked in the way that it is today.

Industrial capitalism dramatically changed this feudal scene and set the stage for what Michel Foucault calls "the great confinement." The spread of free market economy, wage labor, and mechanized systems of production created conditions highly unfavorable for flexibly integrating the impaired through family-based work and support systems of feudal societies. Industrial capitalist systems relied on rapid-paced factory work, enforced discipline, and regulated norms of production, which effectively excluded the integration of a diversity of bodies.

This social exclusion of bodies by the capitalist community of normative work roles created a *social problem.* What to do with the newly dis-integrated bodies? As Foucault documents, Western societies responded with a *social solution.* Foucault uses the example of seventeenth-century France, which created a network of enormous houses of confinement—known as *hôpitaux généraux*—across the country. Within a period of several months time, one out every hundred inhabitants in Paris found themselves confined. Foucault emphasizes that these hôpitaux généraux were not medical establishments. They were a cross between a workhouse and a prison, part of a system of administrative supervision established to create social containment for those "outside" the new capitalist system. The confined in these institutions were not "patients" but a mixed population of the unemployed, the poor, the idle, the criminal, the impaired, and the mad.

The developing bourgeois order of industrial capitalism did not admit these people to the hôpitaux généraux for medical causes or medical treatment. They admitted them because the confined were unable, or unwilling, to cope with the newly established order of rigid work roles. Though internment was billed as a form of public assistance, once placed in confinement, forced labor was the rule. Foucault (1987:68) argues that the compulsion to work, in addition to providing a source of cheap labor, had the role of moral sanction: "In the bourgeois world then being constituted, the major vice, the cardinal sin in that world of trade, had been defined: it was no longer, as in the Middle Ages, pride or greed, but sloth." As a result, the common category that grouped the confined together was their inability to participate in the production and circulation of wealth in the new economy. Exclusion and internment due to inability to work created a new division in social space and a powerful new social solution for the social problems of the industrial order.

Though we no longer have *hôpitaux généraux*, their legacy remains very much with us today. Generalized internment lasted for just over a century when political denunciation began to break up this form of confinement. Liberal reformers argued that generalized confinement created a dumping ground that failed to separate those unwilling to work from those who were unable to work (in other words, it failed to separate the deserving poor from the undeserving). In response to this political critique, the eighteenth- and nineteenth-century reforms created ever more specialized institutions for ever more specialized populations. For example, the English Poor Law Amendment of 1834 stipulated five categories of those unable to work: children, the sick, the insane, defectives, and the aged and infirm. These specialty categories set the stage for the development of specialty institutions familiar to us in current times: orphanages, medical hospitals, asylums, residential care facilities, and nursing homes. All but the first of these institutions are administered through medical superintendents and medical logics of expertise. But, as the history of confinement reveals, medical issues are not the primary social function of these institutions. These institutions retain their function as a social solution that fails to integrate the "disabled" into the community (see Snyder and Mitchell [2003] for a particularly evocative presentation of institutional life and institutional social function).

Recently, the process of reform has started once again. Since the 1960s and 1970s, the broad social movement of "deinstitutionalization" has reduced the population of specialty institutions. But, once again, this reform only reshuffles the deck. The logics of confinement remain firmly in place. In other words, deinstitutionalization has not been effective at community integration. The previous medicalized relations of power continue to exist in the new "community settings." Deinstitutionalized community placement has done little to adjust community rules, norms, and expectations for successful social function and social contribution. Well-established standards of universal design for an accessible environment have not been widely adopted. Even though, for many disabled persons, adjustments to the environment represent the only feasible means of improving lives and joining with the community. Without these adjustments, too many disabled people today are condemned to live indefinitely in the remaining specialty institutions or in newly formed community residences and "back bedrooms"—where they once again become virtually incarcerated without any real chance of interacting with others (Hahn 2002).

There is very little that is voluntary or emancipatory about these deinstitutionalized community settings. People's choices in these community settings too often represent serious compromises based on severely limited options. In the most blatant examples, community confinement is enforced with all the state pressure of previous institutional internment. For example, recently passed outpatient commitment laws across the United States require mentally disabled people to stay on medications, and compliance with these laws is enforced through state sanctions. The common slang for these medications, "chemical confinements," clearly indicates the continuing logics of confinement in the transition from institutional to desinstitutionalized care.

It is important to note that, whether one is currently confined or not, the continued specter of confinement haunts everyone. The failure of community integration should not be understood as a "minority" issue. This failure hurts not only the disabled, it hurts the abled (or temporarily abled) as well. It leaves in place an archipelago of confinement that forms an ideologically oppressive threat for all. There can be no escaping that the failure to set up the structures of accessibility and interdependence leaves everyone either trapped and confined, or caught in the relentless fear of becoming trapped.

In sum, confinement must be understood as a social intervention much more than a medical one. But confinement is a bad social solution to physical and psychological difference. The social solution to the social problem of disintegrated community members is not social exclusion and social confinement. The social solution is social integration.

—Bradley Lewis

See also Deinstitutionalization; Institutionalization and Segregation.

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CONFUCIUS (551–479 BCE)

Chinese philosopher

The teachings of Confucius were adopted as the official moral and political ideology of China in the former Han Dynasty (206 BCE–AD 25). Since then, they have exerted a profound influence on Chinese state and society. Among the Confucian virtues are benevolence (*ren*) and filial piety (honoring one's parents; *xiao*).

Ideals of benevolent but authoritarian rule have shaped a paternalistic approach to society's most vulnerable: those without families and with serious impairments. There are references dating back several thousand years to imperial Chinese emergency relief and tax exemptions for people with specific and serious impairments.

Confucian ideals of state and society are firmly centered on the family and on the concept of order: everyone and everything in their proper place and rigid family hierarchies based on age, gender, and filial obligations. Disorder is inherently undesirable—and this is applied equally to the body as to the family or state. Bodily difference through impairment or illness is constructed as not-complete, not-correct, not-normal, and not-filial. One of the Confucian classic texts (*Book of Filial Piety*) states that to injure even one's hair or skin is to dishonor one's parents. Confucianist teachings also restrict the potential for people with certain impairments from attaining personhood through exclusion from marriage and ancestral rites.

Thus, Confucianist approaches to bodily and mental difference simultaneously afford protection (placing obligations on the family to provide support) while labeling difference as disorder. The result is a strong sociocultural legacy in China and other parts of East Asia of marginalizing disabled people and treating them as the "Other."

—Emma Stone

See also Disability in Contemporary China; Experience of Disability: China; Experience of Disability: Taiwan; History of Disability: Korea.

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CONSENT TO TREATMENT

WHY CONSENT?

Historically, many physicians believed that it was their right and responsibility to make treatment decisions for their patients, particularly if the patient in questions was considered to be incapable of making his or her own decisions. Over time, however, courts have made it increasingly clear that treatment without consent violates fundamental legal principles.

Arguably, modern consent law grew out of the need to protect physicians from allegations of assault for touching the bodies of others without consent. In more recent times, courts have tended to view lack of proper informed consent as an issue of negligence. Practitioners have been held liable if treatment that later results in harm to the patient is administered without proper informed consent and it can be shown that the patient would likely not have consented had he or she been provided with the appropriate information on which to base the decision.

Whatever its genesis, modern consent law represents a fundamental cultural shift and has immense symbolic significance. It marks a fundamental shift away from medical paternalism. It makes the patient a partner in his or her own care and symbolizes the fact that patients, not health professionals, are at the center of health care and the very reason for its existence. It stands for the uniqueness of each individual and the right of each person to make health care decisions if capable of doing so. More than all of this, consent principles stand tall as a monument to personal autonomy and self-determination, the fundamental rights of every individual in a free and democratic society.

THE REQUIREMENT FOR CONSENT

Treatment Requires Informed, Capable, Voluntary Consent

With the exception of certain emergency situations, all treatment requires informed, capable, voluntary consent. If capable, the patient makes the decision. If the patient is not capable, a surrogate makes the decision on his or her behalf.

The Meaning of Consent

Valid consent does not mean a signature on a piece of paper. For consent to be valid, it must be informed and be given voluntarily by a capable person. Consent may be oral or written, expressed or implied.

Informed consent means that the health practitioner has given information that a reasonable person would need to make the decision and has answered any relevant questions that the person asks. The consent must not be obtained through misrepresentation or fraud.

Consent may be withdrawn at any time by a person who is capable of doing so. A person who is capable of consenting to a treatment is considered to be capable to withdraw the consent. A person who becomes capable after a treatment starts is entitled to take over the decision making from the substitute decision maker.

EMERGENCY TREATMENT

A health practitioner may treat without consent in situations where the patient is incapable of making his or her own treatment decisions, a surrogate is not available, and there is a risk of imminent loss of life unless the practitioner has reasonable cause to believe that the person expressed a wish to refuse consent to the treatment while capable.

CAPABLE OF CONSENTING TO TREATMENT

Capable individuals make their own treatment decisions. A person is capable of making decisions about a treatment if able to understand the information relevant to making a decision about the treatment and able to appreciate the consequences of a decision or lack of decision.

Some people are incapable of consenting to one treatment, yet capable of consenting to others. The concept of global capacity or global incapacity does not exist in law. A person may be incapable of consenting to a treatment at one time but capable at another time.

A person is presumed to be capable of making a treatment decision unless there are reasonable grounds to believe that the person is incapable. Persons should not automatically be presumed incapable purely on the basis of age, physical frailty, or diagnosis, although all these factors may be important in the assessment of capacity. In many jurisdictions, there is no fixed age of consent.

INCAPABLE OF CONSENTING TO TREATMENT

An incapable person cannot provide valid consent. Even if a person is willing to have a treatment, a health practitioner may not presume that he or she is capable of consenting to the treatment when it is unreasonable to do so.

A health practitioner who is proposing a treatment may determine that the person is incapable of making decisions about the treatment. The proper surrogate must then make the treatment decision. A person does not become incapable only because a health practitioner does not speak his or her language or has other difficulties in communicating with the patient. The health practitioner is obliged to take the steps necessary to establish communications.

A finding of incapacity must be made on the basis of an appropriate inquiry and objective criteria. The best interests of the patients should not play a role in the evaluation of capacity and the person conducting the evaluation must always keep in mind the fact that capable people have the right to make bad decisions. Capacity determinations should be carefully documented. An otherwise incapable person does not become capable because he or she goes along with the proposed treatment.

SURROGATES

Capable people are entitled to make their own treatment decisions. When a person has been found incapable of consenting to a treatment, a surrogate must make these decisions.

Applicable legislation or common law will generally set out potential surrogates in rank order. Court-appointed surrogates generally top the list followed by surrogates appointed by the patient and then family members in a specified order. It is the obligation of the health practitioner proposing the treatment to identify the legally appropriate surrogate. In some jurisdictions, a committee makes substitute decisions. Depending on the jurisdiction, the committees are commonly made up of health professionals, administrators, and family members.

RULES FOR MAKING SUBSTITUTE DECISIONS FOR TREATMENT

Capable Patients

Capable patients making decisions for themselves are not bound by any rules. They may make treatment decisions as they see fit, even if others see their decisions as ill advised, foolhardy, or even dangerous.

Decision Making by Surrogates: Prior Wishes

Surrogates are generally bound by a set of rules established by statute or common law.

Every person has the right to expect that his or her capable wishes will be respected.

A surrogate must follow a person's most recent capable wishes. Capable wishes may be expressed in writing or in some other way. It is always difficult, however, to decipher the precise nature of nonwritten wishes. Depending on the jurisdiction, written wishes may be set out in powers of attorney, advance directives (sometimes referred to as living wills), or similar documents. Depending on the jurisdiction, alternative formats, such as video statements, may be acceptable as well.

Values and Beliefs

Surrogates are expected to respect the values and beliefs of the patient when making a treatment decision. In some jurisdictions, values and beliefs are to guide the surrogate if there are no binding prior capable wishes. In other jurisdictions, values and beliefs are to be considered together with the other best-interest criteria, set out below.

Best Interests

If there are no binding prior capable wishes (or a decision dictated by the patient's values and beliefs in those jurisdictions where values and beliefs take priority), a surrogate must act in the incapable person's best interests. In deciding whether a treatment is in the best interests of the incapable person, the surrogate must generally consider all of the following:

- The values and beliefs that the substitute knows the incapable person held when capable and believes that he or she would still act on if capable
- If the proposed treatment is likely to
    - Improve the incapable person's condition or well-being
    - Prevent the incapable person's condition or well-being from deteriorating
    - Reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate
- Whether the incapable person's condition or well-being is likely to improve, remain the same, or deteriorate without the treatment
- Whether the benefits the incapable person is expected to obtain from the treatment outweigh the risk of harm to her or him
- Whether a less restrictive or less intrusive treatment would be as beneficial as the proposed treatment

THE USE OF FORCE

Properly obtained substitute consent allows a health practitioner to treat a patient without facing the legal censure that can flow from treatment without legally valid consent. What is not clear, however, is how much force a practitioner is entitled to use when a treatment-incapable patient for whom substitute consent has been provided chooses to physically resist the treatment, leave the area, or simply not appear as scheduled.

It can be argued that substitute consent rules are meaningless unless minimal force can be used to carry out the directions of the substitute decision maker. What is the point, for example, of declaring a person suffering from mental illness incapable of consenting to treatment if he or she is free to simply absent himself or herself or refuse the treatment?

It is equally clear, however, that substitute decision makers are neither the guardians nor custodians of the patient. Health practitioners and their assistants do not possess powers of arrest or detention. In democratic societies, the right to forcibly apprehend, detain, or forcibly interfere with the body of another can be granted only by the appropriately constituted legislative authority and must be subject to clear limitations, regulation, and oversight. No such authority or regulation is generally provided in the case of substitute decision making for health care. There is no clear solution to this conundrum. What is clear is that legislatures and courts will eventually have to sort out the issue if the modern principles of consent to treatment are to be respected and truly integrated in health practice.

THE PROBLEM OF COMPLIANCE

Many physicians and health care professionals understand and respect the principles of consent to treatment and do their best to apply them in their day-to-day practice. Other practitioners are misinformed, disinclined to follow the law, or both. Many practitioners believe that consent is not an issue as long as the patient acquiesces, or at least does not vigorously resist any treatment that is proffered. Others hold the false belief that all patients, regardless of mental capacity, are entitled to reject treatment.

The problem of disregard for consent-to-treatment principles is particularly acute when vulnerable people are involved. Many practitioners are inclined to ignore the voice and rights of vulnerable people who may be legally entitled to make their own treatment decisions. Some practitioners believe that they are entitled to make decisions on behalf of patients who have cognitive problems or severe physical limitations. Others routinely turn to substitute decision makers without any consideration of the patients' capacity to make their own decisions. The problem is particularly acute in long-term care facilities where the elderly are routinely stripped of their fundamental civil right to make decisions about their own care without the benefit of any formal consideration of their capacity.

Progress has been slow and there has been no shortage of bumps in the road along the way, but there is every reason to believe that the picture is not as grim as it might appear. Canadian medical schools, for example, now require that law and ethics be taught as part of the undergraduate curriculum. This process is having a profound effect on the students. Medical students, residents, and young physicians in Canada by and large understand the consent rules and struggle to integrate them into their day-to-day practices. As time moves on and similarly trained and inclined professionals move through the professional ranks, respect for the consent rules should become the norm. In the meantime, there is a clear need for a vigorous training program for health care practitioners and administrators, the development of standard and legally valid consent protocols for health facilities, and the use of enforcement mechanisms including professional discipline to deal with recalcitrant practitioners.

—Michael Bay

See also Competence; Consumer Control; Decision Making; Patients' Rights; Refusal of Life-Sustaining Treatment.

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CONSUMER CONTROL

Consumer control is a principle that refers to the process of individuals with disabilities increasing their decision-making power over services affecting their lives. The principle implies that individuals with disabilities—as consumers of professional services provided by social service and/or health care agencies—have a say in the decisions that affect the quality or quantity of the services they receive. The underlying philosophy of consumer control is that people with disabilities are in the best position to identify their own needs, goals, and solutions to problems with service-providing agencies. This orientation transforms people with disabilities from passive clients to respected citizens. The principle of consumer control recognizes the strengths of people with disabilities and allows them to influence the services that let them participate fully in society.

The principle of consumer control is also predicated on the assumption that people, regardless of their status or condition, have the capacity to make informed decisions in order to gain greater control over relevant aspects of their lives. This position reflects a fundamental belief in people's ability to transform their own social reality. Unfortunately, disability has historically been used to prevent many individuals from engaging in this practice. Even today, many people with disabilities face great obstacles to exert meaningful control over relevant aspects of the services they receive. Negative attitudes toward people with disabilities have led to their status as an oppressed sociopolitical minority group. Treatment of people with disabilities, built on assumptions of incompetence, has led to a false sense of inferiority among many people with disabilities and to limited access to resources and opportunities. As a result, many people with disabilities are ill equipped to make decisions regarding the services or choices that affect them.

Consumer control is a principle integrally connected with the independent living and disability rights movements and it is also a reaction to the historical treatment of individuals with disabilities. In many cultures, people with disabilities have often been abandoned, hidden, and shunned by their families and communities. The negative attitudes informing many societies' treatment of individuals with disabilities have resulted in their physical and social segregation. These attitudes have also led to a lack of opportunity to exercise choice and control over issues affecting their lives.

People with disabilities have often had little consumer control over their medical and rehabilitative services. The medicalization and professionalization that characterize these two service systems have been based on the assumption that the service provider is the expert. Therefore, the service provider is in the best position to make decisions about the need for treatment and the form that the treatment should take. These assumptions have fostered passivity, dependence, and compliance with treatment plans and services among people with disabilities. However, as recognition of the competence and rights of people with disabilities took root, people began to challenge these features of the medical and rehabilitative systems. The process grew stronger with the establishment of centers for independent living (CILs) in the United States in the early 1980s but was ideologically rooted on the grassroots movement to enact the Rehabilitation Act of 1973.

In addition to asserting that people with disabilities have the right to exercise choice, a primary critique of the service system traditions was that for treatment and services to be most effective, they needed to be personally relevant. Personally relevant treatment and services focus on creating solutions that fit within the context of individuals' lives. Such approaches emphasize the feasibility of solutions given clients' life circumstances. In other words, these approaches are most concerned that solutions are practical and beneficial for consumers. Consumer control intends to promote personally relevant services that meet the needs of people with disabilities.

Advocacy efforts related to consumer control have centered on improving three elements of service provision: gains over the types of services offered, the quality of services provided, and where and how services are made available. A critical thrust of the principle of consumer control has centered on improving the variety of service options available to consumers. Except for large urban areas, most communities have very limited choices of programs, supports, and services to individuals with disabilities and their family members. But even where such services are potentially available, long waiting lists for government-sponsored programs or high costs of privately offered services limit their access to those in need.

The movement to increase consumer control has also focused on improving the quality of the services available to people with disabilities. This component of consumer control refers to ensuring that the services people with disabilities receive are appropriate and delivered by qualified individuals and that they are done respectfully, affirming the dignity of the person receiving services. The principle of consumer control also strives to increase the quality of services by creating mechanisms for consumers and families to complain about poor quality, improper treatment, or abuse. An important achievement was the establishment of the Client Assistance Program to address complaints about the services offered by vocational rehabilitation counselors working with state vocational rehabilitation agencies. Finally, consumers have advocated expanding services to underserved areas or populations. A good example has been the gradual growth of CILs by the Rehabilitation Services Administration in the United States. The most limited area of influence of consumer control is probably the way in which services are provided. The independent living movement has been marginally effective in influencing the preparation of future professional service providers in colleges and universities. It is expected that the recent appearance of disability studies programs will generate a more substantial change in the way professionals learn to respect and listen to individuals with disabilities and their family members.

In practice, the principle of consumer control exists along a continuum of control ranging from complete control of service provision to minimal consumer input regarding types of services and service delivery. Several contextual elements affect the level of control experienced by any one client or group of people with disabilities. Among these contextual elements affecting the degree of consumer control are an individual's age, type of disability, and type of service. As expected, given societal norms in general, individuals with disabilities have less control over important decisions as children; their degree of control generally increases with their age but then decreases again with senility. Family members and legal guardians can make all types of decisions regarding care and services for their children with disabilities until they reach adulthood.

There are also differences in the degree of control accorded to groups with different types of disabilities. Determined and reinforced by negative societal attitudes regarding the limited ability of people with some types of disabilities, the principle of consumer control is not always conceptualized and practiced equitably across disability types. In practice, individuals with intellectual disabilities and mental illnesses have been historically denied control over most relevant decisions regarding their housing, employment, treatment, and other services. People with either of these forms of disability often are allowed to exercise fewer of their legal rights and are less respected than people with other disabilities. However, the last generational efforts to deinstitutionalize and promote self-determination among these individuals has resulted in greater consideration of personal choices and options, based on the individual's ability to make informed decisions. Self-advocacy organizations of individuals with mental illnesses and/or intellectual disabilities have been instrumental in advocating for the individual's right to choose where and how to live and to refuse unwanted treatments. These issues have often become contentious, as parents or legal guardians sometimes seek legal recourse to force particular treatment or service options.

Finally, the degree of consumer control afforded to people with disabilities varies with the types of services provided. Highly professionalized services often accord less voice to clients (e.g., individuals who are being treated for severe traumatic brain injuries in rehabilitation hospitals), whereas less highly professionalized services often accord more voice to clients (e.g., support for activities of daily living provided by personal care attendants from community agencies such as in CILs).

To promote the principle of consumer control and thereby perhaps self-actualization, it is critical that governments create and maintain institutional settings and policies that promote such goals. Educational, vocational, and rehabilitative systems, among others, need to work to ensure that people with disabilities have the knowledge and experience required to be informed consumers and be allowed to exercise choice. This transformation implies political will and leadership to transform state agencies and change current policies and practices. In addition to creating and maintaining societal structures that foster consumer control among people with disabilities, people with disabilities themselves must also contribute to this process. Unfortunately, oppression has led to a false sense of inability among many people with disabilities. To challenge those notions, people with disabilities need to be exposed to new paradigms of disability that assert that disability is not inherently negative. New paradigms of disability emphasize how oppressive social conditions handicap the individual's capacity to participate actively and independently in society.

Realizing that the functional limitations experienced by most people with disabilities are often largely a function of environmental constraints is a step toward developing critical awareness. This awareness allows individuals to begin to recognize themselves as having the capacity to affect and perhaps transform their own social realities. It allows people with disabilities to realize their need to take control of relevant services and opportunities in their lives. The promotion of this critical awareness has become a priority among organizations of people with disabilities and is directly related to gains in consumer control around the world.

Several programs have been developed and implemented to assist individuals with disabilities in becoming better consumers and making choices that are better informed. These programs are typically designed to assist individuals with disabilities to identify needs, learn to examine available options to address identified needs, learn to select the most adequate choices for particular situations, and then practice the newly acquired skills. Examples include the following:

- Programs to assist individuals in locating appropriate housing in the process of moving from institutions into the community
- Programs to help individuals who use personal attendant care services in learning to recruit, select, and supervise their attendants
- Programs to aid individuals in managing long-term care services
- Programs to support consumers in selecting services
- Programs to help consumers of rehabilitation services in making informed choices
- Programs to assist youths in becoming actively involved in making choices and planning for their transition from school to work
- Programs to help consumers in making independent living choices
- Programs to support individuals in finding jobs or pursuing education goals

Increases in the degree of voice that people with disabilities have over services that they receive have resulted from advocacy efforts by and for people with disabilities. Through the disability rights movement, people with disabilities have become increasingly organized and able to effect real change over relevant issues in their lives. International organizations such as Disabled Peoples' International (DPI), a global organization to promote consumer control and advance the human rights agenda of people with disabilities around the world, have played important roles in promoting and expanding the principle of consumer control. DPI's central message is that of consumer control and self-representation. This international organization is one example of how the philosophy and values of consumer control and self-determination are shared among people with disabilities on every continent.

The concept and practice of the principle of consumer control have helped inspire the development of many recent policies affecting services to individuals with disabilities in the United States (e.g., the Americans with Disabilities Act of 1990) and other countries. These laws and policies all emphasize allowing individuals with disabilities to take greater control of services and choices relevant to their lives. Here are some examples:

Disability Discrimination Act enacted in Australia in 1992

Disability Discrimination Act enacted in Britain in 1995

Standard Rules on the Equalization of Opportunities for Persons with Disabilities enacted by the United Nations in 1993

Constitutional changes adopted in countries such as Germany, Austria, Finland, Brazil, Colombia, South Africa, Uganda, and the Philippines, among many others

As the disability rights movement gains strength worldwide, the amount of consumer control available to people with disabilities is gradually increasing. Years ago, people with disabilities were hardly ever given the opportunity to participate in decisions about their services and rehabilitation. For example, people with disabilities were often given goals or objectives by professionals that were impractical or irrelevant to their daily lives. Now people with disabilities are sometimes more equal partners with professionals in shaping service goals and objectives. Unfortunately, there are uneven practices and multiple variations of the principle of consumer control across professionals, communities, and national service systems. Despite the progress, there is a real need for consumers to remain vigilant to avoid losing the ground that has been gained over the past 25 years. Regressive political movements always remain a possible antidote to social innovation and have to be carefully monitored.

—Fabricio Balcazar and
Katherine E. McDonald

See also Advocacy; Americans with Disabilities Act of 1990 (United States); Disability Discrimination Act of 1995 (United Kingdom); Disabled Peoples' International; Empowerment and Emancipation; Independent Living; Participation; Self-Sufficiency.

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CONSUMER SATISFACTION

A central goal of all human services is that they, as far as possible, meet the needs and aspirations of their clients. It may seem obvious that producers competing in the marketplace to provide other goods and services should above all be attentive to their consumers' views and preferences. However, only recently has the concept of consumer satisfaction been explicitly applied to the field of health care and social services. In health care particularly, one consequence of the rise to prominence of the medical profession was that the success and value of services were professionally determined. Now it is increasingly recognized that the value of human services must be judged in terms of the extent to which clients or customers are satisfied as well as by more established criteria such as effectiveness, efficiency, and equity in provision.

Clinicians and service providers have come to accept the importance of satisfaction in health care for other, more practical reasons. Patients dissatisfied with their health care are less likely to follow advice or treatments, less likely to return to the provider with whom they are dissatisfied, and less likely actually to experience as many benefits of treatment as do satisfied patients.

We now have much more evidence available as to how consumers and patients view the services that they receive. Consumer satisfaction is widely monitored by services in most health care systems, most frequently by self-completed questionnaires but often also by means of in-depth interviews, focus groups, consumer panels, and other more interactive methods. There are at least 11 aspects of satisfaction with health services that have been shown to be of concern to patients: overall or global satisfaction, satisfaction with access, cost, overall quality, humaneness, competence, information, bureaucracy and waiting times, physical facilities, and attention to psychosocial problems.

The evidence also suggests seven fundamentally important issues of concern to patients and reflected in their responses to satisfaction surveys: dignity (being treated as a person, rather than a case), autonomy, confidentiality, prompt attention, quality of basic physical amenities, choice of care provider, and access to social support networks during care.

Overall, the main aspect of services that has consistently been found to influence levels of satisfaction has been the relationship between the health professional and the patient. The more successful the health professional is in establishing rapport and a personal relationship with the patient, the more likely is the patient to be satisfied. More specifically, the quality of communication between professionals and customers is the biggest single determinant of satisfaction. Numerous studies have obtained independent assessments of communication in consultations and patients' subsequent ratings of satisfaction with their care. Such studies consistently show that satisfaction is more often reported when the health professional adopts a more client-oriented style, asking open-ended questions, eliciting the patient's concerns, being responsive to verbal and nonverbal cues about such concerns, and providing information and advice in ways appropriate to the patient.

One complicating factor in the interpretation of evidence of consumer satisfaction is that properties of the respondent in a survey also appear influential. The most consistent trend is for older patients to report higher levels of satisfaction. It is not likely that this is due to older patients receiving higher quality of care, and it is more likely to be due to modified expectations. Another common observation is that respondents with poorer health status and greater psychological distress are more likely to be less satisfied with their care. From the evidence available it is not possible to say to what extent such trends arise from real differences in the quality of care rather than differences in expectations arising from poorer health status. The one clear implication of such trends is that apparent differences in levels of consumer satisfaction between services cannot immediately be interpreted as evidence of differences in the quality of care without at least adjusting for possible influences of patients' characteristics.

The greater the level of disability, the more likely are patients to be dissatisfied with their care, not only with regard to issues such as access and ease of getting to care but also in relation to overall quality of care, including the quality of communication. Such evidence helps make the case for the need for the physical redesign of health care facilities to adequately provide for individuals with disabilities. However, communication by health professionals also needs redesign to be appropriate to individuals with disabilities.

Reference has already been made to patients' expectations as an explanation for variations in levels of satisfaction. In practice, it is not easy to identify patients' expectations. Individuals may be unsure when asked to articulate their expectations whether they should consider the ideal or optimal or rather what they predict to be likely or realistic. Individuals may also be unsure whether they are "entitled" to hold expectations regarding their care. In any case, we are more likely to infer expectations from expressions of satisfaction than to be able reliably and independently to measure them.

Measurement of satisfaction is not without controversy. Levels of positive satisfaction are almost invariably very high in surveys of patient or consumer views, even with groups such as the young and those with disabilities and poorer health status who, relatively, express more dissatisfaction. Typically, over three-quarters of any sample express positive satisfaction. This regular skewness of consumer satisfaction data raises in some minds the possibility that there is a flaw in our methods of obtaining views and that with better methods respondents would be more diverse in their views. In particular, it is thought that there are strong prevailing norms that make it difficult for individuals to express critical comments about their health care. However, while it is clear that patients often have real difficulties in expressing dissatisfaction, there is no actual evidence to support the notion that different methods than the standard fixed-choice questionnaire would produce more diverse views.

Nevertheless, reservations about whether focusing on satisfaction inhibits respondents has led to increased emphasis on finding out patients' experiences rather than their subjective reactions to such experiences. When asked about experiences of specific problems, a more balanced picture of negative as well as positive aspects of services may emerge. For example, surveys in several Western health care systems reveal that the most common problem across types of hospital, experienced by over 40 percent of patients, is that no one explains the daily routines of the hospital to the admitted patient. Other problems experienced by patients across health care systems include not having side effects of medications explained and not receiving appropriate advice about what to do once discharged from hospital, for example, in relation to the decision of when to resume normal activities.

It can be argued that a focus on consumer satisfaction results in a very inert and reactive view of patients or clients, emphasizing solely how they respond to services received. Increasingly, it is argued that we must seek ways of actively involving the consumer. Collectively, this active involvement may take the form of collective community participation in prioritizing and governance of services. For individual patients, there are growing arguments for shared decision making between patient and doctor with greater emphasis on the treatment preferences of the patient. The evidence base to support both collective and individual-level involvement is not strong and identifies some problems of consumer involvement. For example, collective preferences regarding services may hold back development of public health and preventive health strategies and weaken services for socially undervalued groups. At the individual patient level, there may be minorities of patients who would prefer not to share decision making, and there may also be unwanted distress from the additional burden of greater involvement in difficult decisions. However, there is now in place an irreversible process of enhancing the consumer's role relative to that of experts.

The trend to enhance the consumer's voice regarding services is well under way and will pose fresh challenges for health care systems. Is there a point at which the erosion of professional autonomy excessively undermines professionals' confidence to undertake difficult responsibilities of care? Does consumer sovereignty risk increasing the access of the privileged at the expense of the weak? No model of health care, even one that has completely enshrined respect for the consumer, can be completely free of such tensions.

—Ray Fitzpatrick

See also Accountability; Health Management Systems; Home Support.

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CONSUMER-RUN BUSINESSES

Consumer-run businesses emerged in the 1980s as one way of addressing the systemic exclusion of people with disabilities from mainstream labor markets. Prominent forms include cooperatives, incorporated businesses, societies, partnerships, and sole proprietorships. This entry uses Canadian examples to illustrate these more generic forms and to highlight the strengths and limitations of their practice.

Regardless of how they are organized, consumer-run businesses have a dual purpose. First, they seek to generate income for the people involved through the production, marketing, and sale of goods and/or services. Markets include disability communities, health and social services sectors of the economy, and the general public. Second, equally important is that these initiatives are owned, managed, and operated by people with disabilities. They are concerned with questions not just of employment but of personal and collective empowerment. Consumer-run businesses fall into two general categories: self-employment and community businesses.

SELF-EMPLOYMENT

Self-employment is the predominant form of consumer-run business, referencing what most people in Western societies imagine by the term *business*. It describes the situation in which a disabled individual is the sole proprietor of some kind of entrepreneurial enterprise from which he or she derives a livelihood. In recent years, various levels of government have been encouraging self-employment among marginalized populations by participating in special lending and mentoring programs. So, for example, in Victoria, British Columbia, a woman disabled by a severe illness decided to start a secretarial services company. On the strength of skills acquired in the workforce, she received a loan that enabled her to purchase equipment and to advertise. Along with professional advice, the loan was delivered through a project called Advice and Business Loans for Entrepreneurs with Disabilities (ABLED). The financial base for ABLED was generated by a three-way partnership involving two credit unions and a federal investment organization. That partnership was encouraged by local agencies representing the disability community and by local business groups.

This story, brief as it is, illustrates some of the core dilemmas of self-employment. On the positive side, the woman was able to get to work fairly rapidly under conditions that used her strengths and responded to her needs. She earned enough to offset the fact that she was ineligible for a disability pension. In fact, she reports surpassing every financial goal that she forecast, hiring a part-time worker and beginning to envision hiring other people with disabilities. Her account is energized by a feeling of success and hope. It demonstrates the broadest advantage of self-employment, namely, that it enables disabled people to claim the powerful discourse of business in an increasingly entrepreneurial culture.

There is an opportunity for redefinition here, as those involved move from identifying as unemployed service recipients to productive business people. ABLED argues that "removing barriers for people with disabilities means moving from a service mentality to one that affirms good ideas on their own merits." This is an important shift in that it opens up depathologized subject positions from which people can become active in re/constructing their lives.

In a more critical vein, our protagonist has become the equivalent of a "pieceworker" in the new economy. Catching a wave of contracting out, she is paid separately for tasks that—taken together—used to constitute whole jobs. Her workplace has been blended into and will impinge on her domestic life, space, and time. She is relatively isolated and dependent on her own energy and initiative to keep earning. She has no union to represent her concerns, no way to collectivize the problems that arise with this form of labor.

This disabled entrepreneur must repay her loan with earnings that are probably modest and will fluctuate depending on demand. She is responsible for her own bookkeeping and taxes. If she falls ill in the future, she has no unemployment insurance benefits to draw on. Unless she establishes one herself, she has no pension or disability plan. As an entrepreneur, even though she is significantly disadvantaged, she will still be held accountable for her business according to private sector values and performance measures: individual initiative, competition, and fiscal profit as the bottom line.

COMMUNITY BUSINESS

The second type of consumer-run business is *community business,* sometimes referred to as *social enterprise.* By contrast with self-employment, initiatives in this category are collective. They involve a group of people creating and taking charge of the development and operation of a business. Examples from two different disability communities in Toronto illustrate the general form: Lemon and Allspice Cookery, and A-Way Express Courier Company.

Lemon and Allspice Cookery (the Cookery) is a wholesale bakery and catering business. It began in 1998 with a grant from the Ontario Ministry of Community and Social Services. The parents of a young woman with an intellectual disability were the driving force behind the project. They parlayed their daughter's skills at baking and selling cookies at a service agency snack bar into a legal business partnership that took in seven more disabled people. These eight have a leadership role in the business that includes decision making at monthly partnership meetings.

The partners are also the Cookery's core laborers, working in shifts to produce baked goods, sandwiches, and bag lunches as well as fruit, vegetable, and cheese trays. They deliver the goods personally using public transit. Customers include a core sympathetic market: community living associations, church and community groups, friends, and neighbors. The kitchen operates 35 hours per week plus some weekends. The partners each work 15 to 20 hours per week. A support worker and job coach work alongside them. Their salaries are paid by government grants.

The Cookery is supported in its ongoing evolution by a nonprofit cooperative corporation called Common Ground. Comprised of interested community members, its goal is to use members' collective wisdom to advance this approach to employment for more people with intellectual disabilities. On the co-op's list of concerns is the fact that, under Ontario's current income benefits program, the Cookery's partners are not allowed to earn more than $160 per month without a 75 percent "clawback" to their income.

A-Way Express is a courier service run by psychiatric survivors. It opened its doors in June 1987 following a feasibility study that generated start-up and initial operating funds. By 2001, the business had grown to 45 couriers, 17 part-time office staff, and more than 1,200 customer accounts. While it began as a worker cooperative, the company currently operates on a combination of revenues generated from its service and grants from the Ontario Ministry of Health. Couriers get around the city on public transit: by subway, streetcar, and bus. Many of their customers are located in government offices and nonprofit organizations, but over half are in the private sector. Couriers work part-time on commission. The rate of pay is set at about 70 percent of service charges. A minimum shift is four hours, but couriers may work as many hours as each decides will fit his or her needs. Their decision is strongly influenced by the fact that, because they remain on disability benefits, government policy caps their earnings at the same level it does the partners of the Cookery.

This unique company has been through many stages of development. Its primary growth crisis was the shift from being run by service professionals to being run by service users. For the past 10 years, its executive directors have been self-identified psychiatric survivors. On the 10-member board of directors, at least half are employees. The rest are "outsider" members who may or may not also be psychiatric survivors. The management team includes the executive director, office and marketing managers, head dispatcher, bookkeeper, head phone order-taker, and two courier representatives. This team meets biweekly to discuss current business, and it is responsible for all operations, office administration, implementation of board policies and procedures, and purchases. From the beginning, full staff meetings have been held once a month so that members can raise concerns and make recommendations. Staff members have ultimate decision-making power because of their representation at every level of the business, and through formal reviews of goals and objectives at annual general meetings.

Especially during the late 1990s, A-Way Express both contributed to and was supported by the work of the Ontario Council of Alternative Businesses (OCAB). OCAB is an umbrella organization for psychiatric-survivor-run businesses in the province. The organization's understanding of business development goes well beyond job creation and training to include a complex layering of community development, knowledge creation, and on-the-job, noncredentialed learning. It views the process as a way of bringing survivors together to challenge the delegitimized place that they hold in society. Part of business development then becomes helping employees question authority in their lives, particularly the authority of health and social service systems.

OCAB links the analysis of the psychiatric survivor movement to the emergent practice of alternative businesses. The work is political, not simply technical. Similarly, in a rare support manual, the National Mental Health Consumers Self-Help Clearinghouse in Philadelphia (online) gives as much attention to consensual decision making in consumer-run businesses as it does to financial operations. This reflects the self-help philosophy that underpins community businesses in the American experience and the desire that they act as sites of democratic participation for people whose voices are not easily heard.

Once again, the core dilemmas of these ventures are woven through their stories, crossing the differences they exhibit with respect to the role of families, professional service providers, and the disability rights movement. In a capitalist economy that reinforces the emphasis of disability discourse on independence and autonomy, collective enterprises such as community businesses are highly suspect. Are they not just a fancy new form of ghettoization that reinforces the segregation of workers in the face of attempts at integration?

The answer from the Cookery is that the business form delivers to its partners a mix of contact between people of similar background, language, and culture, and people from a variety of other backgrounds. The psychiatric survivor perspective is more challenging. They view consumer-run businesses as places where people who share similar experiences of oppression can congregate, speak in their own language, for their own purposes, without professional intervention. The connection being facilitated is not with the mainstream but with the mental health self-help movement—to draw from and build its capacities.

So is there a role for professionals in consumer-run businesses? "It depends" is probably the best answer. Clearly, the Cookery has made space for service workers who know how to advance the goals of the business. Organizers appear to be comfortable with this assistance. Psychiatric survivors exclude professional and especially clinical/therapeutic expertise in favor of hands-on peer training and support. At the same time, the most successful businesses connect with a range of people in the broader community who can offer the kind of technical and organizational expertise that will strengthen their operation—usually through board involvement.

But can initiatives such as these truly be called businesses when they rely on government grants, and show no signs over time of becoming self-sufficient? OCAB's response is to make a strong argument for the kind of "hybrid" (public/private) funding that has worked so well for A-Way Express over the past 15 years. This approach recognizes the heavy social agenda carried by community businesses as they work with and for some of the most socially and economically marginalized people of the Western world. It costs money to support these people properly in employment and especially to ensure that the jobs are flexible. All parties involved need to recognize a "multiple bottom line" when it comes to evaluating successful outcomes.

The Cookery and A-Way Express both depend for their local success on strong public institutions and public policies in the broader socio/political environment. Members of Common Ground identify four necessary supports: supportive legislation for incorporating cooperatives and business partnerships; public, cooperative, and private subsidized housing; affordable, physically accessible transportation; and guaranteed employment or day programs. The psychiatric survivor wish list would include short- and long-term strategies for creating and sustaining survivor leadership in survivor-run organizations of all kinds, as well as remedial "training" for service providers so that they can learn what it takes to become effective, less controlling partners to these emerging forms.

Consumer-run businesses in general would be well served if policy makers sorted through the conundrum of a pension/benefits system in which different levels of government (and sometimes private corporations) work at cross-purposes. For community businesses, an immediate and welcome solution would be to raise or remove completely the cap on earnings that currently acts as a disincentive in this sector.

CONCLUSION

In an early literature review, Fontan (1993) divided community economic development activities into liberal and progressive types. Liberal development aims to repair the economic fabric of the private sector to create jobs, while progressive development invests the economy with social concerns. This is a helpful formulation to keep in mind as consumer-run businesses spread. Given disabled people's desperate need for income, and the systemic barriers that exclude them from regular employment, it is difficult to dispute the "goodness" of any type of regular employment. Yet buying into approaches that emphasize work/jobs alone results in repair strategies that ignore deep structural inequities.

As brilliant and hopeful as consumer-run businesses can be, they are not an adequate substitute for using enlightened macrolevel economic and fiscal policies to address the crises of jobs and poverty. The risk of trying them out is to support neoconservative policies that dismantle state-supported social service provision in favor of individual self-reliance through entrepreneurship. Even as attention turns to economic development, disability advocates must continue to fight for access and high-quality support in the beleaguered areas of health and community/social services, subsidized housing, and criminal justice.

—*Kathryn Church*

See also Affirmative Businesses; Employment; Sheltered Employment.

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CONTRACTING OUT SERVICES

Governments throughout the world are increasingly contracting out the health care and social services provided to persons with disabilities. Although historically, most modern national governments have contracted out their purchases of architectural, defense, and engineering services for many years, contracting out the provision of health care and social services to the private sector is a relatively new phenomenon. *Contracting out* can be defined as a voluntary, binding agreement or contract between a government agency and a private firm to do something that is legally enforceable. The number, type, and scope of these service contracts are increasing because of government economic reform efforts and world trade agreements.

Contracting out the provision of services to the private sector is one of the most common forms of government privatization. Governments are increasingly contracting out services to reduce costs and to improve quality. They also are contracting out to obtain special skills and expertise, to meet temporary demands quickly that are beyond current capacity, and to increase services without having to hire permanent staff. Occasionally, governments are contracting out to experiment with vouchers to provide citizens with more choices as to service providers. Last, because of increasing public pressure, legislators are forcing many government agencies to contract out services to hold down taxes, limit the growth of the public sector, and reduce the overall role of government in society.

Proponents of contracting out services argue that the single most compelling reason for doing so is to reduce government costs. They argue that by contracting out services to the private sector, the competitive forces of the market will lead to lower costs. They also argue that unlike large government bureaucracies that tend to maximize their budgets and “build empires,” the profit motive of the private sector firms will lead to greater efficiency in providing the services.

Those advocating contracting out services cite a number of additional reasons why private firms will provide the services to the public at lower costs. They argue that large regional and national firms may provide the services at lower costs because of economies of scale. These large firms will be able to spread the costs of the services over a large number of units or agencies. In addition, the private firms may have lower overhead and startup costs. They may also have lower personnel costs because they do not have public employee unions. Private firms frequently have greater flexibility in the use of their employees, because they do not have to deal with rigid public personnel systems such as civil service. This flexibility may be very beneficial when undertaking short-term projects, using part-time workers, supplying specialized needs, or providing new services to clients.

Proponents of contracting out services expect that competition for contracts among private firms will produce better-quality services for the price paid, since a direct monetary incentive for good performance by the supplier exists. If the services delivered are judged to be inadequate by the overseeing government agency, other suppliers could be granted contracts.

Last, proponents argue that a major benefit of contracting out services is that it will slow, if not halt, the rapid growth of government. They believe that contracting out services will keep government budget growth to a minimum, limit the total number of public employees, and ultimately result in government having greater control over the services it provides.

Critics identify a number of inherent problems with contracting out government services. One major problem is that it may reduce accountability. The ever-present problem of making public officials accountable to citizens is greatly magnified with the addition of private sector firms carrying out the work of government. In a contracting system where structure is not hierarchical and where clear, straight lines of authority are often absent, political and legal accountability of a chief executive or legislative body are difficult to establish and enforce. Critics charge that it is much more difficult for citizens to hold contractors responsible than elected officials and bureaucrats when the services provided are unsatisfactory.

Contracting out services can lead to widespread corruption. Contracts are one of the most common and lucrative sources of corruption in government. Critics argue that purchasing services from one or a few private firms on a continuing basis can produce corrupt relationships between government officials and the companies. These relationships may erode both competition and quality control, which, in turn can lead to higher costs and poorer-quality services. Such relationships have resulted in numerous scandals at all levels of government involving conflicts of interest, bribes, kickbacks, collusive bidding, billing for work never performed, and other illegal activities.

The profit motive of private sector firms may result in incentives to cut corners on service quality. Critics point out that high financial stakes often bring with them temptations to maximize profitability by skimping on quality and discouraging access to services by high-cost clients. To increase profits, private firms may skimp on contract requirements or provide inadequate supervision. The for-profit firms may also avoid clients who are expensive to help, such as individuals with major physical and mental disabilities.

Contracting out services may increase the risk of interrupting services. Private firms are much more likely to curtail, interrupt, or cease operations due to such circumstances as financial problems, strikes, and the rebidding of contracts. Specifically, the services may be disrupted because the contractors have labor problems or are plagued with poor management. Contractors may also close down because of bankruptcy. Such actions can seriously affect client safety and health.

Critics argue that contracting out services is just a method of bypassing public employee unions and civil service regulations. They charge that private firms are able to provide services for less because they tend to hire inexperienced, transient personnel at low wages.

Another problem with contracting out services and a growing reliance on the use of private firms is that it may impede the creation and implementation of coherent public policy by government agencies. This difficulty is particularly great in areas that use a variety of different private firms that are concerned about maintaining their own individual autonomy and accountability. Planning for and coordinating the multitude of fragmented activities of private service suppliers only add to the already confused, overlapping, and complex divisions within government.

Last, some argue that governments are contracting out services as a method of complying with imposed hiring freezes, while at the same time they are expanding programs and services that are increasingly expensive and intrusive. Critics state that the mixing of public and private activities only masks the true growth of government. This illusion maintains the myth of less government, while government actually whittles away at the essential substance of private autonomy.

Some of the problems that plague contracting out services may be prevented by comprehensive contract preparation, careful contractor selection, proper contract implementation, and continuous and comprehensive monitoring of performance.

To ensure a successful outcome, government agencies considering contracting out services should start by conducting a feasibility study. The feasibility study should determine which services, if any, should be contracted out. The study should determine the agencies' direct and indirect costs of providing each service and appropriate direct and indirect measures of performance.

After a positive feasibility study, a well-written, detailed, and explicit contract must be developed. The contract should specify the desired levels of the service and identify specific performance (e.g., number of client visits, number of counseling sessions, and level of patient satisfaction), effectiveness (are the correct outputs, such as reduced number of disability days, being achieved?), and efficiency measures (are the outputs being produced cost-effectively?). The contract should precisely define the scope and quality level of the service, specify service and staffing levels, and identify service event (training sessions) and performance reporting schedules. Exact penalties and incentives should also be clearly stated. To prevent poor performance, the contract should require a performance bond and a termination penalty. The agency should have the right to reduce or suspend payments for a contractor's failure to meet appropriate standards. Incentives such as bonuses for exceptional service should also be specified.

After developing the contract, the government agency will issue either invitations to bid (ITBs) or requests for proposals (RFPs). ITBs involve sealed bids and public hearings and are normally used when contracting for a standardized service that is clearly defined. In contrast, RFPs involve negotiations among the parties prior to signing a contract and are mainly used for personal services, sole-source suppliers, and emergency procedures. Although the processes for ITBs and RFPs differ, success with either method requires competition among contractors.

From those firms that submit bids or proposals, the government agency must select the most appropriate contractor to provide the service. It is crucial that firms that are likely to perform poorly or that are unsuited for the contract be eliminated. When selecting the contractor, the agency must consider the final bid or proposal as well as the firms' professional qualifications, special experiences, capacity to perform the service, familiarity with the work, and past performances on similar contracts.

Once the contractor has been chosen and the work begins, the government agency must carefully monitor the contract for adherence to all of its provisions. Monitoring ensures tighter quality control, more cost awareness, and a reduced likelihood of contract abuse by the contractor. The monitoring process should be both continuous and comprehensive. It should include carefully reviewing the contractor's periodic progress reports, conducting citizen surveys and interviews, listening to citizen complaints, and making frequent onsite observations and inspections of the contractor's work.

In terms of the public policy implications for persons with disabilities, the available evidence of the success of contracting out government services is mixed. Switching to private sector firms to provide services does not guarantee cost savings. Many government agencies could provide the services at the same or lower costs. It also appears that in most instances, the quality of services provided by private firms and government agencies is very similar.

The success of contracting out services appears to be highly situational. It depends on such factors as the particular situations of the government agencies involved, their geographic locations, and the particular time periods. Success is greatly affected by the performances of the current service delivery system, special circumstances such as the number and quality of potential private suppliers, absorption of displaced employees, and the relationship between employee associations and government.

The appeal of contracting out government services becomes less apparent when one takes a closer look. In theory, contracting out these services brings to the public sector all the virtues of the private market—competition, efficiency, and lower costs. In practice, however, contracting out government services begs the ancient political question posed by the Roman satirist Juvenal: *Sed quis custodiet ipsos custodes?* ("Who shall keep watch over the guardians?"). There is a danger that beyond a certain point, government-by-contract may couple the inefficiencies of the public sector with the abuses of the private sector.

—Ross M. Mullner and Kyusuk Chung

See also Health Management Systems; Privatization.

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COSMOLOGIES OF MORALITY AND ORIGIN

A well-constructed cosmology of morality and origin traditionally tells how the world began; what it was made of; who was there; how things went wrong; some laws of correct and incorrect behavior between humans, deities, spirits, and animals; and perhaps a hierarchy of intelligence and moral superiority. A short version should be recitable in under 20 minutes and should require no higher mathematics. Hundreds of cosmologies have been collected and studied during recent centuries. Some involve disability in various significant ways. A few sketches follow.

In the Japanese classic *Nihongi,* versions appear of how Izanagi and Izanami first formed the Japanese islands, then "produced the leech-child, which even at the age of three years could not stand upright" (Aston 1986). The parents put this child Hiruko in a boat, and set it adrift. Their next child was Sosa no wo no Mikoto. His behavior, that is, continual wailing and cruel actions, led to banishment. Interpretations are many, yet the significance of these "strange" offspring remains unclear. Links appear with the deities Ebisu and Sukuna-bikona, the latter supposedly a dwarf.

Partners for the earliest progenitors were restricted to parents and brothers or sisters, for nobody else existed. Some accounts display unease about the inevitably incestuous relations. Another example is the Creator Prajapati who fertilized his daughter (Sky, or Dawn) in Hindu mythology. The cosmology might reflect later taboos, or the realization that endogamous relations increase the chances of congenital deformity; or there may be quite different explanations. These cosmologies suggest a very early human desire to explain congenital impairment.

A Samoan cosmology has the creator Nareau setting up the physical world and a great many creatures, then leaving it to the first two people to build the human world. They tell their son ("Mischief Maker") to take up this job. He finds the created beings inert, deaf, dumb, and responseless, so he massages them into physical activity, gets their ears working, teaches them their names, and evokes speech from them. After a lot of trouble the human world gets organized.

A modern retelling of southern African cosmologies shows the Great Mother, Goddess of Creation, as both immortal and imperfect. She transmits physical imperfections to her creation, and there follows the birth of the first deformed child, the call to destroy this child, and its mother's flight. Saved from death, the baby grows into a monstrous and destructive tyrant. An interpretative postscript suggests this as a reason why Africans used to "destroy crippled and otherwise deformed children" (Mutwa 1998).

A contrasting eastern African cosmology suggests a deity concerned with inclusive attitudes and practices toward disabled humans. The Wagogo tell of several men who tried to obtain fire from heaven. All were sent home empty-handed because they had laughed at disabled people whom they met on the journey. Finally, a woman went to get fire. She behaved sensitively with the disabled people she met, and also got along well with God, so was rewarded with a pot of fire.

—Kumar B. Selim

See also Folk Belief.

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COSTA RICA

See Experience of Disability: Costa Rica

COUNCIL OF EUROPE DISABILITY POLICY

The Council of Europe is an intergovernmental organization that was founded in 1949. At present, it has 46 European member states with a total population of about 800 million. The headquarters are at the Palais de l'Europe in Strasbourg, France. The Council of Europe aims at protecting and promoting human rights and fundamental freedoms; strengthening pluralist democracy and the rule of law; promoting awareness of a European cultural identity, while enhancing cultural pluralism; seeking solutions to problems facing European society and contributing to the reinforcement of social cohesion; and supporting central and eastern European countries in carrying out and consolidating their political, constitutional, legislative, and judicial reforms, thus contributing to developing and consolidating democratic stability all over the continent.

The Council of Europe's activities cover all major issues facing European society other than defense. The main instruments of the Council of Europe are standard setting, policy recommendations, and project management. Legal instruments can take the forms of conventions or agreements, recommendations or resolutions. Conventions and agreements are legally binding on the states that ratify them. At present, some 200 conventions provide the basis for member states to harmonize their domestic laws, for example: the European Convention on Human Rights (1950). Recommendations and resolutions addressed to governments politically commit governments to follow a common course of action, for example. Reports and comparative studies analyze current issues and provide information and advice to decision makers, often by identifying examples of good practice.

Since the scope of Council of Europe activities is so extensive, states wishing to engage in some action in which not all their European partners desire to join can conclude a "Partial Agreement," which is binding on themselves alone. It was on this basis that in 1959 the Partial Agreement in the Social and Public Health Field was concluded to work, among others, for the integration of people with disabilities. Today, that Partial Agreement has 18 member states. Several countries participate as observers, including Canada (the only non-European state).

Human dignity, equal opportunities, independent living, active participation in the life of the community—in short, full citizenship—form the heart of the Council of Europe's activities in relation to people with disabilities. To reach that goal, the Council of

Europe disposes of the following set of instruments, consisting mainly of the Revised European Social Charter, several policy recommendations addressed to member states' governments, and relevant reports to serve as source of inspiration and guidance.

The European Social Charter (1961) is the counterpart of the European Convention on Human Rights in the field of economic and social rights. It protects some 23 fundamental rights in the field of employment and social protection. Article 15 is of particular importance to people with disabilities: "The right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement." Although today the concepts and language used seem outdated, in 1961 they provided a landmark.

To take account of social changes, the Revised European Social Charter was adopted in 1996, coming into force on July 1, 1999. It updates and strengthens the rights guaranteed by the charter and also includes new rights. The scope of Article 15 has been extended considerably and now goes much beyond employment issues. It reads: "The right of persons with disabilities to independence, social integration and participation in the life of the community."

The Social Charter is monitored with the help of a reporting system and an independent committee of experts (European Committee for Social Rights). Since July 1998, however, a revolutionary collective complaints procedure allows also nongovernmental organizations to bring allegations of violations of the charter before that committee.

The Committee on the Rehabilitation and Integration of People with Disabilities (CD-P-RR) has drawn up general policy principles for the rehabilitation and integration of people with disabilities, which are enshrined in Recommendation No. R (92) 6 on a Coherent Policy for People with Disabilities, adopted by the Committee of Ministers of all member states of the Council of Europe in April 1992. This recommendation contains a model program for a coherent disability policy, recommending to member states' governments to develop comprehensive and coordinated national disability policies, taking account of all successive stages in the integration process and all areas of community life, such as prevention, diagnosis, treatment, education, vocational training, employment, social integration, social protection, information, and research. The recommendation has set benchmarks both nationally and internationally, thus prompting numerous amendments to legislation in member states.

The report *Integration of People with Disabilities: Policy and Legislation,* a compendium of current, national legislative texts and policy programs, helps to identify achievements and shortcomings of national disability policies. It is thus an indispensable complement to the Recommendation No R (92) 6 on a coherent policy. The seventh edition of the report (2003) covers 16 European states.

The 1995 Charter on the Vocational Assessment of People with Disabilities calls for a shift in focus: from disability to ability. The person's vocational abilities and not disabilities should be assessed and related to specific job requirements.

The 2001 Resolution on Universal Design aims to improve the accessibility of the built environment by recommending the inclusion of the principles of universal design into the curricula and training of all vocations working on the built environment, in particular architects, engineers, and town planners.

The 2001 Resolution on New Technologies recommends drawing up national strategies to ensure that people with disabilities benefit from the manifold opportunities offered by new technologies, rather than being excluded due to newly created barriers caused by inappropriate technology design or provision. All products and services for people with disabilities should take account of the following quality criteria: availability, accessibility, affordability, awareness, appropriateness, attractiveness, adaptability, usability, and compatibility.

The report *Legislation to Counter Discrimination against Persons with Disabilities* (2000, second edition 2003) takes stock of existing legislation and identifies three main approaches to achieving equality of opportunity for people with disabilities: antidiscrimination legislation, preferential treatment, and compensatory measures.

The report *Safeguarding Adults and Children with Disabilities against Abuse* (2002) aims to make visible the extent and nature of such abuse and to ensure that people with disabilities are safeguarded against deliberate and/or avoidable harm at least to the same extent as other citizens and that where they are especially vulnerable additional measures are put in place to ensure their safety.

The report *Access to Social Rights for People with Disabilities in Europe* (2003) describes general principles and measures designed to give people with disabilities access to social rights in Europe. However, it also identifies those obstacles that still impede access for people with disabilities to social rights and consequently to full participation in society, particularly in the areas of education, vocational training and employment, the built environment and transport, information and communication, health care, and social protection. It gives numerous concrete examples of good practice, that is, action taken by member states to overcome those obstacles. Finally, the report issues cross-sectoral recommendations for integrated policies aimed at facilitating access to social rights for people with disabilities in Europe.

Council of Europe Conferences of Specialised Ministers provides an opportunity for ministers to exchange information, views, and experience on topical matters of political significance. The First European Conference of Ministers responsible for integration policies for people with disabilities, Independent Living for People with Disabilities (Paris, France, November 7–8, 1991), led to the adoption of Recommendation No. R (92) 6 on a coherent policy for people with disabilities in April 1992 by the Committee of Ministers.

The Second European Conference of Ministers responsible for integration policies for people with disabilities, Improving the Quality of Life of People with Disabilities: Enhancing a Coherent Policy for and through Full Participation (Malaga, Spain, May 7–8, 2003), discussed (1) promoting citizenship and full participation by developing effective legal and policy provisions to ensure equality of opportunities for people with disabilities; (2) developing innovative approaches in services, intended to meet the needs of people with disabilities as consumers; and (3) proposals to enhance the integration of women with disabilities and that of people with disabilities in need of a high level of support, as cross-cut issues.

In the Malaga Ministerial Declaration on People with disabilities: "Progressing towards full participation as citizens," adopted at that conference, ministers recommended the elaboration of a Council of Europe Action Plan for people with disabilities: a new European policy framework for the next decade, based on human rights and partnership between different actors, setting up strategic objectives and priority issues to achieve full citizenship and active participation of people with disabilities in the life of the community, through workable, affordable, and sustainable policies. At the same conference, the secretary general of the Council of Europe launched the initiative to extend the disability activities from the Partial Agreement with its 18 members to all Council of Europe member states. Activities are currently under way to implement the ideas emanating from the Malaga ministerial conference.

—Thorsten Afflerbach

See also European Commission Policy; European Disability Forum.

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COUNSELL, JOHN (1911–1977)

Canadian spinal cord injury pioneer

Lieutenant John Counsell became paraplegic in 1942 during World War II, in an era when individuals with spinal cord injury (SCI) lived sheltered lives as invalids. Returning to Toronto, Counsell developed his own rehabilitation program, purchased one of the first Everest & Jennings collapsible, self-propelled wheelchairs in Canada, and had hand controls made for his car. Because of his efforts, he was able to travel independently in the community. Recognizing the value of rehabilitation, he joined with others to lobby the Canadian government to develop new programs and services for all veterans with SCI. He played a key role in the establishment of Lyndhurst Lodge in 1945, the first specialized rehabilitation center for SCI in the world.

In 1945, Counsell, along with other Canadian veterans, established the Canadian Paraplegic Association (CPA), the first association administered by individuals with SCI in the world. CPA pioneered a system of self-help, called "mutual aid" where individuals successfully living in the community helped others with SCI to return to community living. The central philosophy of CPA was full participation of individuals with SCI in all aspects of community life. During the 1950s and 1960s, members of CPA were at the forefront of efforts to develop rehabilitation programs and disability policies across Canada.

When Counsell stepped down as president of CPA in 1967, the organization had spread across Canada with members becoming leaders in the newly emerging disability consumer movement in Canada. The disability consumer movement called for new policies and legislation that would remove barriers to participation in community life for all Canadians with disabilities. Counsell and other members of CPA were pioneers in the history of disability activism.

—*Mary Tremblay*

See also Spinal Cord Injury; Veterans.

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CRETINISM

Cretinism is a state caused by the absence or lack of thyroxine (a hormone produced by the thyroid gland) during the developmental period (congenital hypothyroidism). Intellectual disability and stunted growth are two characteristics of a person with cretinism.

Doubt remains concerning the origin of the term *cretin* despite the numerous etymological explanations that have been advanced. According to Littré's *Dictionnaire de la langue française* of 1873, the word derives, via *Kreidling,* from the German *Kreide* (chalk), because of the whitish tone of the skin of those affected. A more probable derivation would be from the Latin *christianus*, for which a first attestation dates from about the year 1000. In a deed from the Abbey of Lucq in Béarn, a *crestina* is mentioned (Marcel Fay [1907], *Contribution à l'étude de la lèpre en France: La lèpre dans le sud-ouest de la France: Les cagots,* Coulommiers).

In nonmedical literature, the first reference to cretinism in the Alps was made by Jacques de Vitry in his *Historia orientalis et occidentalis* (1220). Illuminated manuscripts of Thomas of Cantimpré's *De monstruosis hominibus* have representations of cretins. The term first appears in medical literature in 1754 in *L'Encyclopédie ou dictionnaire raisonné des sciences, des arts et des métiers.*

Cretinism seems to have been present on all continents and in all ages without it being possible to estimate the number of persons affected. The first epidemiological studies date from the beginning of the nineteenth century. A first official inquiry into goiter, an enlargement of the thyroid gland, was made in the Valais by Rambuteau, prefect under the First Empire.

As in the case of other pathological states, the most diverse hypotheses were formulated as to the causes of cretinism such as the calcareous water of the mountains, the humidity of the air in the valleys, poor hygiene, early marriages, alcohol abuse, drunkenness during intercourse, and masturbation.

The treatment of endemic goiter and of cretinism may have begun in the early nineteenth century. As early as 1820, Dr. Jean-François Coindet showed that iodine was a very active principle against goiter. But it would require 30 years for this discovery to be taken effectively into account.

Boussingault was the first, in 1831, to suggest the use of table salt for prophylactic purposes. Around 1852, as a consequence of work done by Chatin, a variety of prophylactic tests took place in France, Austria, and Italy. But these trials were interrupted. Fears of the effect of iodine on the human organism divided the medical world, since the first tests had not proven conclusive and the secondary effects had proven serious. In 1923, iodized salt was introduced in Switzerland on the recommendation of the Commission on Goiter, and by this means cretinism was eradicated in those regions where it had been rife since the dawn of time.

If cretins were the object of curiosity from a very early date, it was not until the beginning of the nineteenth century that interest turned to the possibility of their education. About the same time as Eduoard Séguin in France, a Swiss physician, Johan Jacob Guggenbühl, attempted to educate cretins. In 1840, he opened the first institution for cretins, the Abendberg. These experiments resonated widely in all of Europe. Experiments were, however, short-lived because of the challenge to the results obtained by this physician. The closure of the institution was ordered in 1858, and Guggenbühl died in 1863. The Abendberg remained the only establishment that had the education of cretins as its exclusive objective.

—Jean-Louis Korpes

See also Changeling; Johan Jacob Guggenbühl; Mental Retardation, History of; Eduoard Onesimus Séguin.

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CRIME AND DELINQUENCY

This entry addresses the problematic interface between disabled persons and the criminal and juvenile justice systems. The issues include, how do disabled people enter a justice system, how are they treated once they get there, and what happens to them following any court intervention? Disabled people may come into contact with the justice system as victims of a crime or witnesses to a crime and, in turn, may be handled responsibly and appropriately or may face possible victimization by officials. Persons charged with a crime may have a disability that may or may not receive proper understanding or treatment. Juveniles, by definition, maintain at the least a disability of age and immaturity. How disabled people, adults and children, are treated in justice, or unjustly, is reviewed here.

ADULT CRIME AND DISABILITY

There are reports that adults with disabilities are more likely to be victims of crimes than adults without disabilities and that the rate of victimization may be shocking while going largely unnoticed. Developmental disabilities and cognitive impairment especially increase one's vulnerability to sexual abuse. The sexual abuse may occur at home, within a protective setting, or in the community. These offenses may go unreported, or if reported may be perceived as less authentic and less actionable than similar offenses reported by persons without disabilities.

Law enforcement officers, particularly those who lack specialized training, may choose to terminate an ostensibly valid injury complaint without forwarding this on to a prosecution official. If forwarded, a prosecution official may choose to avoid bringing this matter before a judge or magistrate, believing the victim will not be a good witness in a court proceeding and the case will not be provable. Developmentally disabled persons, as crime victims or witnesses, may experience a credibility problem when there is a trial, either by judge or jury, although few criminal matters indeed proceed to a full-fledged trial. Yet there is the possibility a judge or jury will be more empathetic on hearing this person's testimony. Disabled persons, called to serve as potential jury members, may well experience difficulty being accepted for this important citizen duty.

A person who may be mentally ill also may experience credibility problems as the justice system confronts his or her complaint of offense victimization. Persons with severe hearing impairments will need particular assistance in providing testimony both at informal and formal levels of the justice system process. Persons with a combination of disabilities are likely to experience more significant problems with these encounters. The use of victim-witness service assistants who enable handicapped persons to better thread their way through the justice system is an important adjunct to the accomplishment of justice.

One needs to carefully examine and evaluate data claims as to the extent of mental disabilities among criminal offenders, as data sets may combine and aggregate both mental illness and retardation under the category of a mental disability. Nonetheless, persons who fit along the continuum of a mental illness tend to be proportionally overrepresented in committing crimes. Persons with disabilities who commit crimes are likely to be handled differently from other offenders, though this will depend on one's nation of residence. Nations that are concerned with one's ability to formulate the criminal intent to commit a crime will have difficulty filing or fulfilling a criminal charge against one who is severely mentally disabled or mentally ill. Not all crimes require proof of a criminal intent, however.

An approach may be to hold such a mentally ill offender in a mental hospital until improvements are noted and the alleged offender is ruled able to proceed to trial and to assist an attorney, provided or retained, with the conduct of the person's defense. Another approach may be to enter a judicial finding, following the production of evidence, that the person is guilty but mentally ill, thus disallowing a matter from continuing indefinitely for adjudication, possibly for years, until a time when witnesses can no longer be found who would have testified at an earlier trial. This form of plea would enable a judge or jury to consider the circumstances of mental illness in fashioning any appropriate sanction.

There are new legal questions, due to today's psychotropic drug availability, as to whether administration of a drug should be done to enable an alleged serious offender to have the capability to stand trial and assist in his or her defense, or be able to perceive for what reason the offender may be executed in jurisdictions that permit the death penalty.

Criminal offenders, with or without mental health issues, are seen as experiencing a disproportionate amount of significant emotional problems during incarceration. Jails and prisons in many nations are seen as inducing or exacerbating these problems. Treatment resources are often extremely limited, even miniscule, in these facilities, and the illnesses of many will worsen.

Cohen (1998), assessing mentally disordered inmates and the law from a U.S. perspective, comments that "the toughest prisons and the most secure cell blocks within them are too often candidates for the toughest, and often sickest, inmates, and creation of this sort of psychiatric ghetto is in no one's best interests" (p. 13.1). The repeated behavioral infractions of these inmates, such as harming other inmates or destroying property, may result in disciplinary proceedings. He suggests that mental health staff employees see this misbehavior as symptomatic of illness and a need for greater treatment provisions, while prison guard staff perceive this as wrongful and requiring punishment. He contends disciplinary proceedings should not take place unless the prisoner is sufficiently competent to understand the charges and aid in his or her defense by way of explanation or mitigation.

More countries prohibit or fundamentally avoid the death penalty (112 nations) than permit its practice (83 nations). China, Japan, Indonesia, Iran, numerous African nations, and the United States are among the countries that retain the death penalty and may carry out executions despite a UN Commission's resolution that urges a death penalty moratorium (or notwithstanding this directive, to refrain from imposing this on one suffering from mental retardation or mental illness). The U.S. Supreme Court finally, in 2002, ruled that executing persons with mental retardation was unconstitutional, as it comprised cruel and unusual punishment. The Court has not categorically banned executions of mentally ill defendants.

JUVENILE DELINQUENCY AND DISABILITY

While definitions of mental retardation and mental illness may have arguable criteria, there is a general international consensus that juveniles under 18 years of age at the time of commitment of a murder or other heinous crime should not be executed. Still, a handful of nations such as Iran, Nigeria, and Somalia allow this to occur. International human rights laws and the United Nations Convention on the Rights of the Child seek to prohibit this. States within the United States have executed a number of persons who committed their crimes as juveniles. The executions, following court appeals, did not occur until the offenders were adults. The U.S. Supreme Court, in 1989, had held executions were prohibited for juveniles younger than 16 years of age at the time the offense was committed but allowed executions for those whose severe crimes were committed at 16 or 17 years of age. The High Court, however, reversed this prior judgment and on March 1, 2005, held that the 8th Amendment to the U.S. Constitution, which prohibits the infliction of cruel and unusual punishments, does not allow the execution of offenders whose offense took place prior to their 18th birthday.

Psychological reasons to explain the commission of delinquent offenses have long accompanied the development of juvenile courts in many nations. In the main, these rationales have not been equated with mental illness, but rather with problems in adjustment, impulse control, overdependence on peer group acceptance, rebellion against one's parents, or other psychologically related issues. Psychological evaluations and recommendations for various forms of treatment of juveniles persist in these courts even though the courts are most often the courts of the poor and poor youngsters may have more overriding social, economic, broken family, and delinquent neighborhood problems to deal with than emotional concerns.

Although juvenile institutions, characteristically, are not very nice places, the euphemistic mantra that these facilities are for rehabilitation and treatment rather than punishment has led numerous jurists to believe that adult-like approaches that seek to equate mental illness or retardation as legal defenses have no place in juvenile court. The rhetoric goes that these courts are to help youngsters and their families, and while juveniles, increasingly, are to be held accountable for their offenses, the court is not to be one of punishment.

Since the purpose is not punishment, then, the court or institution will seek to insert mental health treatment or services rather than entertain strictly legal defenses related to one's disability and criminal intent. Indeed, the ability to formulate a criminal intent is hardly a consideration here as the concern is what to do to help or control a youth while applying a relatively modest sanction, one that is less severe than regularly occurs in adult courts.

Placement onto probation status is the most common juvenile court disposition. Probation status is accompanied with conditions such as attending school, reporting to one's probation officer as required, adhering to any child curfew requirements, performing a community work service or monetary restitution requirement, shunning criminalistic companions, avoiding drug and alcohol usage, and not violating any law. But these conditions are violated frequently, and reoffenses occur often. Juvenile courts, then, depending on the nature and frequency of violations of these conditions or the severity of a reoffense, may scan the horizon to place a youth into either a psychologically oriented residential treatment facility or a secure and controlled institutional setting.

Certainly, numerous youths can benefit from psychological intervention in its various forms, as well as from drug treatment, at the various stages of juvenile justice intervention. But across the world, these services tend to be scant. When available, their effectiveness may be modest. Likely due to limited mental health clinical services in many venues, juvenile courts become the receptacle for youngsters whose problems are better suited for diversion to clinical services.

Juvenile courts tend to grant far more discretion to its officials than is true of adult courts. Skilled probation officers, even prosecutors, may divert juveniles with obvious intelligence or emotional problems to community-based noncoercive program interventions and even dismiss the police complaint. Family group counseling, birthed in New Zealand and Australia and exported from those settings, offers an attractive front-end substitute for court handling of numerous nonserious offenders by mobilizing family, friendship, and community resources to address approaches that might avert further offending. Peacemaking and healing circles, as used over generations by Native American and Canadian First Nations entities, present another inclusive method.

Note should be made of the severe juvenile violence wave in the United States, during the period 1987–1993, that led to legislative changes in virtually all states to expand the transfer of more serious juvenile offenders into the sphere of a criminal court. These jurisdictional changes have been sharply criticized as painting with too wide a brush, allowing far too many youths to be subjected to adult court handling and lengthy prison sentences than is necessary or wise.

Elsewhere, in Japan, a series of horrific murders committed by 14- and 15 year-old youths prompted 2001 legislation that lowered family courts' exclusive jurisdiction from 16 years to 14 years. Highly publicized violent crimes in the United Kingdom led to enactments, beginning in 1991, that dropped the age of criminal responsibility, that is, when one might be treated as an adult, to 10 years, to expanded criminal sanctions for minors, and to custodial sentences that were authorized for longer periods and for younger children.

Juvenile courts, typically, are responsible for another matter that is often known as child dependency, child neglect, or child abuse. Here the court's role is a protective one, to consider a complaint from police or a child protection agency, and direct actions aimed at enabling a safe-and-sound environment for a child. But a child's parents disabled by mental illness or retardation, a physical or language handicap, or a drug addiction have difficult, or at times insurmountable, obstacles to overcome in seeking to regain the custody of their child when officials have removed the child from their custody. Interventions based on drug treatment or psychological theory is commonly used in these matters when services are available.

HIV/AIDS-orphaned street children overwhelm the social services available in countries such as Kenya; an estimated 250,000 nationwide and 75,000 alone in Nairobi. These street children all too frequently move on to commit thefts, property damage, trespass, and child prostitution and become wards of a juvenile court there. The Kenya justice system's handling of these children has been sharply criticized by Amnesty International and Human Rights Watch for allowing jailing in deplorable police cells for prolonged periods, a commingling with adult prisoners, for police brutalities, and for permitting "in need of protection or discipline" children to end up in delinquency facilities, which are, in turn, grossly overcrowded and inadequate.

The several million street children of Brazil do commit crimes. There has been documentation, conversely, that crimes, including homicides, have been committed against more than a few of these children by police officers or adults acting with the acquiescence of police officers. Juvenile facilities used by Brazil's justice system are reported as inhumanely overcrowded, filthy, allowing torture or physical aggression against inmates, and failing to provide adequate education or medical care.

Despite the earnest and committed efforts by countless citizens and officials around the world, too many young people do harm others, or are harmed by juvenile care or justice systems whose mission is to enable bright futures. Both the juvenile and adult justice systems have far to go.

—H. Ted Rubin

See also Death Penalty; Developing World; Substance Abuse; Violence.

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CRIPPLE

A term used to describe people with mobility impairments, especially impairments affecting one or more limbs, *cripple* is an ancient term, first recorded in the Lindisfarne Gospels of the tenth century. *Cripple* is both a noun and a verb. The noun form refers to a disabled person (e.g., "FDR became a cripple after he contracted polio."), while the verb means to disable or impair—to make a cripple of (e.g., "A fall from a horse crippled actor Christopher Reeve."). The adjective form, *crippled,* has also been commonly used (e.g., "hospitals for crippled children").

The term was used as a disparaging epithet as well a descriptor, and in the latter half of the twentieth century, *cripple* fell into disfavor for two key reasons. First, it came to be viewed as a negative and derogatory label, one that focused shaming and stigmatizing attention on one aspect of a person's body and away from the person as a whole. Second, disabled people began to realize that the term focuses on one disability category and does not adequately describe the wide range of impairments that affect people with disabilities. With a growing emphasis on common experiences of disability, the term was seen as limiting and not particularly useful. By the end of the century, *cripple* had become rare in public discourse, though it remained a favorite metaphor of journalists, especially headline writers.

But even as the term receded from common parlance, disability rights advocates, artists, and scholars began to reclaim *cripple* and similar terms (e.g., *gimp*), recognizing the power available in taking over and redefining terms that had previously been used to oppress them. The reclaimed term was often shortened to *crip*–clearly derived from the older term, but transformed. Activist and writer Laura Hershey (1999) explains: "It was short and harsh and uncompromising. It was and wasn't *cripple.* It reminded us of our history, but it took us forward. *Crip* transcended our past subjugation by making fun of an old-fashioned word."

Spurred by the advances of the disability rights and independent living movements, people with disabilities began actively promoting crip culture and crip pride, and the transmuted term *crip* became an important symbol of that cultural transformation. *Crip* came to be seen as less exclusionary as well, since the term was really about claiming a disability identity, claiming a space in crip culture, not about a particular class of impairments.

Some writers have continued to prefer to use *cripple* to describe themselves, preferring among other things the word's greater specificity than more generic terms such as *disabled* or *handicapped.* "As a lover of words," Nancy Mairs (1986) writes, "I like the accuracy with which it describes my condition: I have lost the full use of my limbs." Another benefit for Mairs is the reaction the word receives: "People—crippled or not—wince at the word cripple, as they do not at handicapped or disabled. Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger" (p. 9).

At the beginning of the twenty-first century, scholars used a verb form, *cripping,* to describe the way some disabled people critique the dominant culture's norms. Theater scholar Carrie Sandahl (2003) explains: "Cripping spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects." Cripping, she notes, exposes "the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity" (p. 37), disarming what is painful with sharp-edged humor.

—Jim Ferris

See also Disability; Handicap; Humanities; Impairment.

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CROTHERS, BRONSON

(1884–1959)

American physician and researcher

Born in Cambridge, Massachusetts, Bronson Crothers was the son of a popular Unitarian minister in Harvard Square. He took his M.D. at Harvard and his clinical training at the Massachusetts General Hospital and the Children's Hospital, Boston. After several more years in private practice in Minnesota and the Army Medical Corps during World War I, he developed an interest in neurological diseases, studying in Walter Cannon's physiology laboratory at Harvard and at the New York Neurological Institute. Crothers returned to the Children's Hospital in 1920, in what he described as "the experiment of assigning a pediatrician to the neurology service," when he was made the first chief of neurology.

Crothers had two large fields of clinical research: birth trauma, particularly brachial plexus injuries, and cerebral palsy. His first responsibility became the creation of a highly interdisciplinary outpatient clinic for children with cerebral palsy. Therein he brought together psychologists, nurses, therapists, teachers, surgeons, and social workers to collaboratively help their charges and to explore the nature of the condition. Crothers's work with some 1,800 people with cerebral palsy culminated in a monograph with Richmond S. Paine (1920–1969), *The Natural History of Cerebral Palsy* (1959), which is still consulted today.

Beyond his intellectual contributions, Crothers was a prominent national consultant in issues relating to children with disabilities, chairing President Herbert Hoover's 1932 White House Conference on Child Health and Protection. In addition, he helped found the multidisciplinary American Academy of Cerebral Palsy with George Deaver, Winthrop Phelps, Temple Fay, Earl Carlson, and Meyer Perlstein. Finally, his trainees absorbed Crothers's fascination with interdisciplinary clinical research and, in turn, trained many more leaders. These disciples included Winthrop Phelps, who went on to establish the institute that would later become the Kennedy-Krieger Institute in Baltimore, Maryland.

—Walton O. Schalick III

See also Cerebral Palsy.

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CRUICKSHANKS, WILLIAM

(ca. 1802–1876)

Educationist

William Cruickshanks was abandoned as a young boy at Madras Military Orphan Asylum and became blind at age 12 or 13. His education was irregular but he persevered in memorizing whatever he could, and eventually worked as a private tutor. Cruickshanks was married twice and had children. By 1838, he had so impressed educationists at Madras that they made him headmaster of the Native Education Society's School with 100 pupils. In 1841, he became head of the asylum where he had grown up, and then headed the missionaries' Anglo-Vernacular School in Palamcotta (Palankottai) for 26 years, becoming a famous educationist. Cruickshanks was also a devoted Christian evangelist and brooked no objection from his Hindu pupils to this endeavor. Trading on his blindness, he ignored boys' efforts to leave when he was preaching at them individually—the hapless lads could not use visual signals of their wish to go, and were too polite just to walk away. Some of them, while ignoring Cruickshanks's proselytising, recognized him as a man whose character and spirit influenced them deeply. He continued in educational work until his death.

—Kumur B. Selim

See also Blind, History of the.

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CULTURE

See Deaf Culture; Disability Culture

CULTURAL CONTEXT OF DISABILITY

This entry discusses three significant aspects of disability contexts cross-culturally: (1) the cultural construction of impairment; (2) disability as negative social response to impairment; and (3) the influence of intersecting social categories such as gender, sexuality, class, ethnicity, and age on disability. Throughout this entry, we draw cases from the anthropological literature to illustrate particular points.

In our view, an impairment is a negatively construed, cultural perception of a bodily, cognitive, or behavioral anomaly in terms of individual functioning or some other ethnopsychological or ethnophysiological status. Disability is the negative social response or social exclusion that may come into play because of perceived impairments (Kasnitz and Shuttleworth 1999, 2001a, 2001b; Shuttleworth 2004; Shuttleworth and Kasnitz 2004). We use the hyphenated term *impairment-disability* to highlight the processual and interconnected relationship that can exist between the negatively constructed cultural perception of an impairment and any negative social responses to that perception (Shuttleworth 2004; Kasnitz and Shuttleworth forthcoming; Shuttleworth and Kasnitz 2004). This sociocultural understanding of impairment-disability develops from the growing acknowledgment in disability studies that not only is disability culturally constructed but impairment is likewise not a *natural* category (see, e.g., Hughes and Paterson 1997; Paterson and Hughes 1999; Corker 1999).

TOWARD A THEORY OF SOCIOCULTURAL IMPAIRMENT

In the International Classification of Impairments, Disabilities, and Handicaps published in 1980, the World Health Organization (WHO) defined *impairment* as any loss or abnormality of mental, physiological, or anatomical structure or function (WHO 1980). In this biomedical understanding, impairment is viewed as separable from social circumstances and implies diminishment or limitation of an individual's neuromusculoskeletal capacity or functional ability measured against a normative standard. The WHO's 2001 revision of the International Classification of Impairments, Disabilities, and Handicaps, now termed the International Classification of Functioning, Disability, and Health, de-emphasizes impairment in its model and presents a more holistic biopsychosocial approach to health, functioning, and disability (WHO 2001). Yet its definition of impairment remains similar to the spirit of the biomedical understanding and its own earlier definition. Impairment remains both underlying pathology and its manifestation as problems or deviations in cognitive, physiological, or anatomical function (Hwang and Nochajski 2003; Stewart and Rosenbaum 2003). Deviation from norms, however, inherently refers to an evaluative system. As Canguilhem (1989) observes, "Norms, whether in some implicit or explicit form, refer the real to values, express discriminations of qualities in conformity with the polar opposition of a positive and a negative" (p. 240). However, understanding function in this evaluative way is not only a product of biomedicine. The disciplinary mechanisms of modern institutions, especially hierarchical observation and normalizing judgment (Foucault 1979), also permeate the lay evaluative gaze. Normalizing judgment has become a typical modern cognitive style classifying "people in terms of their relationship to a social norm" (Douard 1995:154). Classifying people in terms of social norms includes not only the categorization of an individual's behavior but also the classification of an individual's bodily and cognitive functions. Thus, in modern societies such as the United States, normalization takes up, as one of its evaluative dimensions, the judgment of individual function (Shuttleworth 2000, forthcoming).

The critique of instrumental rationality has been a pervasive theme in social thought from Weber through the Frankfurt theorist to poststructuralist such as Foucault. Social philosopher Cornelius Castoriadias (1987) contributes to this tradition by showing how modern rationality increasingly focuses on functional efficiency. He argues that modern rationality is obsessed with the perfect lining up of aspects of any particular system in terms of its functional efficiency, but a functional efficiency stripped of an awareness of a raison d'être. It is because functionality has no intrinsic relation to ultimate ends, that Castoriadis sees it as the materialization of "the extreme autonomization of pure symbolism" (1987:159). In other words, function itself has become fetishized. From this perspective, the fetishization of function illuminates the groundwork for the cultural construction of our understanding of impairment as not only referring to the underlying structural pathology at the cellular or molecular level but also as manifesting in cognitive, physiological, or anatomical functional deficitor inefficiency (Shuttleworth 2000, forthcoming). Within the realm of everyday life, evaluations stemming from socially embodied codes of normative function within particular carnal contexts of meaning (Paterson and Hughes 1999) such as mobility or verbal speech are the yardsticks by which an individual's impairment is implicitly measured, albeit in popular understanding the term disability or handicapped may be used.[1]

However, some other societies may not accord the same degree of importance to functional efficiency as modern Western societies do, or at least not individual functioning. Pertinent indices other than an individual's bodily, cognitive, or behavioral functioning may play a more or less significant role in identifying a human anomaly as a *sociocultural impairment.* Burck (1999), for example, while subsuming the concept of impairment within disability as most anthropologists are wont to do, notes how certain bodily conditions attended to within a Shona ward in Zimbabwe are given impairment status but contrast to the modern Western sense of impairment as simply being about individual functioning. An example of one of the conditions included is

> children who [get] their upper teeth first; throughout my fieldwork area this was considered a very serious disability that would affect a person throughout life. . . . Function loss, which is an important determinant in our Western taxonomy, only played a minimal role. In actual fact it was not function loss, but the dryness of the affected part which determined the seriousness of the disability.

The "minimal role" Shona accord to function loss likely tells us we are dealing with a different understanding of impairment not disability. One can infer from Burk's description that for the Shona an important dimension of an impairment is the imbalance between wet/dry and hot/cold within their humoral ethnomedical system. It can be surmised that this negative understanding is a core aspect of the cultural perception of a child who gets upper teeth first. Since Burk mentions that children would be affected by this impairment throughout their life, we can infer from her account that disabling social responses likely follow this cultural perception. After all, there appears to be no physiological or individual functional disadvantage to getting upper teeth before lower teeth.

The task of cross-cultural researchers is to enlarge our understanding of impairment beyond its biomedical diagnostic and also modern lay meanings and conceptualize it so that it lends itself to cross-cultural relevance. What are some relevant points to remember in assessing *sociocultural impairments* cross-culturally? First, while in U.S. society an impairment is primarily seen as an individual affair and functionally limiting at the bodily or cognitive level, in many nonmodern societies what is perceived to be the cause and/or consequence of an impairment may be dysfunctional social relations or the transgressing of social order. Whether or not the individual's functioning is perceived as diminished, it is often the social relational functioning of the family and community that are the sites of major concern. Devlieger (1995), who conducted research among the Songye of Zaire, comments, "It is important to consider . . . that the belief in sorcery and the inquiry into relations within the family assume that the problem of disability [impairment, *sic*] is not a problem of the individual but rather a problem of the family" (p. 101). Burck (1999) states, "The physical condition (e.g., disability [impairment, *sic*]) is seen as a symptom of an underlying social problem" (p. 204). Devlieger discusses how inquiry into the cause of an impairment proceeds via the interrogation of past group and family relations: past social observances of food and sex taboos, envy between family members, proper respect for the ancestors. Perceived transgressions of social taboos or problematic family and group relations may be seen as causing the impairment. Often the impairment itself is not viewed as shameful but the underlying social conditions that caused it are seen as shameful (Burck 1999; Ingstad 1997). If the transgression of social taboos or problematic social relations cannot be blamed, for the Songye, the last resort for a causal explanation is God (Devlieger 1995). This perspective on ill health and impairment is exemplified by the Maasai of Kenya who "perceive disease as a sign of social or cosmic disorder projected onto the human body. Therefore the most effective prevention against disease and other misfortunes is to care for and manage social and divine relations properly" (Talle 1995:61).

Prevention is the watchword and acts as a powerful social control mechanism. The desire to correct or rehabilitate, which is an implication of our understanding of impairment as affecting an individual's functional efficiency, appears to be absent in many of these nonmodern societies (e.g., Devlieger 1995; Talle 1995). Incorporating the above kinds of data, a sociocultural theory of impairment-disability must widen its understanding—viewing impairment as the negative construction of a human anomaly with causal or consequential implications for some combination of physical, cognitive, or psychological functioning and/or social ordering or group relations.

Second, in any particular society or among groups within a society, impairments may be seen as distinct from diseases/illnesses or may be indistinct from diseases/illnesses in people's understanding and in their accommodation and health-seeking practices, depending on many factors including the particular society's medical belief systems, time since onset and social contexts, among other factors. In fact, in many nonmodern societies there may not be a clear if any separation between impairments and diseases/illnesses, especially early on (see, e.g., Devlieger 1995; Helander 1995). For example, Helander (1995) states that "the Hubeer [a community in the Bay region of southern Somalia] do not discriminate firmly between disability [impairment, *sic*] and disease. The practices and ideas surrounding disabled people can be described within the framework of health seeking and health management through which all health problems are processed" (p. 89). This is probably the case in many nonmodern societies. Devlieger (1995), for instance, also notes that among the Songye, disability (impairment) is initially perceived and responded to as illness. Yet there cannot be a clear delineation between these cases from Africa and the health-seeking mentality that pervades the treatment of children born in the United States, for example, with a condition such as cerebral palsy. The difference is likely only a matter of degree of buy-in to health seeking. For while ostensibly, in the case of those concerned in the United States, primarily parents and physicians, they may understand that cerebral palsy is not a disease like cancer, health-seeking behavior (in other words, the search for a cure) may predominate over more pragmatic rehabilitation and accommodation issues for quite some time.

Helander, however, also shows how Hubeer health-seeking behavior for an individual's intractable illness eventually falls off when funds run out and the gamut of therapies is exhausted. Does this perceptual change on the part of Hubeer constitute a foregrounding of impairment, which now trumps the previously dominant illness/disease categorization? In fact, Helander characterizes this shift in perception by Hubeer, as seeing "disability [impairment] as incurable illness." While still subsuming impairment within an illness/disease framework, there is nevertheless here an acknowledgment of the often enduring nature of these kinds of conditions. There is likely some understanding, either implicit or explicit, in all societies of the difference between illnesses/diseases that are amenable to therapeutic treatment and conditions that endure indefinitely. As Burck (1999) also notes among the Shona, "Disability [impairment, *sic*] was considered an illness that lasted very long" (p. 204).[2]

DISABILITY AS NEGATIVE SOCIAL RESPONSE

Depending on the particular impairment and its associated cultural meanings in a society, the person may be easily integrated and assume a valued social role, accorded supernatural status with certain accompanying privileges, or stigmatized and excluded from various social relations and cultural domains (Shuttleworth 2004, Kasnitz and Shuttleworth forthcoming; Shuttleworth and Kasnitz 2004, forthcoming). Persons perceived as impaired who are excluded from various social relations and cultural domains are in the sociopolitical sense in which we are using the term—*disabled.* In this schema, a particular society with its unique cultural meanings defines and situates any functional limitations or other physical/psychological statuses as impairments (see also Marshall 1996), and constructs its social responses as inclusionary or exclusionary, just as it also constructs the meanings of and responses to health and illness. For critical cross-cultural disability researchers, it is the cases of disabling responses that constitute the primary data. Of course, the above schema is meant only for analytical purposes. In actuality, a society may perceive that a person has an impairment and depending on the contexts of everyday life, the person may be included in some cultural domains but not included in others. It is up to the disability ethnographer to document the contextual complexity of impairment-disability in a particular society.

In terms of body and behavior, any out-of-the-ordinary manifestation may be perceived as anomalous. Each society considers some anomalies impairing, which can lead to disabling responses. A 1980 survey on leprosy, an aesthetic impairment, in Nepal found that a majority of persons would separate family members who got leprosy, and a third said they would put them out of the village. Ten years later in 1990, there was little change in expectations (Hyland 2000). Turmasani (1999a, 1999b) reports widespread negative social attitudes toward physically disabled people in Jordan resulting in charity, the attribution of cognitive impairment, and asexuality. The birth of twins constitutes a social disgrace among the Punan Bah, and one of them is usually given away or withers away (Nicolaisen 1995). For the Hubeer, stupidity and madness are viewed as similar to infertility and death, and the mentally impaired are often treated with abuse outside of their family (Helander 1995:89). Talle (1995) states that among the Kenya Maasai mentally retarded or mad persons are regarded not as disabled in a physical sense but as "abnormal" ("fool"). Nicolaisen (1995) echoes an observation made by many cross-cultural researchers about some forms of severe cognitive difference such as severe forms of mental retardation: "among the Punan Bah, I suspect that children born with such impairments 'wither away'. . . or die at an early age" (p. 44).

Much depends on the interplay of beliefs, social expectations, and economic imperatives of the particular society as to whether some human anomaly will be considered impairing and whether the person will experience social exclusions (Groce 1999). For example, in China today the ability for men especially to be active and mobile outside the home in terms of public life and also in one's livelihood is highly prized. Combined with ideas about national development and mobility and the Confucian emphasis that transmutes bodily imperfection into social meaning, men who have difficulty walking experience stigma and discrimination (Kohrman 2000). Here cultural beliefs, social and gender expectations, and also economics conspire and contribute to the creation of a devalued identity based on a negatively perceived bodily difference, that is, an impairment. In the case discussed above for the Hubeer, the termination of health-seeking behavior coincides with a sense of hopelessness by family members and exclusion of the affected individual from many of the social activities that construct their sense of personhood. This exclusion should be considered a disabling social response regardless of the Hubeer's conceptual understanding of the condition, that is, whether they explicitly perceive it as an impairment or simply as enduring illness/disease.

INTERSECTIONS WITH DISABILITY: THE CASE OF GENDER

The kinds of social exclusions faced by disabled people cross-culturally are significantly influenced by intersecting social categories of experience such as gender, sexuality, class, ethnicity, and age. For the purposes of this entry, the focus will be on the intersection of gender and disability. To show concretely how disabled people in various societies can be differentially included or excluded based on perceptions of gender, it is necessary to specify a cultural domain, or a couple of related cultural domains, of action to interrogate. The sexual and marriage domains are ideally suited for this kind of comparison because of the widespread sexual oppression that disabled people experience cross-culturally. In fact, sexual and/or marriage access appears to be greatly reduced for disabled people with various impairments in a wide range of societies (Shuttleworth 2000, 2001, 2004; Devlieger 1995; Nicolaisen 1995; Sentumbwe 1995; Ablon 1984, 1996, 1999; Kohrman 2000). A number of studies specifically note gender differences in the availability of cultural resources and in the opportunities to find sexual or marriage partners (see, e.g., Sentumbwe 1995; Ablon 1996, 1999; Wolf and Dukepoo 1969; Kohrman 2000).

An anthropological study that explicitly examines the differential access to intimacy and sexual experiences for men and women is Ablon's (1996) research on gender response to neurofibromatosis 1.[3] Based on their review of the literature, the sociologists Asch and Fine (1988) reported that disabled women in U.S. society were more likely to be without a partner than disabled men. Although Asch and Fine's work was a long-overdue plea to include gender as an important variable in research on disability and drew attention to the multiple oppression that disabled women are often subjected to in U.S. society, the findings of Ablon's study challenge any blanket assessment of the greater disadvantages that disabled women have compared to men in developing intimate relationships in the United States. In short, Ablon found that of her sample, two-thirds of the women were married, while only one-third of the men were married. In addition, the single men in her sample were much less likely to have had sexual experiences than the women. Ablon notes the persistence of women in finding a partner, while some of the men socially withdrew. She argues that since women have been socialized in U.S. society to be connected in a relationship, these women with neurofibromatosis continued to fantasize about and strategize to connect with a man. Conversely, for men, attachment is overridden by the cultural expectation of male achievement. The lack of individual achievement by some of these single men with neurofibromatosis 1, due to early learning difficulties and social failures, and thus their lack of being able to meet U.S. society's male gender role expectations, negatively affects their gender identity, effectively blocking any desire they might have for an intimate relationship (Shuttleworth 2000, 2004; Kasnitz and Shuttleworth 2004).

Sentumbwe (1995) has provided a finely grained analysis of the cultural knowledge and social dynamics operating in the sexual and marriage arena for blind Ugandan women and compares their situation to that of blind Ugandan men. First, he elucidates why sighted Ugandan men will have sexual relations with blind Ugandan women and/or keep them as mistresses but rarely marry them. Cultural beliefs that blindness is physically incapacitating and blind persons are especially vulnerable compared to persons with other impairments contributes to the assumption that blind women cannot adequately fulfill their domestic role; reinforcement of this assumption by disapproving relatives and friends generally results in the restriction of relations between sighted men and blind women to less socially legitimate relationships based primarily on sex. Sentumbwe suggests that although adequate for sexual relations, blind women are unattractive as marital partners for sighted men because "most men refuse to take on any 'woman's activities'; consequently, men still need competent housewives," which they assume must be physically able and thus sighted (p. 172). On the other hand, blind men are more likely to have sighted wives because sighted women are actively involved with income-generating activities and have "progressively embraced male dominated activities" (p. 172). Therefore, they do not have to totally depend on their blind husbands or assistance from kin (Shuttleworth 2000, 2004; Kasnitz and Shuttleworth 2004).

What Ablon's and Sentumbwe's studies clearly show is that in addition to elucidating the cultural understanding of and response to a particular impairment, an analysis of the different gender role expectations for men and women in a society and the cultural knowledge, values, and practices that legitimize them is important to consider in assessing the avenues open or closed to disabled people in a particular cultural domain, in this case, the sexual and marriage possibilities for disabled people. Whether men or women perceived as having a particular impairment are seen as legitimate sexual or marriage choices by others can sometimes differ drastically depending on the interplay between cultural beliefs about the impairment and, using Bourdieu's (1977) terms, the degree to which they are perceived as embodying the society's gendered dispositions in *hexis*, bodily habits and intentions. Being unable to adequately effect a masculine or feminine performance and being evaluated by others and themselves in terms of this inadequacy may have significant consequences for people with various impairments depending on the society. Divergent patterns of response by men and women with the same impairment (e.g., social withdrawal/continued strategizing) may be due to their perceptions of how well they embody masculinity or femininity and/or differences in the sociocultural resources available to these genders (Shuttleworth 2000, 2004; Kasnitz and Shuttleworth 2004).

Interrogating social categories other than gender would similarly show how disabled people are differentially included or excluded given the divisive terms that organize the particular social category. For example, a disabled person from a privileged class in a modern capitalistic society such as the United States might experience less stigma and oppression in many cultural domains than a disabled person who lacks the cultural and symbolic capital of status, as well as the economic capital to purchase adequate human services and technological aids. An analysis of all relevant social categories that intersect with disability is the goal of a critical, disability ethnography.

CONCLUSION

This entry has suggested that impairment is a variable concept whose meaning will diverge in different societies. Several cases were presented showing how different societies construct impairment from human anomaly. Also presented were a range of examples of the kinds of negative social responses to impairment that *disable* persons in different societies. The intersection of gender and disability as it plays out in the domains of sex and marriage was further presented as an example of how exclusions can differentially affect disabled people given the divisions of a particular social category within a specific cultural domain across cultures. At the very least, critical anthropological study of impairment-disability must elucidate how these three aspects—impairment, disability, and relevant social categories of experience—articulate in any particular cultural context.

—Russell P. Shuttleworth and Devva Kasnitz

See also Anthropology; Gender; Inclusion and Exclusion.

Notes

1. Contrary to the biomedical ideal, the functional aspect of an impairment cannot strictly be separated from the body's normative social uses and cultural meanings. Rather, the context of these normative social uses and cultural meanings are what informs the clinical identification of the functional aspect of an impairment. This identification of individual function by biomedicine is simply a more explicit and conceptualized version of the implicit perception by laypersons of an individual's functional differences and limitations during everyday life with its culturally constructed activities and roles.

2. Although many impairments are enduring, that is, permanent features of a person's physical, cognitive, or psychological makeup, some clearly are not. The example given for the Shona of children who get their upper teeth first exemplifies the latter. This human anomaly is a physiological event and not part of the objective features of a child's physical makeup once her other teeth emerge. What does endure for the Shona is the group members' memory of the event—an event perceived as an impairment.

3. Neurofibromatosis 1 is a progressive, neurological genetic disorder, which manifests in tumors that develop along nerves and nerve sheaths. External tumors may be cosmetically disfiguring.

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CYBORG

The term *cyborg* was originally proposed in 1960 to describe a human altered "by suitable biochemical, physiological, and electronic modifications" (Clynes and Kline 1960) to allow the augmented human to survive in nonhuman environments such as space. The concept was to go beyond simply encapsulating the human in a spacesuit and spacecraft. The idea was to change the human.

Sometimes the *cyborg* term is used in connection with artificial limbs and rehabilitation but more often it is used in the science fiction context. People with artificial limbs have long been a part of literature and the visual arts. In nongenre fiction, the artificial limb has been used as a symbol of traumatic loss or sacrifice as with the characters of Captain Ahab in *Moby Dick* (novel, 1851) or Homer Parrish in *The Best Years of Our Lives* (film, 1946). The stories examine how persons, albeit fictional, respond to a life-changing event. The amputation and artificial limb are dramatic devices to signal to the reader or viewer the severity and personal nature of the loss.

When artificial limbs are used centrally in science fiction, it is often that the prostheses bestow superhuman abilities on the character or lead to dehumanization and alienation from society. The astronaut Steve Austin in Martin Caidin's novel *Cyborg* (1972) is exemplary of the superhuman. Following a devastating crash in an experimental space plane, Austin is rebuilt—"Better than he was before. Better, stronger, faster." Provided with nuclear-powered prostheses, Austin becomes a special agent for the government. Caidin's book led to a popular television series, *The Six Million Dollar Man,* which aired from 1973 to 1978. The concept of better, stronger, and faster through prosthetic enhancements is important in Bernard Wolfe's early antiwar novel *Limbo,* published in 1952.

Science fiction has many Steve Austin type cyborgs who are better because of their prosthetic enhancements, but science fiction also considers the darker side of the human/machine cyborg, treating it as a metaphor for the dehumanizing and threatening effects of technology. Movies such as *Robocop* (1987) and the first *Star Wars* trilogy (1977, 1980, 1983) have central characters that have become so much machine that their humanity appears to have been crowded out. In *Robocop,* a severely injured police officer is rebuilt to serve as a robot-like law enforcement tool. The cyborg struggles to regain its memories and reclaim its humanity from its corporate handlers. In the *Star Wars* trilogy, the galactic emperor's chief enforcer, Darth Vader, is a cyborg striving to enslave the galaxy's inhabitants under the emperor's rule. So removed is Vader from his human origins that he appears prepared, in the climatic confrontation of the third movie, to sacrifice his own son and daughter to the will of the emperor.

In the genres of fantasy and science fiction the artificial limb is often explicitly a part of the story because of some magical power or physical advantage that the prosthetic device provides, but this is not always the case. The members of Jules Verne's Gun Club in *From the Earth to the Moon* (novel, 1865) are Civil War artillery designers. Although "there was not quite one arm between four persons and two legs between six," their amputations were treated as an occupational hazard that did not significantly influence the story. Similarly, characters in Robert Heinlein's novels *Citizen of the Galaxy* (1957) and *The Moon Is a Harsh Mistress* (1967) have artificial limbs. In the first, the use of an artificial leg is concealed by a spy who removes it when disguised as a street beggar. In the second, a variety of artificial left arms are used by the story's narrator, a machine troubleshooter and repairman. In each case, the prosthesis provides the user with an occupational advantage that is valuable but not central to the overall story.

There are many facets in science fiction to the characterization of persons with prosthetic devices. However, one aspect that seems almost universal is that the fictional prostheses are better than anything that science and technology can provide in the real world.

—Craig Heckathorne

See also Body, Theories of; Film; Novel, the.

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CYSTIC FIBROSIS

Since its initial description by Dorothy Anderson in 1938, cystic fibrosis (CF) has been transformed from a lethal diagnosis in infancy to a chronic but ultimately fatal disease of children and young adults. Although the precise mechanism of action is under dispute, the genetic mutations in CF cause abnormalities in a protein expressed on epithelial cells, which occur throughout the body but are particularly important for normal functioning of the respiratory and digestive systems. The disease is autosomal recessive, with a high carrier frequency and more than 1,000 different mutations. One of every 25 Caucasian Americans is a carrier, and one of every 2,500 Caucasian newborns will develop the disease. The mean age at death for CF is now approximately 29 years; the most common cause of death is respiratory failure. Pressure to expand newborn screening is increasing in the United States, supported by those who believe that it prevents so-called late diagnoses; there is as yet no consensus that treatment in early infancy will improve overall survival.

As the patient population ages, chronic symptoms have begun to surface, any one of which can lead to significant disability. Common symptoms include diabetes and its complications, chronic sinusitis, osteoporosis with resulting rib fractures and vertebral compression fractures, hepatic disease, gallbladder disease, chronic hemoptysis, chronic pancreatitis, and chronic pulmonary infection leading to respiratory failure. In addition, previously well-known complications of CF, such as male infertility, have begun to have a more significant impact in the young adult population. Chronic pain, primarily due to headache and chest pain, has also become more frequent.

With the transformation of CF from a cause of early death to a chronic illness, issues of psychosocial adaptation and development become more prominent. The peculiar trajectory of CF compounds the developmental challenges of an adolescent with chronic illness: the respiratory symptoms, and the intensity of medical interventions, usually accelerate at just the time adolescents seek increased independence from parents and caregivers. Adherence to a medical regimen thus becomes more important when resistance to such a regimen may be maximal. Adaptation to changing levels of independence brought about by a fluctuating disease trajectory can greatly complicate other developmental challenges such as schooling, independent living, family life, sexuality, and employment. The psychosocial challenges of advancing CF can place great stress on other family members, some of whom may also have the disease.

The most common illness trajectory in CF is one of intermittent acceleration of symptoms superimposed on a gradual decline in lung function. The paradoxical combination of short-term uncertainty and long-term clarity about outcome makes medical decision making difficult for families and caregivers. The increasing availability of aggressive therapies, including lung transplantation and assisted ventilation (especially so-called noninvasive methods such as BiPAP), has disrupted the previous consensus against the use of technological interventions in the final months of life. Decisions regarding lung transplantation, especially those that involve donation of lung lobes by family members, are particularly challenging. As well, in an era of increasing technological intervention, those who wish to decline aggressive treatments in favor of quality-of-life measures may find it difficult to interact with a technologically driven medical system.

—Walter M. Robinson

See also Childhood, Youth, and Adolescence; Consent to Treatment.

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D

DANCE

Disability dance sees disabled people engaged in dance and movement activities. The personal and social aims of the dance work are multiple, and they relate to the framings of disability. Some disability dance, in particular in the contact improvisation scene since the 1970s, including training organizations such as DanceAbility, explores the multiplicity and specificity of human bodies. Here, impairment recedes, and "difference" remains as bi-pedals, wheelchair-users, floor-dancers, or people with visual impairments explore connections and tensions between their bodies. Companies such as CandoCo (United Kingdom), AXIS (United States), Taihen (Japan), dancer Homer Avila (United States), and Touchdown (United Kingdom) are examples of this kind of modern dance work that emerges from an interest in bodily and sensorial difference as aesthetic impetus. Different historical dance aesthetics are explored within this framework, as well: U.S. companies Cleveland Dancing Wheels and Light Motion use classical ballet approaches to the development of techniques for disabled dancers.

Other forms of disability dance have more therapeutic aims—this dance approach aims to make the disabled person feel well inside his or her skin, using the positive effects of exercise, shared movement, and the pleasures of music to move people. When this form of disability dance reaches a public, it shares the pleasure of being alive and can create positive images of disability in the social scene. At the same time, though, some artists query the political efficacy of these forms of positive images of happy dancing disabled people, as the historical and public oppression of disabled people in the social scene are elided. A more fractured choreography that plays with images of social stereotypes combined with the pleasures of movement as a form of social communication is at the heart of much political disability dance work.

Some of this political disability dance uses the historical framework of dance theater—the affect of the moving body as a kinesthetic spectacle becomes the vehicle for political messages about what bodies are seen on what kind of stages. Examples of this form of dance are Germany's DIN A 13, the United Kingdom's Blue Eyed Soul, Austria's Bilderwerfer, and U.S. dancer Bill Shannon's work, where the act of putting on an act is queried.

Shannon's show AOW Remix (2002) cites the street and the hip-hop club as interlocutors to the theater stage. A brief look at moments in the show can show how different aspects of disability dance merge, in particular disability dance as a take on a particular technique (hip-hop), as a political commentary, as a play on the embodied effects of language, and as a performance of the everyday.

Before the show, the performance starts. The waiting audience in the Dance Theatre Workshop in New York City can watch a video in the foyer. In the video, a man with crutches (Shannon) moves down a flight of steps, he falls, passers-by look, some move in to help. The man with the crutches recovers easily, and he makes a fast getaway. One man in the video steps back and crosses himself.

The reaction of this passer-by in the video to the falling crutch-user is a form of disability dance: not the aesthetic product of artists dealing with bodily difference, but social movement patterns. Multiple scripts exist for dealing with difference—crossing oneself half-unconsciously, warding off evil, is one reaction. In the man's action, various mechanisms are combined: He steps back, puts distance between himself and the spectacle of the fallen man, his hand in his quick cross-shaped weave creates a shield between him and the scene, and the connotations of the crossing evoke a third presence as a godly or saintly helper and guardian is called on to intervene into the little act played out here. The short choreography in the street presents the deep cultural strata of distress, negativity, and fear of disability that still pervades attitudes. No positive images, no disability rights legislation has yet been able to undo these old habits, excavated in the unconscious bodily behavior in the street.

We are finally allowed into the theater, and we find our way to our seats. They are mostly inaccessible to many disabled people. I have trouble storing my crutches. I catch the eye of another disabled person, a woman one row behind me; we talk and acknowledge that we are the only visibly disabled people we've seen tonight in the audience. This checking of numbers, and of assessing venues for access, is a ritual enacted by many politically conscious disabled people who see themselves as part of a minority movement and are aware of the only recent history of access to stages and auditoriums.

The lights go down.

A man appears, and sprays a graffiti handle on the black backdrop of the empty stage. Stage right back, a VJay station is set up, and a man begins to scratch video-loops against one another to heavy, loud hip-hop music. A stylized knife-fight ensues. The dancers throw poses at one another: a slow routine with long held freezes, aimed at the opponent with attitude. The 1986 documentary *Paris Is Burning* explained similar moves in the gay black scene: "shade" is happening, a dissing of one's dance opponent, without touching. Skills are shown off: moonwalking, breakdance, and crutchdancing. As an audience member, I am aware that I lack language to describe what I see: This is not the kind of dance move conventionally seen in stage shows. More and more, the scene takes on the quality of a different place: a club. Six dancers square off against one another, in a solo competition. All the dancers get their turn, and while the circle is watching, they present their moves in a casual yet calculated framing. One of the six dancers is Bill Shannon. He seems older than the others, and various gestures and arrangements show that he is in charge. He is wearing his baseball cap, and I can make out what it says: Crutchmaster—a title he earned in the New York club scene. His first solo sees him flying around his crutches: Gripped by his arms, they stand in the middle, moving from side to side, as his legs swing out behind him in a circle. His dance is powerful and acrobatic, but his choreography is clearly knowledgeable of how his crip performance is likely framed by a nondisabled audience: At the end of his dance, he takes off his cap and sinks down in a pathetic, "handicapped" "cap-in-hand" gesture.

The energy drops. The dance disperses. Shannon is alone on stage. He moves about, seemingly aimless. We hear him mutter to himself, occasionally loud enough to be understood by the audience: "What happened to the show?" "Are we faking the show?" This commentary on transplanting a hip-hop club scene into the theater is expanded on as a man in a trench coat enters. A fake chimpanzee is taken out and played with and finally packed into the suitcase, one hand sticking out, and carried off. Who is the monkey? The "street scene," commodified as a spectacle rather than a participatory event? Bill himself, the crutchmaster, performing tricks on sticks?

The cap-in-hand, the performing monkey, the drops in energy and the agonized whispers of "faking the show" persist throughout the performance, reminding the audience again and again of the price that is paid by the set-up of the stage. The performance emerges *as* a performance, as a set of choices within constraints. Shade and pride are relative phenomena, born out of the knowledge that difference has to fight for its spaces.

Accessible disability dance clearly means physically accessible stages, auditoriums, dressing rooms, and rehearsal spaces, as well as accessible educational opportunities. But fundamentally, it also means accessible aesthetics. Disability dance is one of the practices where the body is queried, where experiments about who can be/should be/ought to be on stages can be explored. What is beautiful? Why are we looking? What are the politics of the stare, what are the politics of shared embodiment and affect? These are the kinds of questions raised in political disability dance. They can affect and play with the ingrained choreographies of the man crossing himself on the street, of the person changing the side of the road when she sees a disabled person approaching, and all the other little choreographies that still speak about the distance between disabled and nondisabled lives.

—Petra Kuppers

See also Aesthetics; Body, Theories of; Disability Culture; Drama and Performance.

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DART, JUSTIN (1930–2002)

American advocate

Justin Dart has been widely recognized as the founder of the Americans with Disabilities Act (ADA) signed into law on July 26, 1990. Dart's grandfather established the Walgreen's Pharmacy chain. However, Dart was also a highly successful entrepreneur himself who made his own fortune by introducing Tupperware to Japan during the mid-1960s. At age 18, he contracted polio and was admitted to the Seventh Day Adventist Medical University in Los Angeles. Doctors told him he had three days to live. While living on the polio ward, Dart found himself surrounded by the companionship and support of other disabled people. As he would explain later: "These beautiful people not only saved my life, they made it worth saving" (quoted on website: http://www.aapd-dc.org/justindart/jdobit.html). In 1951, Dart matriculated at the University of Houston where he studied to be a teacher. The university withheld his teaching certificate because he was a wheelchair user and posed an insurance risk to would-be educational institutions that might employ him.

President Ronald Reagan appointed Dart to be vice-chair of the National Council on Disability in 1981. During this time, the council members drafted a national policy on equal rights for disabled people; the document ultimately became the foundation of the ADA and advocated for an expansive inclusion of disabled individuals including psychiatric survivors and individuals with HIV/AIDS.

—David T. Mitchell

See also Americans with Disabilities Act of 1990 (United States); Polio.

DARWIN, CHARLES (1809–1882)

English naturalist

Charles Darwin did much to stimulate scientific interest in the field of intellectual disabilities. Lacking convincing fossil evidence of intermediate species to connect humans and higher primates, Darwin described persons with intellectual disability as evolutionary stand-ins for missing ancestral forms. The careful observation and reasoning that characterized his work on pigeons, worms, and barnacles was notably missing in his discussions of these human beings.

In *The Descent of Man* (1871), Darwin argued that "idiots" were (1) an intermediate rung on the evolutionary ladder connecting humans and primates; (2) examples of the inevitable waste and loss produced by natural selection acting upon variability; (3) the floor of a scale representing the "lowest," most unfit variety of human being; and (4) atavistic reversions to extinct forms whose study could reveal earlier stages of human development. The latter argument led to an explosion of scientific interest in mental disability in the late nineteenth century, and, in the early twentieth, to the myth of the menace of the feebleminded.

The full humanity of persons with intellectual disability was denied in service of evolutionary theory. If persons with intellectual disabilities were, in fact, the "ape/men" that paleontologists had searched for, there were no benefits to this unnatural designation. Viewing persons with intellectual disabilities as nineteenth-century monstrosities, Darwin and other evolutionists found them useful for proving a scientific point, but not much else.

—Steven A. Gelb

See also Biological Determinism; Evolutionary Theory.

DE LABAT, B. J. G. (1858–1942)

South African educator

Bernabé J. G. De Labat, of Worcester, 80 miles from Cape Town, was asked in 1879 to initiate teaching at a school for deaf and blind children planned by the Dutch Reformed Church, only the second such school in the country. He was a trained ordinary teacher, whose brother Piet was deaf. De Labat took training in the Netherlands, opened the Worcester school in 1881, and ran the deaf side for 45 years. In 1927, he handed it over to his son, the Reformed minister Gabriel De la Bat (*sic*) (1896–1953), who had studied new approaches to deaf education in the United States. De Labat built up the Worcester school from one pupil to 150 enrolled at his retirement, with a few coming from hundreds of miles away in neighboring countries. His methods and curriculum might now seem limited, but an inspector in 1881 reported that De Labat's pupils "mastered the art of reading more quickly than did normal children" (Biesenbach 1972), evidence strongly contradicting the prevalent idea that deaf children could not learn.

—Kumur B. Selim

See also Deaf, History of the.

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DE L'ÉPÉE, ABBÉ CHARLES-MICHEL (1712–1789)

French priest and educator

Abbé (a member of the French secular clergy) Charles-Michel de l'Épée was a Jansenist priest and the founder of the first establishment for the training of young deaf-mutes.

De l'Épée was born in Versailles in 1712. In 1760, he met deaf twin sisters who had received some initial Christian instruction from a teacher named Simon Vanin. When Vanin died, de l'Épée offered to receive the girls at his residence to continue their education and "save their souls." The sisters did not speak, so de l'Épée communicated with them by means of gestures. He had the idea of elaborating a communication system based on gestural signs, to teach them the truths of the Christian faith and the grammar of the French language. But instead of employing only the signs of deaf-mutes, he added others of his own devising, based on Latin and his own imagination. He called these "methodological signs," and they were designed to translate, feature for feature, the elements of French syntax.

Most of de l'Épée's pupils were lodged in nearby boarding houses, and he paid for their room and board from his own finances. The deaf youngsters received catechism and French language lessons on Tuesdays and Fridays at his residence on Rue des Moulins, a building that has since disappeared.

De l'Épée's work was well received by the scholars, men of science, and philanthropists of his time, but the authorities did not act on the state decrees of 1775 and 1786 that his school be housed in an unused convent, Les Célestins. He died in Paris on Christmas Eve 1789, and the following year the Paris Commune installed the bereft pupils in Les Célestins. The director of the institution was Abbé Sicard, an ideologue whom Abbé de l'Épée had trained but would not have wished to see as his successor.

—Jean-René Presneau

See also Deaf, History of the; Pierre Desloges; Sign Language.

DEAF, HISTORY OF THE

The history of deaf people has been written as a history of hearing perceptions of deaf people, as a history of the education of deaf people and as the history of the lives and communities of deaf people themselves. This history embodies some of the major strands of disability studies scholarship: the reactions of outsiders to those with a physical difference, shifting understandings of normalcy, and the existence of a community of people who create lives based on a different sensory universe than that of those around them.

EARLY DEAF COMMUNITIES

Unique among individuals with a sensory difference in that they are also a linguistic minority, deaf people have long formed communities whenever they come together in a specific geographic location. Most scholars attribute the development of Deaf communities to the establishment of schools for the deaf and the desire of its alumni to associate with one another afterward. But there is also evidence that whenever a significant number of deaf people exist in one geographic location, they will form social relationships with one another and with hearing people who use sign language. The island of Martha's Vineyard, off the Massachusetts coast, was an example of such a community. From the seventeenth to the mid-twentieth centuries, a significant population of deaf people coexisted alongside their hearing counterparts in certain towns on the island. In these towns, nearly everyone was able to use some form of sign language and deafness was an accepted, unremarkable fact of daily life.

Communities such as that found on Martha's Vineyard are likely rare. There were few, if any, politically organized European communities of deaf people in the Early Modern era. There were, however, early small-scale attempts by European religious orders to educate the deaf children of rich noble families. Benedictine monk Pedro Ponce de Leon is the most prominent of these early teachers, and in the 1540s taught the deaf brothers Don Francisco and Don Pedro de Velasco, as well as 10 to 12 other deaf people, at his monastery. De Leon's work would be replicated in other small-scale schools throughout Europe, but state sponsorship of Deaf education would begin only in the eighteenth century.

THE EIGHTEENTH CENTURY

The Enlightenment brought about a new faith in reason and a new curiosity on the part of scholars on the ability of deaf people to achieve rational and abstract thought. In this period, the education of deaf people attracted prominent attention, and historians have generally pointed to Paris as the crucible of Deaf education in the modern era. In Paris, the Abbé Charles-Michel de l'Épée founded what would eventually become the first state-supported school for deaf children, today known as the Institut National des Jeunes Sourds (INJS). Beginning with a class for two deaf sisters, de l'Épée's school served as a model and source of inspiration for the establishment of other European schools. These schools generally followed the INJS's use of a signed language to teach deaf children in their national spoken and written language. A school established in Leipzig, Germany, in 1778 by Samuel Heinicke exemplified the "oral method," a method emphasizing training in speechreading and articulation as a means for deaf people to learn their national language.

The Methods Debate

The respective methods used by de l'Épée and Heinicke became touchstones in a centuries-long "methods debate" in the field of Deaf education. On one side are those who supported the use of sign language to teach deaf children in both subject matter and their national written language. On the other side are those who saw the use of sign language as hindering deaf people's ability to learn to speechread and orally speak the national spoken language. (This claim has been disproved. Linguists today recognize the use of sign language actually enhances second-language acquisition in both deaf and hearing children.) Generally speaking, both sides supported teaching deaf people to speak; the difference lay in how much sign language would be used and how much emphasis would be given to speech training. The users of "sign method" or "manual method" decried what they felt was an overemphasis on speech training to the exclusion of academic content. De l'Épée and Heinicke entered a debate in the 1780s over the merits of their respective methods, a debate judged by the rector and fellows of the Academy of Zurich to have been won by de l'Épée. This was hardly the end of the matter, and the "methods debate" has figured prominently in nearly every history of deaf people written to date.

As with any ideological debate, the true positions taken by historical actors have varied considerably across time. Those who supported the use of sign language also sought to minimize its use, and those who supported oral teaching also used some sign language. The popularity of one or another method at different points in history has not been solely contingent on internal factors in the field of Deaf education or the wishes of deaf people themselves (which have generally been supportive of sign language), but also on the surrounding social and cultural context in which deaf people lived.

THE NINETEENTH CENTURY

Deaf education in the first part of the 1800s was largely inspired by an impulse to save deaf people's souls, to ensure they received sufficient religious training to understand the word of God. In the United States, this period is generally known as the heyday of manualism. In 1817, a deaf teacher from the INJS, Laurent Clerc, together with an American evangelist, Thomas Hopkins Gallaudet, established what is today known as the American School for the Deaf, the first school for deaf people in the Western Hemisphere, in Hartford, Connecticut. Aside from a short stint as principal of the Pennsylvania Institution for the Deaf in Philadelphia, Clerc would go on to teach at the school for the next 41 years. Clerc's influence cannot be understated: Through his interactions with his deaf students, his French Sign Language (LSF) influenced the makeup of contemporary American Sign Language (ASL). Through the apprenticeship and training of teachers at the American School, Clerc shaped an entire generation of American teachers of deaf people. A well-educated user of early ASL and written English (as well as French and LSF), a pious Christian and an upstanding citizen, Clerc was an exemplar of what Deaf education could achieve in this period.

The late nineteenth century saw a shift in public discourse on deaf people, which emphasized the need for training deaf people to become good national citizens. While there is some discussion among historians on just how much ASL was suppressed in the United States during the Progressive Era, it is generally agreed that the oralist method had the momentum in this period. The number of deaf teachers in schools declined and the oralist method was predominantly the method of choice in classroom at schools for deaf people. The reasons for its rise are complex, but can be traced back to a shift to assimilation into national spoken-language communities as the primary motivation behind educating deaf people. The influx of immigrants led to nativist fears in American society, and oralists saw speech training as the best way to assimilate deaf people into modern American society. The social Darwinism of the late nineteenth century supported an oralist discourse that portrayed sign language and its users as relics of a primitive era, now superseded by the "modern" use of spoken language and "modern" pedagogical techniques in speech training.

The portrayal of deaf people as evolutionary throwbacks resonated in an era that saw the creation of ideas of "normalcy" and "degeneracy." Deaf people were no longer seen as children of the Enlightenment, but rather as imperfections in the public body. In 1883, Alexander Graham Bell, inventor of the telephone and a prominent supporter of the oral method, posed the threat of a "deaf-mute variety of the human race" and urged measures preventing the "intermarriage" of deaf people. Bell's ideas about educating deaf children with their hearing peers were gradually enacted, but the marriages of deaf people in the United States was never forbidden by legislative statute. In fact, deaf people have consistently married one other in high rates, feeling most at home with one another.

Organized Deaf Communities

From early beginnings in urban centers or schools for deaf people, Deaf communities in the United States and Europe established formal associations at the local, state or provincial, and national levels in the nineteenth century. A number of Deaf community periodicals were established in this period and widely reprinted from their counterparts in other states and nations, thus further expanding community networks beyond local connections. In the United States, these periodicals were either independently run or part of the "Little Paper Family" of papers printed by schools for the deaf. European and Australian periodicals were commonly published by missionaries and religious workers. Through periodicals, associations, and organizations, deaf people sought both to maintain a community of their own and foster their full participation in public life. The United States National Association of the Deaf (NAD), the first organization of deaf or disabled people in the Western Hemisphere, was founded in 1880, and still exists today. Similar associations of and for deaf people were established across the world in the nineteenth and early twentieth centuries. These associations have largely been concerned with ensuring the place of sign language in the education of deaf people and securing the rights of deaf people to participate in all aspects of daily life.

THE TWENTIETH CENTURY

The twentieth century saw the twin factors of the ongoing suppression of sign language in the schools and the increasing importance of clubs and associations of deaf people as sites of cultural and linguistic interaction. International organizations were also established, the Comité International des Sports des Sourds and the World Games of the Deaf (today known as Deaflympics) being founded in 1924 and the World Federation of the Deaf in 1951. Deaf people in the early twentieth century were largely concerned with maintaining a foothold in the new industrial age; access to blue-collar employment opportunities was a dominant concern, and the NAD led several campaigns to ensure employers and the general public saw deaf people as good workers and contributing citizens and taxpayers. Deaf Europeans did the same in their own countries. Books such as Albert Ballin's 1930 *The Deaf-Mute Howls* and the 1932 German film *Misjudged People* tried to counter popular impressions of deaf people as inferior. In their own media, deaf people represented themselves to hearing society as healthy, vigorous, and thoroughly modern individuals.

World War II

World War II proved to be a boon to deaf Americans; as hearing men went to the front, employers hired deaf people to take their place. The rubber factories of Akron, Ohio, employed large numbers of deaf workers and became a Deaf Mecca of sorts during the war years. In Nazi-occupied Europe, however, deaf people became targets of Nazi persecution. During the 1930s, 17,000 deaf people were sterilized. Under Nazi rule, a number of deaf Germans were sterilized, underwent forced abortions, or were killed. Deaf Jews were also sent to concentration camps; only 34 of Berlin's prewar population of 600 deaf Jews survived the war. Altogether, an estimated 1,600 deaf people died at the hand of the Nazis.

The Twentieth-Century Deaf Renaissance

The rediscovery of sign language by Dr. William Stokoe in the 1960s, together with his deaf research assistants Dorothy Casterline and Carl Croneberg, led to a renaissance within the Deaf community. This research in sign language, together with a social climate generally more amenable to difference—be it in hair length, skin color, or language use—brought about a corresponding change in how hearing people saw deaf people and deaf people saw themselves. After years of oralist strength, deaf people were able to advocate for the increased use of sign language in Deaf education. Deaf American Roy Holcomb was a leader in the 1970s total communication movement, which advocated the use of all possible means to educate deaf children, which often panned out in practice to mean speaking and signing simultaneously. ASL was increasingly accepted for foreign language credit in colleges and universities across the country in the 1980s and 1990s. A growing body of research on sign language led deaf leaders, also inspired by research into bilingual education models with other linguistic minorities, to establish a bilingual-bicultural approach to Deaf education, which stressed the use of ASL as the native language of deaf children and the parallel acquisition of English, which would follow from this native language base.

A prominent example of the global Deaf awareness movement of the late twentieth century is the 1988 "Deaf President Now!" protest over the appointment of a hearing person, Elizabeth Zisner, to head Gallaudet University, the world's only liberal arts university for deaf people. After a week of protest by American deaf people and generally positive coverage of their demands for a "Deaf president now" in the national media, I. King Jordan was appointed the first deaf president of the college on March 13, 1988. The "Gallaudet Revolution" was only the most prominent of a number of largely localized political activities by deaf people around the world aimed at putting deaf people in positions of control over their own lives and restoring the use of signed languages in Deaf education.

Deaf communities have prospered across the world for several centuries and are now politically organized in a myriad of organizations on all levels: local, national, and international. Deaf people have long participated both in their own cultural community and that of the larger cultural community they live in. In the twenty-first century, the increasingly widespread use of cochlear implants, an auditory enhancement device, has brought about a resurgence of the oralist philosophy and the medical/education nexus. As well, research into the genetic causes of deafness presents deaf people with, quite literally, an existential dilemma. Hearing perceptions of deafness could very well lead to the elimination of certain genetic forms of deafness and a sharp reduction in the size of Deaf communities worldwide. The history of deaf people to date, however, has been one of survival and indeed, prosperity, in the face of a larger society that knows little of their lives and their languages.

—Joseph J. Murray

See also Abbé Charles-Michel de l'Épée; Alexander Graham Bell; Deafness, on Martha's Vineyard; Edward Miner Gallaudet; Thomas Hopkins Gallaudet; Oralism.

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▣ DEAF CULTURE

CULTURE DEFINED

Culture is quite possibly one of the most difficult notions to grasp at any time in recorded history. As Raymond Williams has said, *culture* is

> one of the two or three most complicated words in the English language. This is so partly because of its intricate historical development in several European languages, but mainly because it has come to be used for important concepts in several distinct intellectual disciplines, and in several distinct and incompatible systems of thought. (as quoted in Ladd 2003:197)

There have been a plethora of attempts to define this concept, with virtually no two reading the same. It is not the goal in this entry to attempt a redefinition of the complex notion of culture. Instead, this entry builds on the prevalent perspectives that define *culture* as a group of people's "way of life," which involves "cultural practices" that function to signify, or rather to "[produce] meaning," including practices in the United States such as pop music, soap opera, and comics (Storey 1998:2). Or in other words. "a set of control mechanisms—plans, recipes, rules, instructions . . . for the governing of behavior" (Geertz 1973:44). Therefore, "by definition, cultures are highly specific systems that both explain things and constrain how things can be known" (Padden and Humphries 1988:24).

DEAF CULTURE

However Deaf culture is approached, it is presented as having to do with this particular group of people and their way of life, their behaviors, their means of interacting, their belief systems, and their systems of knowing and knowledge.

Visual Way of Being: Linguistic

In the United States, and the world in general, the majority culture (hearing) focuses on deaf as an issue of hearing loss, emphasizing the idea that deaf people are people who are lacking something. However, for those members of Deaf culture, hearing is not put to forefront, nor is its supposed loss a concern or factor of identity. Deaf people have a value system that reveals a different foundation—not a value of that which is heard, but instead a value of that which is seen. Edward Hall (1982) points out that "people of different cultures not only speak different languages but, what is possibly more important, inhabit different sensory worlds" (p. 2). As George Veditz (1912), a deaf leader in the early twentieth century, exhorted, deaf people are "first, last, and all the time, the people of the eye" (p. 30). The visual way of being for deaf people is inherent and present in all aspects of their lives. And the foundation of this existence is in their visual communication system. As Bahan (2004) asserts, "Deaf people, being of a human variety, have refused to be reduced to the status of things and found ways to communicate visually and developed visual languages. That is the essence of their being. All other things are constructed around this, channeled through and by vision" (p. 3).

The existence of the use of a visual gestural communication system by deaf people has been documented as far back as ancient Greece. In *Cratylus,* Socrates poses a question to Hermogenes, "Suppose that we had no voice or tongue, and wanted to communicate with one another. Should we not, like the deaf and dumb, make signs with the hands and head and the rest of the body?" (Plato 1961:457).

It has been observed that a deaf child born anywhere in the world will, as she grows up, whether surrounded by visual linguistic input or isolated from regular communication among those who hear and speak, develop home signs as means of expressing herself. This development has been shown to emulate the natural language acquisition process. It is within the being of deaf people to do so given that society does not intervene (see Lane, Hoffmeister, and Bahan 1996; Goldin-Meadow 1985, 2003). As Deaf schools were established, different deaf people were brought together and with them different home signs, allowing for the emergence and eventual development into a complete linguistic system. Various signed languages of the world, such as French Sign Language and Nicaraguan Sign Language, were born from such situations (see various essays in Lane 1984; Social, Behavioral and Economic Sciences 2004). In using sign languages, it is not just that the language is produced using the hands and understood through the eyes that suggests a strong visual center of deaf people. As Bahan (2004) explains, "Signers manifest many different kinesthetic features which are depicted visually: the body, head, hands, arms, facial expressions, and the physical space surrounding the signer and his/her eyes" (p. 4). They also develop over time various adaptations for vision and visuality, among them we see increase in saccadic (rapid eye movement) and head movement, enhanced peripheral vision, multilayered use of eye gazes to transmit and receive communicative and linguistic function (for more information, see Bahan 2004).

In the United States and Canada, American Sign Language (ASL) is another example of a signed language rooted in visual gestural communication that, as mentioned briefly above, was allowed to develop when deaf people were brought together in the first deaf schools in the United States shortly after the beginning of the nineteenth century. ASL today is a language that "has a grammar, with rules of word and sentence formation" (Lane et al. 1996:43) and is "a symbol of social identity, a medium of social interaction, and a store of cultural knowledge" for the Deaf-World (Lane et al. 1996:67).

Visual Way of Being: A Way of Life

Not only is the visual essence of a deaf person seen in the existence of signed languages, but research has shown that, "among signing deaf people, the role vision and the use of eyes expands exponentially" (Bahan 2004). Therefore, the recently discussed visual way of being "is carried over into the cultural lives, values, consciousness, social spaces, and literatures of signers" (Bahan 2004). This is due to the fact that, as language flourishes in complexity, rules of engagements are naturally formed. In other words, standards for how the language is used and the sociocultural constraints for language use are developed as the language becomes more and more intricate.

From these engagement culture rules, values and behavior systems come into being over time. Thus, within American Deaf culture as an example, many of the values expressed are directly related to the idea of Deaf as having a visual orientation. In the well-known text on deaf studies, *A Journey into the DEAF-WORLD,* the authors state that the values of Deaf culture "are stored in sign language, so to speak, for transmission across the generations" (Lane et al. 1996:70). Thus, each value relates directly to the visual language used to convey this value. The values of the American Deaf culture include the identity of being, thinking, and behaving like a deaf person when among other deaf people. Also, deaf people value their signed language and have a tendency to prefer group-decision making, reciprocity, and mutual aid as important parts of how they believe they should interact with one another. As part of the value of cultural reciprocity, one can find deaf people exchanging various adaptive strategies for being a visual person in an auditory dominant world through narratives of personal experience. Examples of such adaptive strategies include how to be aware of the ways sound bounce off visual cues, and so on (Bahan forthcoming, 2004). Deaf culture also values informality and physical/tactile contact, along with the promotion of unity among members of this community.

Visual Way of Being: Expressions and Locations of Deaf Culture

The previous section reflects on the notion that culture itself can often be thought of as adaptation systems where people "relate their community to their ecological setting" (Keesing 1974:74 as quoted in Ladd 2003:201), doing so in order to survive (Meggers 1971:4 as quoted in Ladd 2003:202). This leads us to examining various environments, places, and sites where these visual cultural ways are expressed.

There are numerous organizations run by and for deaf people, at local, state, regional, national, and international levels. These organizations, including athletic, social, religious, educational, and political associations and institutions, serve a variety of purposes and roles in the lives of deaf people. Some examples in the United States include local Deaf clubs, Deaf residential schools, state associations of the Deaf, the USA Deaf Sports Federation (USADSF), National Congress of Jewish Deaf, the National Association of the Deaf (NAD), and the World Federation of the Deaf (WFD) (for more information, see Lane et al. 1996:131–138).

Deaf people who grow up in residential schools often see the place as their home and consider their classmates, peers, and the deaf mentors as an extended "family." So Deaf schools are more than just an educational site. It is often the first place deaf persons come to be a part of this visual world and a place where they began to learn sign language. A sense of sacredness is often adhered to these places. Many deaf people return annually for homecoming, football games, and special events. Many deaf people, upon graduation, will stay in the area near their school, get jobs at their school, or, if they do move away for college or a job, may later return to the area where they grew up, maintaining close ties to the school (Lane et al. 1996:70–71).

As in all cultures, the Deaf-World also includes and values artistic means of expression. At these community sites, one will find a rich history of ASL literature. ASL literature includes a variety of genres, including stories, poetry, folk tales, legends, anecdotes, and allegories, to name a few. Within the Deaf-World, there are story-tellers, poets, and comedians who are known for their abilities and called on to give performances in a variety of venues. Many of the deaf artists travel around the country and around the world entertaining and inspiring deaf and hearing audiences, while passing on Deaf culture, language, and history through their stories and poems (Bahan forthcoming).

Yet another site where the visual culture of deaf people, along with their history and language, are conveyed is through deaf theater. "The earliest plays by deaf actors on Deaf-World themes in the U.S. probably originated in the mid-nineteenth century in the residential schools, where plays develop around Deaf school life, Deaf history, and Deaf family situations" (Lane et al. 1996:145). In the 1940s, Gallaudet University started providing formal drama classes, and deaf actors founded the National Theatre of the Deaf (NTD) in 1967. After almost 40 years in existence, NTD can boast more than "fifty touring seasons and twenty-eight foreign tours, and more than 6,000 performances of some fifty productions and numerous awards for its work" (Lane et al. 1996:145–147; Peters 2000). One of its most well-known pieces has had a huge impact on the perception of ASL and Deaf culture. This play was titled *My Third Eye*, and it included five parts about ASL and deaf people. Both NTD and other regional deaf theaters have had a large impact on deaf people not only in the United States but also around the world (Lane et al. 1996:147–148; Peters 2000).

Finally, an important means of expressing Deaf visual culture is found in deaf art, which conveys various deaf themes, such as pride and beauty of deaf identity, expression of frustration or anger related to a lifetime of oppression, and visual images that represent the deaf experience in the hearing world. In 1989, during Deaf Way International Conference in Washington, D.C., nine deaf American artists came together to establish a manifesto about deaf art, naming this form of art De'VIA (Deaf View/Image Art), "meaning one which 'uses formal art elements with the intention of expressing innate cultural or physical Deaf experience.' The manifesto explains that De'VIA often includes focus on the hands and face" (Lane et al. 1996:140). Deaf art can be seen in many places, with a large collection housed at Gallaudet University and displayed in various locations across campus (for more information, see Sonnenstrahl 2002; www.deafart.org). Deaf art allows deaf artists to express who they are, while visually representing their language, culture, and experiences. In so doing, other deaf people find something to which they can relate, be inspired by, and an art form that reflects their lives.

These examples give a general view of the ways that Deaf culture as a visual culture are expressed. They very much exemplify what Padden and Humphries (1988) described as a Deaf center, referring to a Deaf-centric, rather than a hearing-centric, perspective of the world, "where DEAF, not HEARING, is taken as the central point of reference" (p. 41). As one deaf community leader has pondered,

> In retrospect I can't help but wonder about the "what ifs," because it has taken society so long to acknowledge the role of vision and signed languages in the lives of Deaf people. So many generations of signers

> have been handcuffed in a society intoxicated by the ideology that speech is language and vice versa. It is amazing that with these impositions, deaf people have developed into one of the most visual groups of people on the face of the Earth. One wonders what the possibilities would be if they were allowed to proceed in life unbounded . . . how far would this human variety push the boundaries of vision? (Bahan 2004: 21)

DEAF CULTURE AND MICROCULTURE

Based on this presentation of deaf people as visual people, it might seem that Deaf culture results in a community that is a completely separate, self-contained entity. This is not really the case. In his recent work *Understanding Deaf Culture: In Search of Deafhood,* Paddy Ladd (2003:224–225) presents the idea of Deaf culture as a minority culture that is embedded in majority culture. Similarly, Graham Turner explains that deaf people and their culture are indeed a minority culture in majority speech cultural community, resulting in most members of Deaf culture being bicultural in the sense that they share the values and language of a larger culture but also have language and values of another culture within. As Turner (1994b:98) explains, deaf people, regardless of where they live, "share more or less fully in the wider culture of the nation, region, or tribe they belong to." Thus, Deaf culture cannot clearly be separated from the hearing culture of which it is a part (p. 98). These structural descriptions correspond with the definition of microculture put forward by Spradley and McCurdy (1987), who describe it as "subsystems of cultural knowledge characteristic of subgroups within larger societies. Members of a microculture will usually share much of what they know with everyone in the greater society, but will possess a special cultural knowledge that is unique to the subgroup. . . . It is this shared knowledge that makes up their microculture" (p. 13 in Turner 1994a:113).

However, this approach is also complicated by the fact that Deaf culture cannot be compared to other microcultures, such as a biker microculture or a punk microculture. The complicating factor involved in tackling the analysis of Deaf culture and microculture is the fact that another language is used that has lead to the creation of a Deaf culture. But it is also true that deaf people are not leading separate lives. They are usually bilingual and bicultural to a various degree and are very much part of the majority culture. This issue of language is the reason that Deaf cultural studies does not fall in to any one of the cultural studies categories that exist presently. Thus, a creative approach is needed in studying Deaf culture (Ladd 2003:208). Possibly the idea that "people of different cultures . . . inhabit different sensory worlds" (Hall 1982:2) coupled with this idea of Deaf culture as a microculture is just such an approach.

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and Elizabeth Parish

See also Disability Culture.

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DEAF PEOPLE AT THE OTTOMAN COURT

Deaf people worked as Ottoman Court servants at Istanbul from the fifteenth to the twentieth centuries. Their sign language became a recognized means of communication among hearing courtiers from the late sixteenth century. Courtly use of sign language may date from Mehmed II's reign (1451–1481). He cultivated an image of imperial sacredness, withdrawing from public appearances and speaking with very few people. During Suleiman I's reign (1520–1566), some deaf people certainly served him and he communicated with them by sign. From the 1570s onward, more visitors witnessed signing at court, and the deaf servants numbered between 50 and 100. In the mid-seventeenth century, the linguist Bobovius, a senior court interpreter, specified the place in Topkapi Palace where the older deaf men taught sign language to younger deaf people. The number of deaf servants had probably fallen by 1700, but in the 1880s Sultan Abdul Hamid was recruiting deaf people from Africa. A photo published in 1917 shows two deaf servants signing. The Ottoman deaf servants were in a rare historical situation where their sign language was needed by hearing people, and they taught it to Sultans, courtiers, and the younger generation. Recent linguistic research on modern Turkish Sign Language (Türk Isaret Dili) suggests that it has existed for centuries independent of other sign languages.

—Kumur B. Selim

See also Deaf People in African Histories; Sign Language.

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DEAF PEOPLE IN AFRICAN HISTORIES

Deaf people have left traces in African history and legend over several thousand years (Miles 2004). Records suggest that they often had little status in society and were sometimes targets for abuse or ridicule. Yet some also won respect and honor from hearing people. Deaf people's sign languages were noticed in antiquity, and they were studied in greater detail in the past century. The great majority of deaf people seem to have led ordinary lives like anyone else, living with their families in villages and towns, while using some different methods of communication. They worked with agricultural, domestic, or artisan skills, and more recently in the full range of modern jobs.

ARCHAEOLOGY, FOLKLORE, HISTORICAL TEXTS

Evidence of deafness exists from the twenty-fifth century BCE in North Africa, when hearing loss in old age was lamented (Erman 1927). The Ebers Papyrus shows that deafness was well understood 3,500 years ago, and clinical knowledge had developed in ancient

Egypt (Nunn 1996; Pahor 1992). Mention of "one who is deaf and does not hear, to whom men make (signs) with the hand" appears in the Koller Papyrus dated ca. 1200 BCE (Gardiner 1911). Among the earliest named and located deaf people was Munah the Deaf (in Arabic: "Munah al-Asamm"), house-owner and head of family at Tutun in the Fayyum province of Egypt. Two sale contracts dated 962 and 963 CE mention the house belonging to "the heirs of Munah the Deaf," which delineated one border of properties that were being sold (Frantz-Murphy 1981).

The African theologian Augustine, writing at Tagaste (now in Algeria) in the late fourth century CE, gave perhaps the earliest clear and positive description of deaf people using sign language in Africa, "to ask and answer questions, to teach and make known either all their wishes or, at least, a good many of them" (Augustine [ca. 389]). Sixteen hundred years would pass before governments in Africa began to take sign language as a serious medium for education and communication.

HOW MUCH FOR THAT DEAF GIRL?

Folk legends from the southern Bantu people mention the woman Luojoyo communicating by sign with her one hand. The "deaf-mute" Muwende-Lutanana and others also used signs (Mutwa 1998). Signed communication was a recognized activity in these stories handed down over centuries. Folklore and also current African literature sometimes portray deaf people as "dumb," meaning stupid and useless (Odebiyi and Togonu-Bickersteth 1987; Sarr 1981; Naniwe 1994; Oteng 1988). Yet some Malian folk tales involving a deaf wife suggest the need for patience and understanding rather than denouncing stupidity (Calame-Griaule 1987). Deaf Africans were also found useful as servants. At Kuka, capital of Bornu, west of Lake Chad, deaf slave girls fetched high prices to serve the wives of businessmen in some Arab countries (Nachtigal 1971–1987). Some deaf people were presented as valuable gifts to the Ottoman Sultan, who was traditionally served by deaf people (Gaden 1907).

The balance of abuse and exploitation, as against everyday acceptance and integration, is hard to estimate. Abusive treatment of deaf people certainly happened and was sometimes recorded, while any amount of "ordinary life" passed unnoticed, as it does today. For example, in 1848, Charles Orpen, minister at Colesberg, South Africa, saw that the chief constable had an excellent African servant, "sober, honest, and faithful." The servant also happened to be deaf, and this was noticed by Orpen, who had earlier founded a deaf school in Ireland (Le Fanu 1860). Many other deaf servants probably remained "invisible."

READING THE SIGNS

In rural South Africa 200 years ago, the traveler Henry Lichtenstein was delighted to understand "home sign" by Mr. Gildenhuis, a good-humored deaf craftsman who flourished in the 1790s and 1800s. Gildenhuis was "uncommonly clever in handicraft employments, and was exceedingly useful to the inhabitants of the country, in making gun-locks, tools for all kinds of work, and in general in all the finer kinds of smith's work," as well as artistic carvings and engravings (Lichtenstein 1812). Lichtenstein described some of Gildenhuis's wittily executed gestures, which are easily recognizable. More formal documentation efforts were begun by James Sibree in the 1880s, with brief descriptive notes on sign, gesture, and symbolic acts used in Madagascar (Sibree 1884).

The missionary educator David Forbes, reporting work at Rumasha, Nigeria, in 1917, noted that "the deaf and dumb are not forgotten, and two boys are receiving instruction in the signs of the deaf and dumb language. Every morning a short lesson is given to all the boys to enable them to communicate with the two mute lads." This suggests that a recognized sign language existed and was taught to deaf and hearing alike, 40 years before education for deaf children would officially begin in Nigeria. It is one of the earliest descriptions of deaf children being integrated in a thoughtful way in an ordinary school in Africa.

The first substantial historical group of African deaf people with a documented sign language lived at Adamorobe in Ghana, probably from around 1800. Formal research on signing at Adamorobe began in the early 1970s, and the inheritance of deafness over several generations was also traced (David 1972). Systematic linguistic study is in progress, comparing

Adamorobe Sign with other African Sign Languages. Hausa Sign Language and South African Sign Languages already have scholarly documentation (Schmaling 2000; Penn and Reagan 1999). More than twenty African Sign Languages have had some formal study, and the field is growing steadily in complexity.

Some observations in Ghana, Mali, Niger, and Nigeria suggest a high level of social integration of deaf people. In Kano State, "Many hearing people, old and young alike, are able to converse with the deaf freely and effectively through signs or sign language, at least on a basic level" (Schmaling 2000). However, earlier experiences of the deaf writer Florence Serwaa Oteng give a less positive picture, from southern Ghana (Oteng 1988, 1997). The lengthy battles of this intelligent Ghanaian woman, deafened in early adulthood, appear in her largely autobiographical novelette set amid the petty politics of a boarding school for deaf children.

DEAF PEOPLE OF DISTINCTION IN AFRICA

Gallaudet University's "Deaf Biographies Index" lists Nelson Mandela and Desmond Tutu, whose hearing impairments arose after they became public figures, and also Francisco Macias Nguema (1924–1979), who became deaf during his unhappy dictatorship of Equatorial Guinea 1968–1979. By contrast, Godfrey Huggins (Lord Malvern), who became ruler of Rhodesia and Nyasaland (now Zambia, Zimbabwe, and Malawi), had seriously impaired hearing from childhood (Gann and Gelfand 1964).

Many years of scientific work in North Africa earned Charles Nicolle the 1928 Nobel Prize for medicine, the first awarded to a deaf person. Nicolle lost his hearing as a medical student. He became director of the Institut Pasteur at Tunis in 1903, and died there in 1936 (Lang and Meath-Lang 1995). Another Nobel Prize winner, the Algerian writer Albert Camus (1994), was raised by a deaf uncle and a partly deaf mother. His unfinished autobiographical novel includes a chapter on the uncle, Etienne Sintès, who worked locally as a cooper. It is a vivid portrait from the 1920s of a lively, sporting, deaf man in Algiers, popular among his hearing friends, an expert hunter with gun and dog, and a surrogate father to the young Camus.

The Senegalese writer Moussa Ly Sangaré (also known as Dono Ly Sangaré) reports a more personal experience with deafness, starting ca. 1953 when he was a schoolboy. He began asking people to repeat what they said, a habit noticed both at home and at school. His kindly teacher, M. Diabâté, asked young Moussa if he had difficulty hearing, which the boy denied, unaware that the problem might lie in his own capacity. One day, however, during a dictation exercise, silence fell upon him. Moussa saw that his teacher was still speaking and the other boys still writing, but for him there was only a distant jumble of sound. Between one phrase and the next, his hearing had gone (Sangaré 1978).

Deaf people with nationally recognized artistic skills in Africa include an Ethiopian, Afework Mengesha; an Egyptian woman, Hanan Marzouk; a South African, Tommy Motswai; and doubtless many more. An earlier generation produced the prize-winning Algerian/French monumental sculptor Joseph Ebstein, born at Batna in 1881. Ben Hurwitz, a champion chess player in South Africa, was deaf and then became blind (Blaxall 1965).

For many deaf people in Africa, the outstanding role model of the twentieth century was a charismatic deaf African American, the Reverend Dr. Andrew Foster. He studied at Gallaudet University and went to West Africa in 1957 on a mission to reach deaf people. Before his untimely death in 1987, Foster had trained and inspired a generation of deaf African leaders who carried forward the work of educating and equipping deaf people across the continent for independent living on equal terms with the hearing world (Okyere and Addo 1999).

DEAF PEOPLE IN ORDINARY LIFE

Fr. Lechaptois, missionary in Nyasaland in 1890, pictured a deaf man's hands at work: "There was another craftsman close by, a deaf mute, who was making a magnificent fishing net. . . . The mesh was beautifully even and neatly tied . . . it looked deceptively simple" (Mponda Mission diary 1889–1891). Simple goodness characterized the young deaf workman in a novel by Kenyan author James Ngugi (1971). He was strong, good looking, popular with other young men, caring for his old mother, using his hands to communicate.

Apparently, this figure was based on Ngugi's own deaf stepbrother Gitogo, who was shot by troops during a disturbance in the 1950s.

Between spells of work, many deaf people could find themselves in difficulties such as befell Moses, Simon, Piet, and others, lost between cities, illiterate, without papers, arrested by the police, unable to give an account of themselves. For some of these in South Africa in the 1930s, the Reverend Arthur Blaxall would be called in to mediate:

> In due course I find myself confronted by a grimy man in dishevelled clothes. I lift an eye-brow and smile, at the same time touching my ears with an enquiring look—a faint glimmer springs into his eyes as I go on with natural signs of sleeping, growing up, and a wide gesture of both hands with an open expression of surprise. Where do you come from? Where did you grow up?—he surely recognises the signs. (Blaxall 1965)

The impulse to protect and teach was not exclusive to missionaries. Mrs. Oyesola, a Nigerian leader of Girls Brigade activities in the early 1960s, was faced with her own Brigade girls' scorn and rejection of a poor, homeless, deaf girl, Seliatu. Mrs. Oyesola adopted Seliatu and set about finding some ways to teach her. Eventually, she got training at Gallaudet to become a teacher of the deaf, and she opened the Ibadan Deaf School in 1963, starting with Seliatu and three deaf boys (Ojile 1999).

Many deaf children learned to fend for themselves. Karen Blixen observed a deaf nine-year-old living on her farm in Kenya in the 1920s. Karomenya was tough, a skilled stone-thrower and an eager fighter with other children. Blixen gave him a chance to learn domestic work and make himself useful, but the boy did not care for such tasks. The Danish lady left him free, though she saw that he would have a hard time later in life (Blixen 1954).

VOICE AND VALUE

Acquiring a voice and presence in public affairs has been a long, slow process for deaf people in Africa. Probably the earliest public meeting about deaf people was at Bloemfontein in 1928, organized by Blaxall, concerning education. Hearing professionals "represented" deaf people. The next known conference, organized in 1965 by Andrew Foster at the University of Ibadan, Nigeria, had deaf people speaking for themselves. Yet it would be another 25 years before most countries would have deaf organizations that could make an impact at a national policy-making level. The World Federation of the Deaf (WFD) included "legislation" in a survey of national situations of its members, and it received replies from Benin, Burkina Faso, Egypt, Gambia, Ivory Coast, Kenya, South Africa, Swaziland, Togo, Zaire, and Zimbabwe. Responses suggest a very slow movement toward recognition of the value of deaf persons, whether in legal systems or the societies that run them (Michailakis 1997).

—Kumur B. Selim

See also B. J. G. De Labat; Deaf People at the Ottoman Court; Experience of Disability: Sub-Saharan Africa; Hearing Impairment.

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DEAFBLINDNESS

The term *deafblindness* describes a disability in which an individual has both a hearing impairment and a visual impairment. Deaf-blind individuals form a highly heterogeneous group that tends to have varying degrees of hearing and visual impairments. Deaf-blind individuals tend to prefer being referred to as “Deafblind,” “Deaf-Blind,” “Deaf-blind,” “deaf-blind,” or “deafblind.” As with other disability classifications, deafblindness can be viewed from two opposing perspectives: the medical model and the cultural or social model. The terms *deafblindness* or *deaf-blindness* tend to emphasize the medical condition of the disability, whereas the terms *Deafblindness*, *Deaf-Blindness*, or *Deaf-blindness* tend to focus on the cultural membership of the individuals with the disability. The labels *deaf/blind* and *individuals with a dual sensory impairment* should be avoided because they are ambiguous. The term *deaf/blind* is ambiguous because it seems to refer to deafness or blindness instead of the combination of both impairments. The term *dual sensory impairment* leaves open to interpretation which two senses are actually impaired.

An individual is diagnosed with a hearing impairment if the individual has a hearing loss greater than 30 db in the better ear. There are different types of hearing loss. A conductive hearing loss consists of damage to or obstruction of the outer or middle ear. A sensorineural hearing loss is caused by damage to the inner ear or the auditory nerve. A mixed hearing loss is diagnosed when an individual has both a conductive and a sensorineural hearing loss. Cortical deafness is caused by damage to the auditory cortex of the brain. A hearing loss of any kind can range from mild to profound. A conductive hearing loss can often be aided with hearing aids and/or surgery. A conductive and a cortical hearing loss often cannot be improved by hearing aids or surgery because of the nerve damage, which causes distortions of sound.

A visual impairment is commonly defined as poorer than 20/70 visual acuity after correction or a restricted visual range of 45 degrees or less in the better eye. A visual impairment can be caused by damage to the eye itself, damage to the visual nerve, or damage to the visual cortex.

The causes of deafblindness vary greatly among the population of deaf-blind individuals. The potential causes of deafblindness include genetic syndromes (e.g., Usher’s syndrome, CHARGE Association, Goldenhar syndrome), illnesses or diseases of the mother or child (e.g., rubella, meningitis, cytomegalovirus, and tumors), or accidents (e.g., head injury). A combination of any of the above causes is also possible (e.g., an individual is born deaf due to a genetic syndrome and later loses her vision due to an accident or illness). The most common genetic syndrome causing deafblindness is Usher's syndrome and the most common disease to cause deafblindness is rubella. Depending on the underlying cause of deafblindness, the type of hearing and vision loss is also likely to vary. For example, individuals who experience a vision and a hearing loss secondary to Goldenhar syndrome are most likely to have a conductive hearing loss and damage to the eyes due to differences of the structure of the skull, whereas individuals who had meningitis tend to have a sensorineural hearing loss and a vision loss due to damage to the visual nerve.

Deafblindness must definitely also be viewed from a cultural perspective. Similarly to the medical background of deaf-blind individuals, deaf-blind individuals' cultural identity varies greatly. Depending on the age at which individuals became deaf and blind, they are more likely to associate and feel close to others most similar to themselves. This similarity is often based on the preferred method of communication used within the different groups. Individuals involved in the blind community and the mainstream community are likely to use spoken language as their main means of communication, whereas individuals involved with the Deaf community are likely to communicate by using a signed language. The Deaf-blind community is the community with the most diverse communication methods. Some may use a signed language, while others may use a spoken language; others may use writing, Braille, Tadoma (i.e., tactile speechreading), while still others may use a combination of all of these.

For a number of decades, research on the Deaf community has yielded a wealth of knowledge about Deaf culture as a minority culture. Deaf individuals tend to view themselves as members of a linguistic minority within American society and often do not view themselves as disabled. Members of the Deaf community tend to have a number of characteristics in common: They share a physical attribute (i.e., their deafness) and tend to identify as members of the Deaf community. Most Deaf individuals are very proud of their language (e.g., American Sign Language), which is commonly used in poetry and art. Deaf individuals also display a number of culturally characteristic behaviors. The most pronounced are possibly the attention-getting behaviors, which include stomping feet, waving arms across a large room, tapping on the shoulder, or even flashing lights. Deaf individuals tend to marry other Deaf individuals. Similarly to members of other minority groups, Deaf individuals often experience oppression by mainstream society.

Individuals who were born blind or became blind early and later became deaf are more likely to use spoken language as their main means of communication. Due to their hearing loss, they might later add some signs, fingerspelling, Tadoma, or other forms of manual communication (e.g., printing on the palm) to aid in communication. These individuals tend to identify with and therefore associate primarily with the blind community, individuals from the mainstream culture, or the disabled community. Due to their deafness they are later also likely to associate with the Deaf-blind community where they are more likely to have more equal access to communication.

Individuals who are born or become deaf early and later become blind are likely to use a signed language as their main communication method and therefore associate with other members of the Deaf community and be mostly involved in Deaf culture. Because of their ties to the Deaf community, they are likely to remain involved with Deaf culture, but later also be involved with the Deaf-blind community. At least one scholar has argued that a substantial number of deaf individuals who become blind feel ostracized by the Deaf community and thus withdraw and associate more with the Deaf-blind community.

The individuals who are born deaf-blind are likely to associate either with the Deaf community, the blind community, the Deaf-blind community, the disability community, and/or mainstream society. It will most likely depend on the severity of their hearing and vision loss, on the community in which they grew up, on the type of schools they attended, and on which language they prefer to use. For example, individuals who consider their deafness to be the most important aspect of their identity and who use a signed language are likely to associate with the Deaf community, whereas individuals who have significant amounts of residual hearing and vision and primarily rely on spoken language will associate mostly with mainstream society.

The individuals who spent most of their lives as sighted and hearing individuals and then all of a sudden became Deaf-blind are most likely to feel the most disoriented regarding culture and community membership. They are most likely to have spent most of their lives in mainstream society and to have used spoken language to communicate. As Deaf-blind individuals, they are likely to need to learn alternate methods of communication and depending on which of the plethora of options they choose and prefer they may join any of the communities. This group is especially likely to be drawn to either the Deaf-blind community or the disability community because in both of these communities a diversity of communication options seems to be accepted allowing these individuals full participation and access.

When considering deafblindness from a developmental perspective, it is possible to consider deafblindness from both the medical and the cultural or social perspectives. Researchers following the medical perspective, the most common point of view within the field of developmental science, tend to focus on the deficits of deaf-blind children and on the delays they experience in comparison to their typically developing peers. Within the developmental science framework, the cultural model, however, allows researchers to study the plasticity of development in general and to learn about the development of identity and cultural affiliation of minority groups.

From a developmental medical point of view, the most important aspects of deafblindness are the age of onset and the severity of the hearing and visual impairments. According to the developmental model, the two sensory impairments multiply the effects of one another and intensify the impact each one has on an individual. Having two impairments likely inhibits the compensation of one impairment through the use of the other (e.g., compensating for deafness by lipreading). Consequently, the earlier the auditory and the visual impairments occur and the more severe the level of each impairment is, the greater are the consequences on development.

Deafblindness is likely to affect cognitive, language, social, and emotional development. Individuals who are born both deaf and blind commonly experience significant delays because they are not able to observe and thus learn about the world as readily as sighted and/or hearing infants. According to Piaget, whose research focused on cognitive development, individuals need to gain experience within their environment to acquire the skills and the knowledge necessary to successfully complete the tasks for each of the four developmental stages. The sensorimotor period, the stage between birth and two years of age in which infants learn about the basic properties of objects, progresses through a series of substages, and culminates in the infant's ability to mentally represent objects. Infants acquire object permanence, the knowledge that objects continue to exist even when they are hidden. This is considered a difficult task for blind and deaf-blind infants because they only learn about the world within their reach. There are limited or no visual and/or auditory clues to provide them with information. Interesting objects within the environment encourage infants to investigate their surroundings. For blind and deaf-blind infants, this is not the case. Therefore, they spend a lot of time in the position they were put down in often resorting to self-stimulating behaviors. Similar observations can be made throughout deaf-blind children's development. With increasing age, the delays become greater and it becomes difficult for them to catch up to their peers. It is therefore beneficial for the development of deaf-blind infants that they are diagnosed and that age-appropriate stimulation is started young.

Deaf-blind children's language development is also at risk for significant delays. First, deaf-blind children, as blind children in general, are likely to be delayed in their mental representation abilities and subsequently in their language development because language requires mental representation and actually is considered a complex form of mental representation. Second, deaf-blind children with a significant hearing impairment tend to be delayed in their language development because they are likely to not have access to language. They cannot hear spoken language and they cannot see and thus imitate gestures or signs. Some deaf-blind infants, similarly to deaf infants, may develop their own rudimentary gestures for certain objects or events. However, due to the likely lack of mental representation skills, infants born deaf-blind are even less likely than deaf infants to be able to string together individual gestures to form complete thoughts or express desires. On the other hand, those young children who either became deaf-blind after already acquiring mental representation and those who have significant residual vision and/or hearing are likely to learn mental respresentational skills more easily than their peers who were born completely deaf-blind.

When discussing the medical model within the field of developmental psychology, it is important to ask whether this model provides a complete picture with all the answers. Most likely this is not the case. As research studies have shown, the environment is essential to the prediction of later outcomes in children. This is particularly the case for deaf-blind children. If deaf-blind children are provided with an accessible language and an accessible environment in which they are stimulated and encouraged to investigate their surroundings, they learn at a similar rate as their hearing and sighted peers.

In summary, deaf-blind individuals represent a highly diverse group of individuals. Deaf-blind people can acquire their impairments at different ages. They have varying degrees of hearing and vision impairments, which can affect their developmental pathways. They may communicate in a plethora of ways. They can identify as members of a variety of cultural groups. Each one of these factors can have an impact on the individual who is deaf-blind. As will all people, it is important to view and respect each deaf-blind person as an individual.

—Ingrid C. Hofmann

See also Blind, History of the; Laura Dewey Bridgman; Helen Keller.

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DEAFNESS, MILAN CONGRESS OF 1880 ON

In 1880, a congress for the Deaf was held in Milan. The delegates saw an attack on sign language and thereby on the possibilities for their emancipation. Even for some years previously, the "oral method" for the instruction of the deaf had predominated in state institutions and private schools in Europe. Yet there was still not unanimity in the matter. Some schools remained faithful to the French method inherited from Abbé de l'Épée, which consisted of gestural signs and writing. And within certain national institutions, some teachers, deaf and hearing, defended the use of signs despite the increasing hegemony of partisans of the oral method. Among the latter are some of the hearing teachers at schools in Paris, Bordeaux, and Chambery; the instructors in the schools created by the Pereire family; the Brothers of St. Gabriel, a religious order devoted to the education of the deaf; and the Protestant teachers of St. Hippolyte du Fort in the Cévennes in the south of France.

All these educators wished to ratify the dominance of the oral method and make it exclusive. Debates took place at the Milan congress, and they were at times quite fierce, especially on the part of Italian delegates, who advanced religious arguments: the need for communication in order to confess and be absolved, or the fact that, since God had given man the faculty of speech, all good Christians ought to speak whereas signing was proof of mental retardation or degeneration.

A vote was taken, and an overwhelming majority of delegates (almost all hearing; France had only one deaf teacher as representative) passed resolutions that all had the same orientation: The oral method was to be preferred over mimicry. Since deaf signing had the disadvantage of being detrimental to speech and even to the precise expression of ideas, it was preferable to suppress sign language. Yet all deaf-mutes needed to be educated and governments were encouraged to take the necessary steps. Not all participants supported these resolutions and the American representative, Edward Miner Gallaudet, criticized them sharply, arguing that the country with the greatest number of deaf pupils, the United States, had only 5 delegates at the congress, while Italy had 87 and France 56, of a total of 164.

Since their passage by state and private teachers, and by administrators from France and Italy, the resolutions in favor of the strict oral method have been experienced by the deaf as an injustice and a denial of their language—sign language—all the more so since they were thenceforth also excluded from the education of their peers. The oral method, far from facilitating social integration of deaf children, had the opposite effect: withdrawal, underpaid employment, and medicalization while at the same time the deaf were proving their social competence through the creation of newspapers, the foundation of mutual aid societies, and the administration of athletic associations, in particular, for cycling. The newspapers, aid societies, and associations were confiscated from the deaf on the pretext that they should stop signing and that they must speak. Otherwise, they would be abnormal, disabled.

—*Jean-René Presneau*

See also Abbé Charles-Michel de l'Épée; Deaf Culture; Edward Miner Gallaudet; Sign Language.

DEAFNESS, ON MARTHA'S VINEYARD

For 300 years, the island of Martha's Vineyard, Massachusetts, was home to a population with recessively inherited deafness. Such deafness is usually caused by a genetic mutation in an individual whose descendents mate in subsequent generations.

The mutation for Vineyard deafness—which appeared as complete deafness at birth with no associated anomalies—occurred in the British county of Kent. The inherited trait was brought to America by settlers who came as members of a Puritan congregation in 1634. A group of these immigrants arrived on Martha's Vineyard in the 1670s, where their descendents still live.

The overall rate of Vineyard deafness was high: In the nineteenth century; while 1 in every 5,728 Americans was born deaf, on the island the overall rate was 1 in every 155, and in one small island community, 1 in every 4.

The first individual with Vineyard deafness was born in 1657. This man used a highly developed sign language, probably based on a language brought from Kent. (This sign language may have also made a contribution to American Sign Language [ASL], as Vineyard children were in the first classes at the American School). What is noteworthy about this individual and all who would follow is that hearing islanders were able to communicate with them freely, adapting to the deafness by becoming bilingual in English and sign language. Hearing islanders learned sign language in childhood and used it regularly throughout their lives. With so many family, friends, and neighbors deaf, sign language was a necessary part of daily life.

This use of sign language raises an important question: What happens to individuals with a disability such as deafness when nondisabled members of society are willing to adapt to the disability? On Martha's Vineyard, individuals with disability fared well. With no communication barrier, deaf individuals were fully integrated into island life, making comparable livings as fishermen and farmers and participating in all social, civic and religious activities. Interestingly, there was no "Deaf" society—no activities exclusive to the deaf. Indeed to have had a separate social network, deaf islanders would have had to exclude spouses, family, and neighbors. Signing was so much a part of life that nineteenth-century visitors reported regular use of sign among hearing individuals when no deaf islanders were present—on boats and farms and during social gatherings.

The only identifiable difference began with the founding of the American School. Because the state paid for this education, nineteenth-century deaf islanders were somewhat better educated than many hearing islanders and would occasionally be asked to interpret newspaper articles or legal documents by hearing neighbors.

The number of deaf Vineyarders began to decline in the 1880s with improved transportation, as islanders began marrying off-islanders who did not carry the inherited trait. The last deaf Vineyarder died in 1952 (although a child with Vineyard deafness could be born tomorrow).

Martha's Vineyard provides an example of how well individuals with disability in general—and deafness in particular—can fare if society is willing to adapt to ensure inclusion for all. It is not unique. Worldwide, communities with inherited deafness—many yet unstudied—have been identified. These will provide models of adaptations that warrant careful consideration.

—Nora Ellen Groce

See also Deaf, History of the; Sign Language.

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▣ DEATH

"When all is said and done," observed a 1968 editorial in the *Journal of the American Medical Association* (*JAMA*),

> it seems ironic that the end point of existence, which ought to be as clear and sharp as in a chemical titration, should so defy the power of words to describe it and the power of men to say with certainty, "It is here."

More than irony attended a perceived uncertainty about how to define death. Physicians at this time identified an increasingly pressing issue. The expanded use of respirator and intensive care technology after the mid-twentieth century started to concern physicians and the public alike that some seriously ill patients were kept "alive" in appearance only. The ability to keep familiar signs of breathing and heartbeat going seemed no longer satisfactory as meaning someone was alive, especially when brain function in particular was perhaps hopelessly lost.

Correct determination of when death occurs would seem to be one of the most fundamental tasks of a society. Historically, there has always been discussion and even dispute over the correct signs of death, stimulated at times by waves of fear that people were mistakenly determined dead and consigned prematurely to the grave. But the ambiguity that surfaced in the 1960s, and pointed to the eventual widespread adoption of the idea of brain death, reflected a set of new challenges especially relevant to thinking about the notion of disability. What "death" meant changed, and it became a more explicit topic of discussion. This happened as a part of increased scrutiny that fell as well on the appropriateness of "heroic" medical care, and the related growing emphasis on a patient's cognitive impairment as a barometer of the value of continued medical treatment.

THE HARVARD BRAIN DEATH COMMITTEE

On August 5, 1968, a report of the Ad Hoc Committee of the Harvard Medical School appeared in the pages of *JAMA*. Known since as the Harvard Brain Death Committee, the report set out specific neurological criteria that should be used to diagnose *irreversible coma*. Those criteria were, essentially, the following: unresponsivity, complete areflexia, apnea, and confirmatory loss of brain waves as determined by electroencephalography (EEG). The report was arguably ambiguous about whether irreversible coma was a condition that was in fact equivalent with death or was predictive of it. That ambiguity continued to animate debate over the criteria and coherence of brain death in decades since.

The Ad Hoc Committee was, literally, an ad hoc committee of the Harvard Standing Committee on Human Studies, a forerunner to institutional review boards and research review groups later uniformly established through federal law to oversee and approve human subjects research throughout the United States. The chairman of this ad hoc group was Henry K. Beecher, chairman of anesthesiology at Massachusetts General Hospital (MGH). Beecher established this ad hoc group from his role as chairman as well of the larger human subjects committee. This reflected how Beecher tended to view the issue of brain death through the topic of experimentation. By this time, he was a nationally recognized authority on human experimentation ethics. In several of his own speeches and writings, he framed the increasingly apparent problem of the potential overuse of medical technology to sustain futile care and hopelessly ill individuals within his understanding of experimentation ethics. Brain death provided a clear line beyond which treatment became unethical experimentation.

Thus, brain death, at least within the small group that first established widely supported criteria and clinical description for it, was seen as a solution to a long-standing and growing concern about the need to define parameters for increasingly extraordinary and intrusive medical interventions. Other advocates for brain death were instead much more focused on the necessity of such a legally recognized definition in order to develop the field of transplantation, especially the transplantation of vital organs such as the heart. In either case, framing a definition of death based to a large degree on the particular needs or challenges posed at a given time by medical technology raised certain problems. In the decades following the report's appearance, a torrent of literature was produced, especially by writers and thinkers who identified themselves with the bioethics movement (the early work of which appeared soon after the Harvard report), seeking a theory, concept, or argument that justified brain death as a reliable description of death, independent of the exigencies of medical care. At the same time, a clinical literature flourished that sought to better clarify what medical features, tests, and neurological phenomena best comprised the brain death diagnosis.

AFTER THE HARVARD COMMITTEE

In terms of philosophical and conceptual challenges, the ambiguities of brain death as death indeed, or instead as death as needed in the context of certain medical necessities, motivated efforts to come up with logical proofs and conceptual descriptions of what death fundamentally meant, and the degree brain death, or some other sort of criteria, concretely captured those fundamental meanings. So, for example, arguments that death was essentially the loss of biological integration of the body was argued by some to provide both a rigorous, experiential, logical, and philosophical justification; it could as well be manifested in brain death criteria since the brain arguably performed these fundamental integrative functions. Others argued for a conception of death as the loss of personhood, focusing on certain categories of cognitive and experiential capacity as the sine qua non of life. Their loss thus indicated death. This conception was often used as a criticism of brain death as generally practiced, pointing instead toward a "higher" notion of brain death, which would involve the loss not of the functions of the "whole" brain, as with the Harvard criteria, but of the more intellectual and cognitive functions generally associated with the cortical regions of the brain, as opposed to the "lower" midbrain and brainstem regions.

As many of these conceptions had trouble neatly describing a more messy reality, increasing calls were heard toward the end of the twentieth century to give up on the notion of brain death since criteria would never be able to live up reliably to the conceptions advocated to justify them. Higher notions were compelling but the ability to identify reliably and clinically the injuries and symptoms that indicated something as elusive as the capacity for adequate "awareness" was particularly problematic with presentations of actual patients with severe comas and persistent vegetative states. Similarly, the notion of death as loss of integration through loss of the whole brain was challenged as closer study and improved intensive care revealed the capacity of the body to sustain many complex metabolic tasks while meeting Harvard criteria, and the capacity for physicians to sustain such impaired functions. Both rendered brain death more a gray area than the solid line it needed to be.

Parallel with efforts to sort out the conceptual consistency or inconsistency of one notion of death over another was work in clinical medicine to tinker with the Harvard criteria themselves and the neurophysiological understanding of increasingly detailed types and degrees of severity of coma. Soon after the Harvard criteria appeared, several large-scale studies were performed to see how well these criteria, or whether a more streamlined set, predicted death. The irony in this is apparent. The gold standard for brain death criteria was its prognostic power for predicting ultimate cardiopulmonary death. Which, then, was really death? The original Harvard criteria were themselves justified through a similar sort of prognostic validity by MGH neurologist Robert Schwab, through the 1960s. With the ink barely dry on the report in *JAMA*, the Ad Hoc Committee of the American Electroencephalographic Society on EEG Criteria for the Determination of Cerebral Death collected through questionnaires more than 2,000 instances of flat EEG to corroborate the reliability of that specific finding as a predictor. A more sophisticated prospective study took place over several years in the 1970s;

it focused more in the predictive value of other clinical characteristics as well. The National Institute of Neurological Diseases and Stroke coordinated the work of nine medical centers to study brain death criteria. The Collaborative Study of Cerebral Death followed more than 500 patients who eventually died and who at the outset demonstrated a minimum of unresponsivity and apnea. A range of factors was followed to establish a minimum set that could reliably predict cardiopulmonary failure. The authors of the study concluded that an absence of brainstem reflexes, apnea, unresponsivity, and a flat EEG for at least 30 minutes' duration at least 6 hours after onset of coma and absent intoxication, hypothermia, or other clearly treatable illness (e.g., cardiovascular shock) were adequate criteria. Curiously, they did so despite the lack of relative independent predictive importance of loss of brainstem reflexes. However, the study authors concluded that "semantically, the absence of brainstem function, as demonstrated by inactivity of these reflexes, should be included in the criteria of brain death." The degree that EEG, brainstem findings alone, or brainstem findings in addition to other signs was important was the subject of much debate and ongoing consensus group revisions of the criteria.

A distinction was often made between brainstem advocates, particularly in Great Britain, who emphasized the loss of brainstem and cranial nerve functions as the crucial and adequate signs of brain death, and whole-brain clinicians, more typical of practice in the United States, who were more concerned about the complete loss of reflexes and responsiveness and loss of all EEG. For American practice, the President's Commission on Ethical Problems in Medicine and Biomedical and Behavioral Research published its conclusions with regards to these controversies in its 1981 report, *Defining Death*. That publication rejected higher and lower views, opting for the whole-brain criteria and a "biological integration" rationale, which also, somewhat controversially, was used to support the argument that brain death was thus a more precise updating of the familiar heart-based custom of declaring death. Still discussion along these lines continued. An array of "confirmatory" tests of brain death have been advocated and studied such as the use of angiography, cerebral ultrasonography, and radioactive brain scans, or cerebral scintigraphy. Detailed methods for apparently more reliable measures of apnea have also been developed and debated.

In many ways, however, the general framework of Harvard remains—unresponsiveness, apnea, and absence of reflexes with EEG confirmation. What has also importantly continued, however, is the ambiguity as to whether brain death describes versus predicts a state that is death itself. Increasingly refined imaging of brain activity, studies of the severely brain injured, and more aggressive efforts to rehabilitate severely comatose individuals have left open the question of how far the boundaries can be pushed in terms of establishing the brain's death, and the death of either an experiencing person or simply a responsive physiological organism. In addition, the "better dead than disabled" philosophy highlights the close apposition that severe disability and medical definitions of brain death have experienced. Severe brain injury in particular continues to challenge the boundary between rehabilitation, euthanasia, and definition of death.

While, as mentioned, these ongoing uncertainties and conceptual inadequacies have led some to question the value and use of brain death, they perhaps instead reflect an important aspect of the nature, and value, of this sort of definition. As it grew out of a search for a sensible marker of the end of salvageable humans as persons and as organisms within the context of medical possibilities, marking the point at which medicine turned into intrusive experiment, the fact that brain death may be a moving target should not be a surprise, or necessarily a problem. New knowledge about neural regeneration and neurobehavioral rehabilitation should also not surprise us with even further possible future complexities as to how much of death can be defined though the brain. Such developments would further illustrate how the brain, a logical choice under the circumstances, became the focus with which to flexibly ponder and set the dividing line, in an age of increasingly intrusive medical technology, between the disabled and the futile.

—*Gary Belkin*

See also Bioethics; Euthanasia.

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DEATH PENALTY

OVERVIEW

After reaching a postwar maximum of 157 in 1947 U.S. executions fell to zero from 1968 to 1977. In 1972 in *Furman* the Supreme Court ruled that the death penalty was unconstitutional. Some states then passed death penalty statutes that provided for guided discretion in the application of capital punishment. In 1976, the Supreme Court in *Gregg* and other cases reversed and ruled that these statutes were constitutional. Guided discretionary statutes attempt to achieve uniformity across state courts by requiring that standardized instructions be given listing aggravating or mitigating factors that must be considered by juries in the now mandatory separate sentencing stage of capital trials (Zimring and Hawkins 1986; Paternoster 1991), but this goal has not been reached. After *Gregg*, executions grew sharply, reaching a maximum of 98 in 1999. The great majority of executions are conducted by the states although offenders can appeal to the federal courts after exhausting their state appeals. Appeals are critical as less than 10 percent of death row inmates are executed. Almost all offenders who win appeals are resentenced to long prison terms (Liebman et. al. 2000). In many states, largely due to state appeals and perhaps some reluctance on the part of state officials, mean time on death row before an execution has grown to beyond 20 years (Aarons 1998; Zimring 2003).

INSANITY

A core tenet of U.S. law is that the blameless must not be punished. The law therefore forbids the execution of the insane. Legal tests include whether the defendant knew the difference between right and wrong, whether the defendant was compelled by an irresistible impulse, or, most commonly, whether the defendant had the capacity to appreciate the criminality of his or her conduct or to conform to the law (Neubaurer 1988). As the burden is on the defense to prove insanity and because defendants who successfully use this tactic typically are incarcerated in mental institutions for long periods, this plea is unusual, and it rarely is successful. Yet many of the condemned have committed heinous acts. Some common legally aggravating factors that increase the probability of a death sentence include the deliberate killing of a child, multiple killings, or victim torture. Defendants, however, typically reject claims that they are insane. Yet given the nature of such crimes, such denials often are questionable. And decades spent on death row are unlikely to improve the already tenuous mental health of such offenders. One ironic consequence is that states have successfully engaged in litigation to force clearly insane offenders to take medication so they can be executed.

MENTAL RETARDATION

The same blameworthy principle implies that the retarded should not be executed, but the courts were slower to act on this logic. In *Thompson* the Supreme Court held that defendants under the age of 16 cannot receive the death penalty. Most definitions classify individuals with a child's mental age as retarded. Capital punishment opponents therefore claimed that mental development should determine death penalty eligibility and that retarded persons with a child's mental capacity should not be executed (Streib 2003). During the 1990s, public action forced many legislatures to address this issue. Nearly half of the states with a legal death penalty excluded offenders with IQs below 70 from capital punishment. In 2002, in *Atkins* the Supreme Court followed this evolving standard of public decency and held that retarded persons have less culpability for their crimes and thus do not merit the retribution imposed by the ultimate punishment.

—David Jacobs and Stephanie L. Kent

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DECISION MAKING

There are a variety of competing models of how individuals and organizations make decisions. While the dominant model continues to be the rational perspective, there is a broad array of alternative approaches including bounded rationality, behavioral decision making, and political, escalation, and garbage models. These reflect the broader intellectual turmoil over the nature of reality and both mirror and can inform current disputes over competing models of disability.

While specific formulations of rational decision making vary, a representative example might consist of the follow steps. A problem or opportunity is identified. All the possible alternatives to address the problem are generated. Agreed-on criteria exist to evaluate the alternatives. Complete information is gathered. Each potential course of action is evaluated. The course of action that maximizes utility is selected.

To illustrate this model, let us take the example of an individual who is involved in a serious car accident. Several months after being discharged from the hospital, the woman is experiencing numbness in the legs, a symptom not clearly associated with the accident. Soon she is experiencing complete paralysis from the waist down.

Under the rational decision making formulation, all potential tests are undertaken to evaluate the disabled person's status. All potential treatment interventions are considered. The best intervention is then undertaken to "cure" the patient of her disability.

The rational model continues to be the dominant model in the social sciences and the applied fields based on them. Acceptance of this maximization framework enables a variety of elegant and rigorous analytic techniques to be brought to bear on complex decisions. Yet each step of the rational decision making model has been subject to aggressive criticism for a lack of descriptive accuracy.

The bounded rationality perspective provides a long-standing alternative to the rational model. Proponents of this perspective argue that because of limitations in individuals' and organizations' information processing capabilities, pure rationality is impossible to achieve. The bounded rationality model suggests that decision makers have limited perspectives in their initial grappling with problems or opportunities. When decision processes are undertaken, there is a sequential evaluation of alternatives. The alternatives themselves are generated using heuristics or simplifying "rules of thumbs." A common heuristic would be to search for solutions similar to those already being used. Finally, decision makers do not maximize utility but instead "satisfice"; that is, they select a solution that meets the criterion of being "good enough" and thus stops the evaluation of further alternatives. This descriptive model provides a powerful alternative to rational decision making while remaining palatable to those embracing rationality as a desideratum.

In the past 30 years, psychologists from the behavioral decision making camp have devoted enormous energy to an in-depth, if extraordinarily narrow, examination of how individual decision makers employ or diverge from basic rules of logic and probability theory as they assess information to arrive at decisions. In general, these investigations declare off-limits assessments about the values and preferences of decision makers. Even within these narrow confines, a formidable body of evidence has been assembled documenting systematic and widespread departures from basic rules of logic and probability theory. Specific examples include prospect theory, sunk costs bias, representativeness heuristic, and deviations from logical reasoning.

Prospect theory documents that individuals often do not attach equal utility to gains and losses. People appear to be risk averse in gains but risk seeking in losses.

Researchers examining sunk costs bias point to the fact that costs previously expended in a course of action are supposed to be irrelevant, since they are in the past. Yet there is substantial evidence that sunk costs are not sunk psychologically but instead continue to influence decisions about future courses of action.

The representativeness heuristic refers to people's tendency to assess whether an individual belongs to a certain category based on the degree to which the individual resembles the prototypical class member rather than through the use of probability information.

There is also substantial evidence that people systematically depart from simple principles of logical reasoning. When reasoners are asked to evaluate whether sets of assertions are consistent, they succumb to predictable illusions. Thus, when information is presented in some fashions (e.g., "A or B or both"), respondents may have difficulty in corresponding to rules of logical reasoning.

Returning to our case of the woman disabled subsequent to the car accident, bounded rationality perspectives would suggest a different decision-making process. For instance, not all potential tests would be conducted to assess the patient's condition. Nor would all potential interventions be considered. Rather, alternative assessments and interventions are likely to be sequentially considered, often based on the training and experience of the attending physicians and staff, until one approach appears to be "sufficiently" appropriate.

Behavioral decision makers would point to systematic biases and shortcomings in how information is gathered and interpreted. Thus, even among highly trained sophisticated professionals, whether a treatment's likely impact is framed as a gain (50 percent chance of improvement) or a loss (50 percent chance of further suffering with no improvement) often produces a different decision.

These findings of systematic departures from rationality are perhaps especially impressive given how conservative the investigations are. The research situations examined are typically both simple and sterile. Emotions, unwieldy as they are, have been banned from most of the examined contexts. This is despite that current evolutionary biologists would argue that emotionally hardwired features are essential to understanding how human being respond to stimuli. This wealth of experimental data strongly undermines the pure rationality formulation. Yet these studies also support the notion that human choices are orderly, even if not strictly rational.

A number of alternative models of decision making criticize the rational framework not for its assertions about how data are gathered and assessed but instead for the assumption that there exist agreed-on criteria for the evaluation of alternatives. These perspectives focus on how decision making in groups or organizations is invariably a political process in which the elements most worthy of attention are the varying points of view or values of the actors.

In these perspectives, decisions are made not by reified entities such as organizations but rather by fluid coalitions of actors. These actors begin the decision process with different viewpoints and interests—factors that influence both problem identification and problem solutions. Decisions that are arrived at simply reflect the interests of the dominant coalition at a particular point in time.

In our example of the individual disabled following the car accident, the perspectives of the medical team and the disabled person are viewed as identical. In reality, we know the interests of these parties (as well as other parties such as family members, insurers, and employers) often diverge. Economic and psychological incentives may push the medical team to favor certain interventions, while the disabled person and other groups may view the situation very differently.

While political perspectives on decision making generally have high descriptive face validity, they are not without their critics. There are a variety of organization models that suggest the political models are themselves too rational—that they too directly assert that decisions are a manifestation of some group's intentions. Some critics of the political perspective would argue that "conspiracy theorists are optimists"—for they assume that someone is in control.

Organizational theorists have developed a number of models that incorporate both individual psychological factors and also broader organizational and contextual factors to explicate decision making. One such approach, escalation theory, focuses on understanding commitment to failing courses of action. Rational decision making and theories of efficient markets would suggest that individuals and organizations quickly correct decisions that lead to poor outcomes. Yet everyday observation reveals that long-run persistence with failing courses of action is commonplace for both individuals and organizations

Escalation theory suggests that four classes of determinants combine to contribute to commitment to failing courses of action. Project determinants pertain to the objective features of the decision or course of action. Examples would be whether a setback was viewed as temporary or permanent and the number of attempts that had previously been made to obtain the objective. Psychological determinants would include the cognitive limitations and heuristics currently the focus of behavioral decision makers but would also include factors such as reinforcement traps, which create difficulties in discontinuing previously rewarded activities and individual motivations such as the need for self-justification.

There are also a variety of social determinants that contribute to escalation. Decision makers may continue along a previously selected course of action not just because they do not want to admit to themselves that they may have made an error, but because they do not wish to acknowledge that error to others. Social norms such as the "hero effect" and modeling may also play a role. Organizational and contextual factors may also lead individuals and organizations to persist with failing courses of action. Prominent among these determinants are simple administrative inertia, political constituencies favoring the course of action, and a linkage of the course of action to organizational values and identity.

Thus, our individual disabled following the car accident may follow the strong advice of a physician to undergo surgery to increase her ability to use her legs. The surgery is intrusive, expensive, and yields no improvement in the patient's condition. Objective observers and statistical evidence might well suggest that further surgery is unlikely to be effective. Yet escalation research suggests that individuals who feel personally responsible for failed decisions often do not respond objectively to negative feedback. Thus, both the patient and the physician may be biased toward investing in still further surgical interventions.

Other organizational perspectives on decision making emphasize the randomness and anarchy components of decisions, particularly those emerging from large organizations. For instance, the "garbage can model" suggests thinking of organizations as having streams of participants, streams of problems, streams of solutions, and streams of choice opportunities. These different streams collide with often difficult to predict outcomes. Some problems do get solved. However, there are a variety of other outcome possibilities not recognized by either rational or political perspectives. Solutions may be proposed or implemented when there is, in fact, no problem. In other instances, problems may continue to go unaddressed. The entire thrust of these perspectives is to emphasize the unpredictability and at times unresponsiveness of our institutions to anyone's agenda.

Our individual disabled subsequent to the car accident may find herself having to interface with a wide variety of groups and organizations. These might include doctors, hospitals, rehab centers, insurers, and government agencies. Each of these groups faces constant changes in personnel, alterations in missions and funding, upheavals in domain, evolving information systems, and changing core technology. As a result, the interactions with the disabled person may take on a Kafkaesque character. Effective and responsive treatments may coexist with completely irrelevant or even damaging interventions as potential decision-making outcomes.

There is an interesting overlay between these contemporary models of decision making and the evolution and current areas of dispute in the disability literature. Certainly, a dominant dispute in the disability literature is between the medical model and social model of disability.

The medical model sees disabled people as a series of individuals with specific medical problems. Thus, the response is typically a deficit interpretation followed by a cure or care intervention. This model fits very closely with the rational model of decision making and, like the rational model, has predominated the area in the past decades.

There are studies that suggest that the modest revisions to the rational decision making framework are equally appropriate in the context of applications of the medical model to the disabled. The rational calculus of medical intervention implicitly suggests a joint decision by the physician and patient, in which the patient's value system is assessed to ensure a maximum utility intervention subject to the existing limitations in medical technology.

Both the bounded rationality of decision making and critics of the medical model of disability would agree that many medical interventions fail to maximize the utility of the disabled patient. Bounded rationality would emphasize that the treatment of a patient as a person requires resources of time, energy, and involvement, resources that are quite scarce in most health care delivery contexts.

The behavioral decision making framework also supports those who suggest suboptimal treatment outcomes. Information is not rationally combined and assessed, either by medical professionals or by the disabled themselves. Laypeople rely on physicians to frame the results of tests and provide guidance about how to proceed. Yet, consistent with prospect theory, how the information is presented both to and by physicians results in different preferences for action and treatment on the part of both physicians and patients. Research also indicates that medical patients have difficulty in accurately processing information about treatment outcomes. Even within the scope of the medical model of disability, the potential for wider investigation and appreciation of behavioral decision making models' implications would seem to be great.

The major alternative movement in disability studies has been the development of the social model. For many espousing the social model, the central reality is that disabled people and their organizations are almost completely absent from the decision-making process, both in regards to individual treatment decisions and also more broadly in the planning and delivery of services that affect disabled people's lives. This perspective depicts disabled people as a collective that is often oppressed by a dominant outside group. From this perspective, the key to understanding decision making vis-à-vis the disabled is power. This mindset, proponents suggest, leads to new perspectives on the real cause of disabled people's problems and thereby on methods for eliminating them.

There is an obvious natural affinity between the social model of disability and political models of decision making. Both would question the rational model of decision making's assumption that there are agreed-on criteria that can be used to evaluate alternative courses of action.

Advocates of the social model of disability would urge that decisions in regards to the disabled should result in enabling and empowering the disabled in the same manner that these decisions currently serve the able-bodied. In some instances, this will involve challenging the taken-for-granted assumptions of the dominant able-bodied class. Extreme advocates of the social model might also "push the envelope" of the behavioral decision making model that values or preferences are not themselves irrational. Thus, deaf individuals might assert their desire to produce deaf children because they see such children, as themselves, as simply differentially endowed as opposed to creations of some lesser god.

The conflict between medical and social models of disability occurs not only at micro-level interpersonal interactions but also at the macro level of structural policies and institutions. Thus, there is emerging interest and research on the history and current status of organizations representing and acting on the benefit of the disabled. Here, as in the general literature on decision making, those adopting a social model of disability or a political perspective may come to be viewed by some observers as optimists—for they would assert that a lack of organizational and institutional responsiveness is the result of the intended actions of oppressive "Others," and thus subject to ready remedy.

Escalation perspectives in disability research would dispute this. Escalation theorists would argue that whether it is in individual treatments of the disabled in the "medical model" formulations or in the actions of organizations designed by and for the disabled in the more radical version of the "social model" of disability, resources may long continue to be expended in courses of action despite a lack of successful returns.

Similarly, garbage can perspectives of decision making may enlighten and enrich both proponents of medical and social models of disability. Problems of extreme specialization and division of labor adversely affect the performance of both for-profit and not-for-profit organizations. With the ever-growing complexity of modern organizations and institutions, randomness and unpredictability will remain components of both individual treatment protocols and broader institutional responses. Garbage can models of decision making fit with the broader poststructuralist's abandonment of a search for underlying causes of how particular decisions are "made."

The rational decision making and political decision making perspectives fit well with the medical model versus social model debate in the disability literature. Future studies in the disability area that more deeply incorporate a wider range of decision making perspectives, such as behavioral decision making, escalation, and garbage can models, may result in a broader and more nuanced appreciation of factors affecting the disabled and their organizations in contemporary society.

—*Jerry Ross*

See also Ableism; Consent to Treatment; Consumer Control; Empowerment and Emancipation; Models; Normality; Patients' Rights.

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DECLARATION ON THE RIGHTS OF DISABLED PERSONS (UNITED NATIONS)

See United Nations Declaration on the Rights of Disabled Persons

DEFORMITY

A *deformity* is a significant difference in the shape, color, or other aspect of appearance of some part of the body in relationship to the perceived statistical average shape of the part in question. Deformities can result from complications during birth, genetic mutation, accident, growth or hormone anomalies, reconstructive surgery following severe injuries, and rheumatoid disorders such as arthritis.

Deformity is a very problematic term, because the concept itself is based on two assumptions: first, that there is such a thing as a "normal" body from which the deformity can be said to deviate; second, that there is widespread agreement on what attributes in fact constitute such a deviation. Much of the subjective definition of deformity is a function of context and power. Sarah Baartman, for example, possessed physical attributes very common to her tribal ancestry in South Africa but was described as "deformed" by the white Europeans who forced her to appear semi-nude before European audiences as "the Hottentot Venus."

Historically, cultures have responded to deformity in many ways. In the ancient world, deformity was often seen as a bad omen, a sign of wrathful gods, or the influence of demons or wizards. Some babies with deformities were killed at birth, often by ritual exposure. There is evidence, however, that other children with deformities were considered holy or magically powerful, and these children could become shamans and priests. Leviticus, from the ancient Hebrew Bible, specifically forbids the participation of deformed persons in religious rituals. Most cultures imagine a link between deformity of body and the moral corruption of character; the Greek poet Homer does so in the *Iliad*'s Theristes, but elsewhere Greek culture seems more tolerant: Clever god Hephaestos is deformed, and King Theseus seems to accept deformity when he slays the wicked giant Procrustes, who killed anyone who did not conform to his ideal of bodily perfection. The Romans also sometimes linked deformity to magical power, and certain deformed persons became highly regarded figures in Imperial courts. In medieval times, deformity was often scourged as a sign of God's wrath, but it was sometimes welcomed as an opportunity to practice Christian charity and mercy, and in some persons, such as Gregory of Tours and Teresa of Avila, deformity was even regarded as a mark of saintliness. During the explosive emergence of science in the eighteenth and nineteenth centuries, deformity became a titillating challenge to scientific classification, and such titillation gave rise to the golden age of the freak show. In modern times, deformity is seen as a marker for disease, and doctors regularly give patients the option of aborting fetuses who may exhibit deformities.

In some persons, fear of deformity in oneself can become so grave that mania and suicidal obsession can result. This condition is known as *dysmorphophobia,* and it can be generated from conditions as minor as skin lesions or male pattern baldness. People with dysmorphophobia are so appalled by the prospect of their own bodies deviating from a perceived norm of beauty or regularity that they chronically go to great lengths to conceal their "defects," visit doctors multiple times, and develop compulsive, often dangerous habits, such as plucking incessantly at nonexistent hairs.

—Michael M. Chemers

See also Aesthetic Surgery; Folk Belief; Freak Show; History of Disability: Ancient West.

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DEGENERATION

The word *degeneration* was used in the eighteenth century in the natural sciences to describe variation in certain living species. At the start of the nineteenth century, it also referred to modification in body structures as shown by pathological anatomy. Representatives of the natural sciences, finding that the word had a somewhat negative connotation, attempted a new definition for its use in their domain. Those who considered variation a perfectly normal phenomenon in the evolution of living species wanted to restrict its use to define unwelcome alterations such as stoppage of development for physical aberrations, many instances of which can be seen in humankind.

It is against this background that a French doctor, Bénédict-Augustin Morel (1809–1873), introduced a new term—degeneracy—and a new definition in a book he published in 1857. The shift from *degeneration* to *degeneracy* was necessary because of the radical change he brought into the definition by synthesizing the concept used in natural sciences and the one used in the pathological anatomy.

Morel's intention was twofold. On the one hand, he linked degeneracy to a modification process that is in essence pathological, variation as formerly referred to in natural sciences becoming deviation. On the other hand, he claimed that degeneration, considered henceforth as a disease, is contracted by humankind when in contact with harmful natural surroundings and is passed on to its descendants. Morel did not use the word *heredity* because he introduced two new ideas with this concept, understood then as the mechanism of morbid transmission: the law of double fertilization and the law of progressivity, as he called them. The first law established that degeneracy emerges only by the coming together of several factors. The second law introduced the accumulative character of the transmission process: the further away in time from the starting point of the disease you go, the further away from the normal features of humankind you drift, descending deeper into a deviation process.

The term *degeneracy* did not replace the term *degeneration* except in France and some French-speaking countries. The concept was well received in psychiatric circles in the second half of the nineteenth century both in Europe and the United States, but it was subject to a plurality of interpretations. The most prominent one was the hereditary process, and this helped the determinist and fatalist approach of mental disease and allowed notions such as incurability and chronicity to develop and remain popular well into the twentieth century.

The term *degeneracy* became obsolete with the advancement of genetics, but insanity has nonetheless remained associated with the notion of heredity in psychiatric circles despite the dissemination of new concepts brought about by dynamic psychiatry and psychoanalysis.

—Jean-Christophe Coffin

See also Friedrich Nietzsche.

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DEINHARDT, HEINRICH MARIANUS (1821–1880)

German educator

The German reform pedagogue Heinrich Marianus Deinhardt was born on January 29, 1821, near Weimar, Germany. Deinhardt studied theology, history, and philosophy in Jena and Halle, but he never graduated. He is said to have been an intimate expert of the dialectic philosophy of George W. F. Hegel (1770–1831). He acquired his knowledge in pedagogy through private instruction. Even as a student, Deinhardt had already written radical position papers arguing for the restructuring of elementary pedagogy in the interests of the lower classes, and he also developed thoughts in the direction of a polytechnic education system. He played an active role in the German Revolution of 1848 and avoided arrest by fleeing to Switzerland. After returning to Germany, Deinhardt found himself banned from professional practice and instead had to give private lessons.

In 1857, he followed Jan Daniel Georgens (1823–1886) and Jeanne Marie von Gayette (1817–1895) to Austria. There they founded Levana, a model institution for nondisabled and disabled children. By 1861, however, Deinhardt had already abandoned the joint project. In 1861 and 1863, the special education lectures, which he had given with Georgens in 1860, were published. The two-volume work was titled *Die Heilpaedagogik. Mit besonderer Berücksichtigung der Idiotie und der Idiotenanstalten* (*Pedagogy of Special Education: With Special Consideration to Idiocy and Institutions for the Feeble-Minded*) and provided a theoretical foundation of the special education discipline. After the personal disagreement with Georgens, Deinhardt was not able to secure a stable livelihood for himself. He was repeatedly fired from schools in Vienna and had to eke out a living through hourly wage positions. Deinhardt died in Vienna, Austria, on March 11, 1880.

—Anne Waldschmidt

See also Heinrich Hanselmann; Special Education.

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DEINSTITUTIONALIZATION

Deinstitutionalization is a profound historical movement that advocates the transfer of physically and intellectually disabled people, the mentally ill, and other incarcerated individuals from public and private institutions such as hospitals, nursing homes, and prisons back to their families and to community-based homes. The philosophy behind this movement is the use of least restrictive alternatives to permit individuals to live as active a life in the community as possible. In a historical context, *deinstitutionalization* refers to the transfer of activities from one institution to another.

Before speaking of deinstitutionalization, institutions and institutionalization must be defined. Although there is debate among sociologists, *institutions* may be defined as a specific social group's ways of acting, thinking, and behaving that have become crystallized; almost constant, they are distinctive, recognized, and sanctioned. Thanksgiving Day in the United States and Bastille Day in France, for example, have been *institutionalized* as holidays and comprise certain fixed expressions. They are not institutions like the Senate or a court of law, but they nevertheless meet the criteria of the general definition of institution, since they constitute days, crystallized and official, devoted to memorialization and ceremony.

Deinstitutionalization, then, occurs when a complex of customs, structures, and activities is modified or even loses its reason for being. Let us consider three examples of deinstitutionalization.

Deinstitutionalization of the family. In essence, this means that the family, which was a public matter, responsible for the formation of socially conforming adults, became privatized in the sense that it became the site of well-being and affectivity, based on mutual attraction and love, something that can be constructed and deconstructed. Even procreation is understood in affective terms. It then follows, for example, that in the juridical sphere, the normal motive for divorce becomes mutual agreement. The justice system no longer has to express an opinion with respect to the rules of an institution; rather, it registers the consequences of a meeting of private wills. As Philippe Ariès has shown, beginning in the seventeenth century the family has been invested with something other than a purely social alliance, up to the point where the dependency of women came to an end in the sweeping revolution in relations between the sexes in the 1950s and 1960s.

Quite clearly, the limitations and difficulties of this form of deinstitutionalization become most acute in the matter of children. People do not divorce their children, and the indissolubility that was earlier ascribed to the couple now references the bond with children. The essence of this deinstitutionalization lies in the fact that the family no longer is the site where one becomes a citizen but rather where one develops affective dimensions; the family no longer is asked to produce social beings but rather happy individuals. Thus, the institution of the family lost several of the institutional characteristics of its first function.

Deinstitutionalization of the school. A second example can be found in the schools. In France, for example, schools during the Third Republic (1870–1940) had as their function to instruct and through this instruction, regulated by the public authority, to produce the kind of man who was in conformity with revolutionary morality, who had interiorized his allegiance to a fatherland and to a precise history, and who was equipped with a basic knowledge that allowed him to situate himself and find his place in society.

But, with mass education, changes in the family, cultural diversity, and the opening to a wider world, the relationship that school must maintain with the world beyond the school changed—the school no longer knows how to exercise its very diverse functions, functions that may even be contradictory, to instruct, socialize, educate in the widest sense, contribute to the happiness of children and yet subject them to a discipline, and inculcate them while preparing them for the world of work. The school is pulled between opposing demands; its exact function is no longer clear-cut, and we see, throughout the immense body of writing on schools, the most irreconcilable theories being formulated. The school, like the family, has lost its fixed points of reference and seeks to determine a new identity.

Deinstitutionalization of the church. All religious institutions are confronted with the weakening of their regulatory capacity. It is not primarily the loss of influence of these institutions, but rather that the relationship between individual believers and the institution has been modified—the exclusive authority to state what shall be believed and what shall be done. Personal initiative will supersede believer conformity.

The institution of the church is not disappearing, but it is no longer as capable as before of establishing its points of reference and finds itself confronted with a culture of the individual, which relativizes the norms of belief and practice. The institution is no longer asked to define a common identity, but rather to accommodate and support a personal agenda.

In these three forms of deinstitutionalization cited here, two far-reaching features of modernity are present and also go some way toward explaining them:

Modern individuals more and more lay claim to irrevocable rights and to the freedom to construct their own worlds. The essential task has become the work of the individual alone to take a place and a role in a society that, admittedly, defines its members less than before but no longer supports them in the same fashion as did the school or the family of an earlier time. As a consequence, modern individuals want to be, and are obliged to be, mobile, changeable, in circulation. Deinstitutionalization is less the disappearance of institutions than modern individuals' claims and demands that such institutions be engaged in their projects. This, then, is the challenge to the regulatory and normative role of institutions.

Concurrently with this social uncertainty, strong claims for the recognition of identity are being made: "we women," "we the disabled." These claims to self-defined identity are to be understood in a society where traditional institutions no longer function in the same way and where individuals are obliged to find their own bases from which to present themselves, bases other than those offered by the family and the school: cultural bases, religious bases, gender bases. In this dual and at times contradictory individualist movement, traditional institutions appear to offer little help.

This long historical development is paralleled by psychiatric deinstitutionalization.

PSYCHIATRIC DEINSTITUTIONALIZATION

In Milos Forman's 1975 film *One Flew over the Cuckoo's Nest*, we saw the incredible treatment of the mentally ill of only 30 years ago. Not all the traces have since disappeared. Treatment in a closed environment, a closed universe sure of its uncontested right and its science (which later would reveal its unsound foundation), had an urgent need to evolve, in the name of human dignity.

Thus, a massive social movement was born, in a North American context even though the theorists who transformed the American vision were often European. What were the principal factors?

The great influx of psychotropic medications, which better permitted the mentally ill to regain a life among others and to overcome what had been called "crises." Once we had gained mastery over this new pharmacology, excursions, walking cures, and reimmersion in the community could be envisaged. Insanity gave way to mental illness, even to the fuzzy but revealing vocabulary of "psychological problems" or simply "psychological suffering."

The influence of psychoanalysis, which introduced a noninstitutional type of cure. "Madness" had been addressed in an institutional framework, with treatments still drawing their fundamental inspiration from Philippe Pinel and Esquirol, that is, a context in which institutionalization was supposed to cure, or at least relieve, by means of its own internal dynamic: application, internal socialization, work. All this complemented by various techniques such as electroshock therapy and baths. Obviously, in the 1960s and 1970s institutional psychiatry had a vision where psychoanalysis had a recognized place. But in larger terms, the arrival of psychoanalysis contributed to the emergence of the concept of deinstitutionalization, since work on the psyche could be undertaken in dual relationships, quite outside any institution.

The antipsychiatry movement. From these same decades, 1950–1970, the ill-named movement of antipsychiatry emphasized that social factors played a significant role in psychological disorders. It focused on social pathologies and on the deindividualization of mental illness. At the same time, this movement held that in the link to the community lay the best path toward amelioration and affirmed that institutional confinement was fundamentally harmful.

To these factors must also be added economic analyses. In the United States, for example, but also in France, the thesis was advanced that the welfare state, by developing segregative models of social control, incurred excessively high and hard-to-justify costs.

It is fair to say that by the end of 1975, the advocates of deinstitutionalization dominated the public scene. Opposition to deinstitutionalization was strong but divided. In certain environments, there was panic at the possibility of former internees from psychiatric hospitals being present in public places. In the United States, there was strong opposition from trade unions because of the risk of unemployment and intensive lobbying by professional associations professing concern for standards.

When the effects of deinstitutionalization were reviewed in the early 1980s, there were serious concerns. The report by K. Jones in 1984 found alarming similarities everywhere and stated that reform in Italy was only a late and poor reaction to reforms carried out in the United Kingdom and the United States. The overwhelming argument against suppression of the psychiatric institution was that deinstitutionalized persons were even more unhappy, ill-treated, and stigmatized than they had been in the institutional setting. Predictably, the defenders of deinstitutionalization readily responded that the deficiency lay in the fact that the community had not been given the means to receive and accommodate the mentally ill in its midst.

In Europe, it is the Italians who went farthest, since, as a consequence of Franco Basaglia's struggle against abuses in institutions for the mentally ill, they passed a law closing the psychiatric hospitals. It is not possible in this entry to give a full account of the differing and opposing views that were advanced by the advocates and adversaries of antipsychiatry and of deinstitutionalization in the United Kingdom, France, and Italy. It may be stated that the great merit of the Italian advocates was their concern for the initial stages of institutionalization in a psychiatric hospital and the direction of their analysis toward the sphere of the social reproduction of poverty and its associated conditions, thus to be concerned with the determining factors which led people to a psychiatric institution, and to link firmly the social and the health related. To project our vision beyond the institution we must also analyze what happens before admission to the institutions.

The forms taken by deinstitutionalization, both in the United Kingdom and Italy, have been numerous and diverse, such as alternating periods in the institution and in the community, host programs in the institutions, and the creation of work cooperatives. This means, it must be emphasized, that the struggle against institutionalization should not be made an object of caricature by setting up a radical opposition: everything institutional or everything community based. And it is perhaps these efforts, in their various forms, to leave the psychiatric institution that have permitted the extension of the deinstitutionalization movement into areas well beyond psychiatry.

As concerns disabled persons, three principal claims have been voiced. The first of these claims is the affirmation that society is unadaptive and that disability is not initially a deficiency but a series of social obstacles. Opposed to the medical model, which emphasizes the deficiency of the individual and finds its fullest form in rehabilitation, is the social model, which asserts that if society were fully accessible, on all levels and in all domains, disability would be only one small difference among thousands. This is a systemic model, which attempts to understand the exact relationship between the "deficient" individual and disabling society. By means of a certain number of accommodations, life among others is possible and desirable.

The claim that society is unadaptive. In the early 1960s, we were in the grip of a notion of unadaptation, defined as the defects or insufficiencies of the individual, quasi-natural in being. We have already overturned the idea of disability that emphasizes the exogenous burden that weighs on persons with perceived deficiencies. It is the complex of social institutions that creates obstacles to the life and development of "deficient" persons.

The claim of the disabled themselves that individual rights must be affirmed. We return here to ideas earlier expressed on the way in which contemporary individuals situate themselves on their social path. The affirmation of individual rights, based on the declaration of human rights, and the desire to construct oneself, have led to currents, fed by disabled persons themselves, to criticize those institutions that Erving Goffman has called "total."

We should not confuse rejection of the institution with rejection of specialization. Those who wholly reject the institutions would certainly not deny that the specialized actions that the institutions offer are necessary to them.

Deinstitutionalization is not simply exiting or avoiding specialized establishments; it is the fact that these institutions are now being called on to play another role than that which earlier devolved onto them or which they assumed. But it is not because deinstitutionalization is not coincident with avoidance of specialized agencies that the latter do not consistently conceal their temptation to remain "total" institutions, that is, with pretensions to dominate the whole person and this for a long period of time.

The claim that deinstitutionalization can be carried out in the facilities. Deinstitutionalization can be carried out in the facilities, just as institutionalization can occur in hidden form in ordinary community surroundings, but the temptation is certainly greater to try to establish full control over disabled persons within facilities than if one strives simply to be of service to them in the midst of our common social realities.

As for the influence of European and UN policies, these revolve around the principle of nondiscrimination. These international instances, strongly marked by developments in English-speaking countries, have insisted on this fundamental principle, issuing from the declaration of human rights, that discrimination should not occur by reason of a disability any more than on grounds of gender, skin color, or ethnicity. This has occasioned an interrogation of the systems, such as those in France, that still widely practice sequestration within structures and facilities whose rules, aims, and forms are predetermined.

Discrimination can be conceived of in positive terms as the totality of aids that permit each individual to live in the communal space. It is within the context of the common space that the human singular must find the means to live, to develop. The common space must be equipped with the means to accommodate each one of us. It should not be hard to understand that it is the *metamorphosis* that is at issue.

Deinstitutionalization, then, with regard to disabled people, is less the disappearance of institutions or specific assistive resources than their mutation to meet new social demands and a new historical context.

—Henri-Jacques Stiker

See also Antipsychiatry Movement; Modernity.

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DELIRIUM

Delirium, a complex neuropsychiatric syndrome comprising a diminished level of consciousness, cognitive impairment, and perceptual abnormalities including both hallucinations and illusions with reduced ability to focus, sustain, or shift attention, is a common disease state that has been described for centuries. Delirium occurs in about 15 to 25 percent of all general admissions to hospital. Most at risk are elderly, postoperative, and terminally ill patients. Although it is a common cause of morbidity and mortality, it is often unrecognized. The consequences are prolonged hospital stays, nursing home placements, prolonged cognitive disturbance, or protracted disability.

Delirium is a highly distressing experience for both caregivers and patients. Appropriate evaluation and treatment of delirium should be an imperative, not just for psychiatrists but for all physicians.

The term *delirium* has a very long history since the early Graeco-Roman period and has been used with many different meanings. In modern psychiatry, it was used to cover all types of acute disturbance of consciousness with general impairment of cognition, whether or not the patient was overactive and disturbed. Unfortunately, etymological confusion remains common, especially in medical fields; some of them are encephalopathy, acute confusional state, and acute organic brain syndrome.

The symptoms of delirium are wide ranging with poor specificity, but their fluctuating nature is highly characteristic and serves as a valuable diagnostic criterion. The core disturbance involves an acute generalized impairment of cognitive function that affects orientation, attention, memory, and planning and organization skills. Other disturbances, such as those of the sleep-wake cycle, thought processes, affect, perception, and activity levels, are underemphasized in diagnostic systems but are important in identifying and managing delirium. Much attention has been given to differentiating delirium from dementia, by noting temporal factors and by recognizing the level of consciousness and attention. The electroencephalograph shows diffuse slowing of background activity. Diagnosis can be improved by clinicians becoming more aware of hypoactive as well as hyperactive presentations, incorporating cognitive assessment with the Mini-Mental State Exam (MMSE) into routine practice, and using screening instruments such as the Delirium Rating Scale (DRS).

Underlying general medical conditions, substance intoxication or withdrawal, or multiple etiologies can cause delirium. Prescribed drugs (particularly those with anticholinergic properties, sedating drugs such as benzodiazepines, and narcotic analgesics) as well as cardiovascular disease and acute infections are perhaps the commonest causes, particularly in elderly people. Delirium tremens is caused by alcohol withdrawal.

The four main aspects to management of delirium are identifying and treating the underlying causes, providing environmental support (e.g., attention to noise, lighting, and mobility levels), pharmacotherapy (e.g., haloperidol, risperidone, olanzapine, trazodone), and regular clinical assessment and monitoring severity with use of an instrument such as the Memorial Delirium Assessment Scale (MDAS).

—Yutaka Matsuoka

See also Neuropsychiatry; Substance Abuse.

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DEMENTIA

As the baby boom generation reaches retirement age, and increasing numbers of individuals are surviving into older age ranges, the prevalence of dementing illness is also rising. Alzheimer's disease, the focus of this entry, is the most common cause of dementia, accounting for more than half of all dementia cases.

Currently, 4 million people in the United States have Alzheimer's disease, and estimates project that its prevalence will rise to 14 million by 2050. Its devastating consequences will continue to escalate and affect us either directly or indirectly in many ways. In short, Alzheimer's disease will increasingly become the dominant disorder in late life.

Alzheimer's disease is a progressive degenerative brain disease that is characterized by neocortical atrophy, neuron and synapse loss, and the presence of senile plaques and neurofibrillary tangles. The plaques and tangles were first identified and reported in 1907 by Alois Alzheimer, a German physician and neuropathologist, who autopsied a patient who had recently died from what appeared to be a mental illness. A definitive diagnosis confirming the presence of significant neurofibrillary tangles and neuritic plaques can be made only at autopsy or with a brain biopsy. As no effective cure for Alzheimer's disease is currently available, strategies for the management of disease symptoms focus on behavioral modification and the use of medications for behavioral management or slowing of the progression of disease.

The dementia of Alzheimer's disease is characterized by severe memory defects with additional deficits in language, "executive" functions, attention, and visuospatial and constructional abilities. Patients may also experience depression, psychosis, agitation, or changes in personality as well as a loss of awareness of their deficits (termed *anosognosia*) and impaired judgment. The cognitive, behavioral, and emotional changes result in an increasing dependency of dementia patients on others in their day-to-day functioning.

CLINICAL FEATURES

Definition of Dementia

Dementia refers to a syndrome of acquired cognitive impairment sufficiently severe so as to interfere with social or occupational functioning. According to the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*–Fourth Edition (*DSM-IV*; 1994), "Dementia of the Alzheimer's Type" involves memory impairment and cognitive deficits in at least one other domain, demonstrated by defects in language, praxis (or skilled movements), knowledge (agnosia), or impaired executive functioning, which are not due to other neurological disorders, medical conditions resulting in dementia, or substance abuse. The cognitive decline must be gradual, progressive, and severe enough to interfere with social or occupational functioning. The cognitive impairment must also represent a significant decline from a previously higher level of functioning, and it must not occur in the context of delirium. Other forms of dementia (e.g., dementia due to Parkinson's disease, dementia due to head trauma, and dementia due to endocrine dysfunction) will share at least some symptom overlap with Alzheimer's, although the pattern of cognitive deficits and underlying neuropathologies will differ.

Diagnosis and Course of Alzheimer's Disease

Because the dementia syndrome is associated with more than 50 different causes of brain dysfunction, and there are no known peripheral markers for Alzheimer's disease, a definitive diagnosis still requires autopsy verification of the presence of histopathological neurodegenerative abnormalities (i.e., neuritic plaques and neurofibrillary tangles. However, documentation of the presence of dementia and the exclusion of all other known potential causes allows Alzheimer's disease to be clinically diagnosed during life with relative certainty (i.e., 90 percent). Once diagnosed, patients with Alzheimer's disease often live for many years, eventually succumbing from conditions like pneumonia or organ failure. The duration of the disease varies widely and can be as long as 20 years or more, although the average length is 4 to 8 years.

Prevalence

Studies suggest that approximately 6 percent of persons over age 65 have severe dementia, and 10 percent to 15 percent have a mild to moderate dementia. The prevalence of dementia is age related, doubling approximately every 5 years after age 65. Not surprisingly, the prevalence of dementia is higher among hospital and nursing home residents than among those living within the community.

Risk Factors

A number of reliable risk factors for Alzheimer's disease have been identified. First, age is the single most important risk factor for dementia. Prevalence rates rise exponentially between the ages of 65 and 85. Second, women may have a slightly greater risk for Alzheimer's disease than men, although this finding may be due to their longer life expectancy. Third, the risk of developing dementia is increased fourfold by a family history of Alzheimer's disease. Given the discovery of certain specific gene mutations, there is now little question that this familial association is genetically based.

Finally, the risk of developing Alzheimer's disease is doubled for individuals with a history of a single head injury that led to a loss of consciousness or hospitalization. If one assumes that these risk factors are simply additive at the population level, then the attributable risk of developing Alzheimer's disease from these and other lesser known factors appears to be between 40 and 50 percent, or perhaps more.

Neuroimaging

A variety of neuroimaging techniques have been used to characterize brain changes in dementia. Some of the most recent techniques include structural analysis of the brain with magnetic resonance imaging (MRI), computation of regional cerebral metabolism with positron-emission tomography (PET), regional cerebral blood flow with single-photon-emission-computed tomography (SPECT) and determination of regional biochemical concentrations with magnetic resonance spectroscopy (MRS). More recent work with functional MRI techniques offers considerable promise as a noninvasive method of studying brain dysfunction associated with Alzheimer's disease. All of the above techniques may provide complementary information to the usual diagnostic procedures and may contribute to the early and more specific detection of the disease, although their routine use—apart from identification of alternative causes of the dementia syndrome (e.g., presence of tumors)—has not been recommended for diagnostic purposes.

NEUROPSYCHOLOGICAL DEFICITS

Failure of recent memory is usually the most prominent feature during the early stages of Alzheimer's disease. Numerous studies have shown that tests measuring the ability to learn new information and retain it over time are quite sensitive in differentiating between mildly demented patients and normal older adults.

In addition to memory deficits, patients with Alzheimer's disease, for example, also experience deficits in attention and concentration abilities. In fact, subtle impairments in the earliest stages of Alzheimer's disease may be seen on complex attention tasks depending on divided and shifting attention. Some patients in the early disease stages do not have attention problems, but such deficits typically emerge and increase in severity as the disease progresses.

Deficits or disability in some aspects of language increase in severity throughout the course of Alzheimer's disease. Certain language abilities tend to remain intact, however. Patients exhibit little impairment in articulation abilities, and they also have little of the severe grammatical deficits seen in other neurological disorders. With relatively few phonetic and syntactic deficits, the fluency of patients' spontaneous speech and oral reading typically remain intact. Difficulty with word finding is seen early in Alzheimer's disease patients, although usually not as early as memory deficits.

Disability in spatial cognition is evident in some patients with mild Alzheimer's disease, and in nearly all patients in the later stages of the disease. A progressive decline in drawing ability is also characteristic of patients with Alzheimer's disease. An early onset of impairment is often seen on complex tasks. For example, patients are significantly impaired compared to healthy older adults when asked to draw a clock or when copying complex geometric designs.

Although patients are typically aware of their earliest symptoms, such as memory problems, there is an increasing loss of insight as Alzheimer's disease progresses. Gradually, patients are unable to recognize their cognitive impairments and to judge the quality of their own behavior. Progressive decline in patients' executive function is also seen in their ability to think abstractly and to solve problems, with deficits occurring early in the course of the disease.

AFFECTIVE AND PERSONALITY CHANGES

Personality changes represent one of the most common alterations in Alzheimer's disease, affecting upwards of 75 percent of patients at some time during the course of the disease. Changes can vary widely in a number of ways such as disengagement or disinterest in one's surroundings, disinhibition or inappropriate social behavior, psychosis, delusions, or other disruptive behaviors. Affective changes can occur as well, and depressive mood and symptoms are common in Alzheimer's disease (e.g., 50 percent report symptoms of sadness or demoralization), and anxiety is reported in approximately 50 percent of patients as well. Hallucinations, which occur in approximately 25 percent of Alzheimer's cases, are typically visual or auditory in nature, although gustatory, olfactory, and haptic hallucinations have also been reported. Delusional preoccupation is not uncommon either. For example, Capgras syndrome, in which the individual believes that his or her family member has been replaced by an imposter, represents one of the most common types of delusional disturbances. Finally, agitation is also one of the most frequently cited symptoms in patients (up to 75 percent), which creates a tremendous burden for caregivers. In sum, abnormal behaviors as a consequence of affective or personality changes in Alzheimer's patients are quite common and typically give rise to more caregiver-related burden than do the cognitive sequelae.

—Mark W. Bondi

See also Alzheimer's Disease; Neurological Impairments and Nervous Disorders; Neuropsychiatry.

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DEMOCRACY

It is impossible to give a fixed definition of *democracy*. It has taken diverse forms both historically and theoretically. North American democracy is significantly different from European democracies. Democracy is not only what is carried out in its name, it is also what people think it is and should be. It is more a "horizon" than a definitive reality, a set of principles and desires that constantly guide and inspire us but that are never fully realized.

Democracy is always ahead of us. In one sense it is as imaginary as it is real. Democracy is a task, something that must be constructed. One can, however, draw the principal lines of this horizon. Democracy is above all the affirmation that sovereignty should belong to everyone, and its first principle is the liberty of individuals and their civic rights (this is political democracy). But for sovereignty and liberty to be exercised, access to goods and services must be as equal as possible, and there must be a form for the distribution of common wealth (social democracy).

In turn, the achievement of political and social democracy requires solidarity among the people, the sharing of fundamental values, and a desire to live together according to these values. This level might be called ethical democracy. Since democracies are always being made and remade—which constitutes their dynamism but also their fragility—they evolve and continuously face new questions. Today, democracies are confronted by certain issues that have become more crucial than they were in the past, questions that concern disabled people in particular. These questions are centered on *participation*, a word that tries to cover both the sphere of political freedoms and a part of the sphere of distributive justice. Second, democracies have to resolve the multicultural fact of how to bring individuals and groups with very diverse religions, languages, ethnic origins, traditions, and customs to live in a space that must remain a common space.

Throughout history, disabled people have often been excluded from democracy in its concrete form and thus from active participation in social life, from respect for their specificities, and from the solidarity that would have allowed them a life with dignity. When they were not put in a kind of ultra-human category (signs from the gods), they were, at least in extreme cases, relegated to an infra-human one (between animal and human), or, in less radical fashion, put under total guardianship and confined to institutions or, more recently, sequestered in specialized structures and aid programs. Certainly, since institutional democracy in the United Kingdom and France, fundamental rights were recognized for disabled people as for everyone else, but their citizenship continued to be conceived as conditional, since the essential concern was their well-being, their protection, and their adaptation to existing society.

The intent of legislation, the practices of social work, and the demands of the families themselves were all directed at the assumption of responsibility rather than the affirmation of the disabled as citizens. This constituted a movement toward the disabled that did not solicit their own contribution. Even when they were the object of close attention, even a disinterested love, they were in principle subaltern, not autonomous. Even when they had guarantees of public or private forms of solidarity (foundations, gifts, or allocations), the disabled were most often within the framework of "total" institutions, to employ Erving Goffman's phrase. Even when the principle of nondiscrimination was exercised with respect to them, they were not asked to engage themselves and to contribute, on one level or another.

Seen at close hand, our democracies, which we believe so advanced, here affirm liberty, there equality, elsewhere nondiscrimination, and beyond that even positive discrimination. But only rarely, and perhaps never, do we gather together the full set of notions that contribute to democracy, in their reciprocal limitations and their organic articulation: dignity, liberty, equality, nondiscrimination, equality of opportunity, equalization of opportunity, positive and specific acts. We must affirm, one at a time, each of these requirements to better establish those preceding, and not allow them to come into competition, even when they appear opposed or difficult to reconcile.

We know that if we develop only liberty, injustice will take the place of the idea of equality. If we enhance only equality, we create a form of totalitarianism that denies liberty. If we agree to set aside the idea of equality in favor of simple equity, we reinforce privileges to the detriment of citizens without them, but if we want equality without equity, we neglect the insurmountable social division. If we allow only the rule of nondiscrimination (which, moreover, is only a development of the recognition of the equal dignity of all human beings), we risk falling back into the formalism of abstract human rights, but if we go too far in the direction of specific measures to come to the aid of vulnerable or excluded groups, we stigmatize them and set them apart.

It is possible to continue at some length, showing that breaking the components of democracy down into constituent parts poses a threat to democracy itself. It is starkly obvious that no present democracy or other form of government groups the full series of elements that make up the democratic horizon in coherent and balanced fashion. Any given state may be more or less deficient in one respect or another.

Now, we must note two important challenges involving disabled people that make democracies vulnerable: participation and multiculturalism.

PARTICIPATION

The first challenge is that of participation. Participation is doubly threatened at the very moment when it is increasingly claimed, and in particular by the disabled. The first threat is overdriven individualism: When an interest in and preoccupation with "me," disregarding others and indifferent to the common good, is unilaterally in force, participation has scarcely any meaning. What counts is not the social link but rather the expansion of personal subjectivity. The social factor, other social beings and common agencies (e.g., the justice system, taxes, unions, and athletic associations), is there to serve the individual, and the individual's concern for them is only proportional to his or her self-interest. It is doubtless because of this individualism that demands for participation are becoming more insistent. Disabled people, sensitive to the weight of past exclusion and the risk of present individualism, demand to be the actors in their own existence and thus not only to be consulted but also to be implicated in the processes and policies that affect them. Beyond even their personal destiny, they increasingly want to become citizens concerned for the general life of their cities and their countries. Gaining such recognition is a difficult struggle, even if it is supported by the international community, for example, through the International Classification of Functioning, Disability, and Health.

Disabled people contribute to the advancement of democracy in proportion to their numbers and their dynamism. If they need democracy, democracy needs them. Along with other groups and social categories that are calling for greater participation (immigrants and women, to name two examples), disabled people are a factor in the progress of democracy.

Another threat lying in wait for participation is the huge number of people involved. This is an old problem, since the exercise of sovereignty within a nation takes place through representation. The power that theoretically belongs to all the members of the community in question must be delegated through the electoral process. The complexity of election modes makes such delegating opaque. Moreover, once elected, representatives can betray the people from whom they have received their mandate. In any case, how are we to be assured of their legitimacy over time and even more of the legitimacy of the weighty and complex administrations that have been put in place to govern? Another problem of our modern democracies is public opinion. How are we to organize it without manipulating it? How can we manage to establish public debates that are not cut short? How to reach minimal consensus?

There are no good and easy answers to these questions. Clearly, disabled people can play only a modest role. However, by calling to public attention their circumstances and their questions more and more, by denouncing the physical factors of their surroundings that impede their existence, by being members of international organizations (e.g., Disabled Peoples' International and the United Nations), they can contribute to greater transparency in the public debate and to a redisposition of society that is profitable to everyone.

MULTICULTURALISM

The second challenge to be reviewed here is that of multiculturalism. All democratic countries are experiencing an influx of populations with ethnic, religious, and cultural origins different from those of the population already present. The overriding question is one of the inclusion of persons and groups that are so diverse—inclusion in the same legal system, in the same school and same business, in the same values of respect, tolerance, freedom of opinion. The entry "Inclusion and Exclusion" in this encyclopedia develops some models for this relationship with the "other." On the one hand, assimilation may end in blindness toward differences through an overdriven normalization—this model is the current tendency, and thus the current temptation, in Europe. On the other hand, differentiation, through excessive fissuring, may end up destroying every real community in favor of a simple juxtaposition. This is the tendency, even the risk, in North American democracies.

The principle of nondiscrimination provides a response to this challenge. But it cannot alone be sufficient. We need the daily exercise of proximity, integrated neighborhoods, reciprocal recognition, and understanding. Here, disabled people can play an emblematic role. They exemplify a difference in comparison with average citizens, each in his or her own way. They highlight the question of living in proximity. By increasingly refusing separate treatment, special institutions, denials of or limitations on activities and participation, they force all those sites where social life takes place to be receptive and equipped so that every person, just as he or she is, finds fulfillment there.

Disabled people can show the way toward democratic inclusion. They are pushing to find means of every kind to accomplish this: physical accessibility to spaces of every kind, educational accessibility to schools, the establishment of support measures, and the techniques to practice the arts, to play sports, to travel, and to live without obstacles in their own homes. In this way, they impose their presence and point up the fact that every difference must find its own place among all the others. To take the example of schools, disabled children would have their specific needs met but within the framework of regular classes, with all the necessary support. As Stainback and Stainback wrote (1990):

> Total inclusion does not mean that special educators are no longer indispensable; they are even more necessary in order to work with regular teachers and with appropriate school programs that are stimulating for all pupils. On the other hand, special educators need to be integrated and to become regular or general teachers, and thus competent in areas relative to teaching, school programs, and the control of knowledge. (p. 4)

This idea has been articulated in different ways. David Cooper wrote of being oneself with others, a simple formula that illustrates that the community and the individual should advance together.

It would be better to conclude an entry on democracy with concrete examples rather than with abstract concepts, for democracy is, at base, what people actually make of it. But these visions can be understood only in the wider perspective that is opened by the word *democracy*, in which lies the very power of our life together.

—Henri-Jacques Stiker

See also Cultural Context of Disability; Inclusion and Exclusion.

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DEMOSTHENES (384–322 BCE)

Athenian orator and statesman

Demosthenes is today both an emblem of rhetorical skill and a model of overcoming speech impairment. It is commonly reported that Demosthenes overcame his speech impairment by various exercises such as holding pebbles in his mouth while speaking. We do not actually know what sort of speech disorder Demosthenes had, if any. In fact, we have little information about any individual in the ancient world with a speech disorder. Oddities of speaking were seen as personal characteristics, not as pathology; still, these oddities, if not the people affected by them, were seen unfavorably. More than a mere interpersonal skill, articulate speech was necessary for civic participation. Public speaking was an important mark of civic responsibility, duty, and membership in ancient Athenian society. The course of the Athenian community was steered by the one who had the most convincing argument. A good argument, though, had everything to do with presentation: The quality of the voice itself had the potential to sway one's audience. In addition to Demosthenes' surviving works (available in a seven-volume Loeb Classical Library translation), Plutarch's biography of Demosthenes is an important source of information, though it was written approximately five centuries later.

—M. Lynn Rose

See also Speech and Language Pathology.

DEPRESSION

Depression has been recorded since antiquity. It is estimated that the prevalence of depression in U.S. populations ranges from 3 to 13 percent, with an average of 20 percent of the adult population experiencing some depressive symptoms at any time. The lifetime incidence of depression is thought to be between 20 and 55 percent. The incidence of depression in women is twice as high as it is in men; this has been shown in many different countries and cultures. In elderly populations, depressive symptoms range between 11 to 59 percent among the medically ill elderly. These prevalence rates and gender differences are comparable in most countries where there are sufficient data to compare.

TYPES OF DEPRESSION

There are many forms of depressive disorder, such as major depression, dysthymia, and bipolar disorder. Major depression has a combination of symptoms that affect individuals' working ability, study, sleep, eating habits, and participation in pleasurable activities. Frequently, depression reduces capacity for work or results in unemployment; according to the World Health Organization, it is one of the leading causes of work-related disability of all medical disorders. Depression may occur only once but more commonly occurs several times during lifetime. Dysthymia is a less severe type of depression. Chronic symptoms may not lead to disability, but they do prevent individuals from ideal or even good functioning and chronically detract from enjoyment of life. Another type of depression is bipolar depression, which is characterized by cycling mood changes, from severely high mood, or mania, to low mood, which is depression. Sometimes mood fluctuates dramatically and rapidly, but most often changes are gradual. Once the person is in a depressive mood, he or she can have any or all of the symptoms of major depressive disorder. However, when he or she is in manic cycle, the individual may be very hyperactive and expansive, engage in high-risk-taking behavior, and make decisions that can be hazardous to his or her health and personal and social life.

Some types of depression may run in families, and genes may pass biological vulnerability. People with low self-esteem always consider themselves as overwhelmed by stress and are therefore prone to develop depression. Research shows that physical changes in the body are highly associated with depressive symptoms. Chronic medical illnesses such as stroke, heart attack, and Parkinson's disease can cause depressive disorder, which makes people apathetic and unwilling to take care of themselves. Likewise, medication for medical conditions including steroids, antihypertensives, and cardiac medicines are also associated with depression. Also, a serious loss or any stressful change in life pattern may trigger a depressive episode. Significant risk factors for depression among elderly people include bereavement, sleep disturbance, disability, prior depression, and female gender.

People with chronic illness are at high risk of developing depression. They are less able to control many aspects of their lives. Their functional impairments will be further exaggerated by the perceived limitations. Reduction of their psychosocial resources in terms of mastery, self-efficacy, and social support may also lead to depression. This hypothesis is supported by data showing that nearly one-third of widows experience symptoms consistent with a major depression during their first year of widowhood.

People with depression suffer from depressed mood or loss of interest or pleasure in activities on most days. They may also have appetite loss, significant weight loss, sleep disturbance, fatigue or loss of energy, and difficulty thinking, concentrating, or making decisions. Some of them may think of death or possess suicidal ideation.

People with depression decline in health-related quality of life. The degree of depression is associated with levels of energy, emotional well-being and social function, bodily pain, and general health perceptions. People with depression experience disabilities in family, job, and social aspects of their life. Depressed individuals often have negative self-perceptions of their social competence and have a negative impact on people around them. They may have behavioral skill deficits. They tend to be less assertive and less positive, have negative facial expressions and poor eye contact, and participate less actively in group interactions.

In addition to checking for the symptoms listed, each patient should be carefully evaluated for a contributing medical illness or medication or the presence of disorders related to and/or occurring with depression including dementia and substance abuse.

Depression, especially among elderly, seriously affects one's health status. Major depressive disorder has been associated with the decline of immune function in adult population. The depressive symptoms found in older people increase the risk of subsequent decline in physical functions. In the extreme case, death is the result. The most compelling consequence of depression among elderly is increased mortality from suicide as there is a causal relationship between depression and the hopelessness associated with suicide.

Depression is often associated with physical disabilities. The psychological problems in people with disability and depression are commonly associated with pain. About 20 to 35 percent of patients with rheumatoid arthritis show depressive disorders. Reduced physical competency also induces depression. In one study, some 37.8 percent of stroke victims during the first year showed depression; 25 percent of people with myocardial infarction suffered from major and minor depressive disorders; and 10 to 15 percent of people with diabetes were observed with major depression. Selective serotonin reuptake inhibitors (SSRIs) are considered the first line therapy for depression in recent years and are better tolerated by patients than the heterocyclic antidepressants, although occasional agitation, insomnia, gastrointestinal distress, and delayed ejaculation are known side effects. The dosage of antidepressant medication used during acute phrase often is also appropriate dosage for use during long term or maintenance.

As other drugs, traditional antidepressants bring about other side effects. People receiving heterocyclic antidepressants may have dry mouth, blurred vision, urinary retention, constipation, delirium, sedative effects, cognitive deficits, speech blockage, excessive perspiration, and weight gain.

For those who are nonresponsive to antidepressants, electroconvulsive therapy (ECT) may be prescribed. It is believed that ECT works by using an electrical shock to cause a seizure and a short period of irregular brain activities. However, people receiving ECT may have high rates of relapse and recurrence even if switched to continuation and maintenance drug therapy following response ECT and often experience difficulty in their memory for recent events for several weeks following ECT.

TREATMENT OF DEPRESSION

Psychological and Behavioral Treatment

Cognitive-behavioral therapy (CBT) is commonly used in treating people with depression, and studies show it to be nearly as effective as medication for less severe forms of depression. Cognitive-behavioral interventions or behavioral therapies involve the teaching of skills and assignment of homework to patients. During these therapies, specific achievable goals are set to help provide a new cognitive focus for patients. By addressing cognition, a therapist can help patients focus on positive life events, instead of just focusing on what makes them depressed.

Social skills training and interpersonal psychotherapy address the social interaction deficits experienced by people with depression. Skills such as communication, behavioral productivity, social interaction, assertiveness, decision making, problem solving, and cognitive self-control are taught during training sessions. Assignments aim to help patients generalize skills learned during treatment to real-life situations.

Complementary and Alternative Treatment

Recently, a kind of Chinese physical and mind exercise, *qigong*, has been shown to be beneficial to some depressed elderly with chronic physical illness especially in the Chinese population. Qigong features postures and movement, state of mind, and breathing. Patients' psychosocial functioning improved after practicing qigong, which included feeling more relaxed, more comfortable, and more optimistic and experiencing better sleep. This may be due to the fact that qigong emphasizes breathing relaxation. When the body and mind are calm, physical and mental functions improve. Correct posture, proper movements, clearing the mind of stray thoughts, and long and deep breathing all help a person attain a state of well-being and reduce mental and physical tension.

—Hector W. H. Tsang and Ellen Y. L. Chan

See also Acute and Chronic Conditions; Anxiety Disorders; Behavior Therapy; Bipolar Disorder; Psychiatric Disorders.

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DESLOGES, PIERRE (1742–ca. 1790)

French author

Pierre Desloges was born at Grand Pressigny in Touraine, in central France. He became deaf as a consequence of an infectious childhood illness. A member of a well-to-do family, he learned to read and write, but because he had an oral deformation that made his voice inaudible, he chose to remain mute. Near the age of 20, he took up residence in Paris, where he learned the trade of bookbinder and billposter.

He was a frequent companion of Abbé de l'Épée, who introduced him to Abbé Copineau, a disciple of Condillac, who would assist him in the preparation of a response to a book published in 1779 by Abbé Deschamps on the education of the deaf. Desloges's work, titled *Observations d'un sourd et muet sur un cours élémentaire d'éducation pour les sourds et muets* (*Observations of a Deaf-Mute on a Course of Elementary Education for Deaf-Mutes*), is of interest in several respects. Drafted in a new style, inspired by Copineau, that consisted in dropping double letters and those that were not pronounced, for example, *fam* instead of *femme* "woman," it furnishes information on the Deaf community of Paris and illuminates early French Sign Language usage. In sum, Desloges judged Deschamps's method reprehensible and useless for the deaf, since it consisted of teaching them articulated speech.

—*Jean-René Presneau*

See also Abbé Charles-Michel de l'Épée; Sign Language.

DEVELOPING WORLD

Seventy to 80 percent, or approximately 400 million, of the world's disabled people live in the developing world and of the world's poorest of the poor, 20 percent are disabled. The number of people with disability in developing countries is increasing due to poverty, malnutrition, violent conflict, HIV/AIDS, traffic accidents, work-related injuries, and "lifestyle diseases" such as heart disease and diabetes. Many efforts have been made to address disability in the developing world, from grassroots community programs to United Nations declarations and strategies. Despite this, the vast majority of disabled people in developing countries remain socially, politically, and economically marginalized and among one of the most vulnerable groups in the world.

This entry discusses the context and experience of disability in the developing world; the cycle between disability and poverty; the role of rehabilitation professionals in developing countries; and approaches that have been taken including community-based rehabilitation, rights-based approaches, inclusive education, and prevention. It examines the work of the "development sector," looks at reasons why disability has been ignored by the sector, and discusses reasons for and approaches to ensuring that disabled people access the benefits of development. The entry lists the major agencies working in disability and closes with a discussion of what the future holds for disabled people in the developing world.

Various terms have been used to describe the developing world, including "developing countries," "the South," "the majority world," "low-income countries," and "the third world." Classification of countries is derived from comparison of variables such as life expectancy, literacy rate, enrollment ratio, per capita income, percentage of people without access to safe water, percentage of people without access to health services, and percentage of children under age five who are underweight. Nonindustrialized countries are generally considered "developing countries" and these include all countries other than those in the Organization for Economic Cooperation and Development (OECD). Readers are referred to the United Nations Human Development Report for greater detail on classification and ranking of countries.

DISABILITY IN THE DEVELOPING WORLD CONTEXT

The context of living with and responding to disability in developing countries is significantly different from that in industrialized countries. The majority of people live in rural areas and have farming lifestyles, where water is often accessed from a central pump or well; bathing and washing clothes is done in rivers or from a bucket; and accessing services generally requires walking to the village and catching a bus to the nearest town, which can be many hours away. Urbanization is increasing as countries modernize and people move to towns and cities seeking education and employment. Increasingly, millions of small-scale farmers are unable to compete with imported foreign agricultural products since the deregulation of world markets, and they are having to give up their land and move to cities, looking for work. In many places, this has led to an increase in urban slum populations. The experience of disability in urban slums is very different from rural village settings; slums are often crowded with narrow, uneven paths between improvised shacks or tents; people are frequently living close to sewerage with limited access to clean water; slums may exist along train tracks, on flimsy huts on stilts overhanging water, or on the edge of towns; accessibility is difficult and privacy is often unachievable.

Access to basic health care is limited for the general population in many developing countries, and options for those with rehabilitation needs are a rarity. Health budgets are often very restricted and it is common that priority is given to preventing "killer" diseases such as malaria, tuberculosis, diarrhea, and HIV/AIDS, over the less evident issue of disability. Social welfare programs and pensions are rare, and the responsibility for supporting the elderly, sick, or disabled generally lies with the family. In some cultures, begging is an accepted means of society supporting the needy, and having a visible disability can be a viable means of income.

Massive indebtedness of most developing countries to industrialized countries has a major impact on disability. As a condition for receiving loans, most developing countries must adhere to structural adjustment programs, which frequently include cuts in social, health, and education expenditures; removing subsidies on basic foods and fuel; reducing public sector employment; increasing interest rates; introducing user pay systems for social services; increasing taxes; and a shift to export orientation. Budgets are cut to public health programs that would have prevented disabilities, such as immunization or water and sanitation programs; staff in health settings are overstretched and less able to provide the time required for disabled people; school class sizes are increased, making it even more difficult for teachers to cope with disabled children in the classroom; and inflated interest rates for small loans make it more difficult for disabled people to make a successful business from income generation activities. Producing export cash crops rather than growing locally eaten food crops further exacerbates malnutrition, which increases the risk of disability.

Developing countries experience disproportionately more natural disasters and violent conflict, acutely affecting disabled people. The ability of families to support disabled members is gravely tested in crises, where survival may depend on the ability to escape by foot or to find shelter, food, and clean water. Within refugee or displaced populations, disabled people are often left behind to fend for themselves. The incidence of disabilities increases in disaster or conflict situations because of combat injuries, land mines, breakdown in medical services, and interruption of preventive health programs. Sexual abuse as a weapon of war has had an impact on the mental health of some populations, particularly the women.

Marginalization of disabled people is widespread, although it differs from place to place. In some communities and families, disability is accepted as a normal part of life and disabled people participate to their capacity and are assisted with tasks beyond that capacity. However, these situations seem to be the exception, according to the vast majority of studies and reports on disability, in which significant discrimination is recorded. Discrimination may occur because of fear, ignorance, and assumptions regarding lack of potential of disabled people. Laws that prevent disabled people from marrying, attending school, owning land, or voting are structural forms of discrimination. Disabled girls and women often miss out on health care, particularly reproductive health care; they are disproportionately affected by sexual abuse, which is exacerbated by lack of knowledge of sexual health and rights.

Accessibility restrictions prohibit many disabled people from entering public buildings and using public transport. Dilapidated roads, chaotic traffic conditions with no pedestrian crossings, and dilapidated footpaths mean that many disabled people cannot move much beyond the area around their house. People with intellectual and sensory impairments or mental illness experience significant exclusion as their conditions and needs can be less obvious than physical impairment.

As in richer countries, many disabled people in developing countries are "protected" by families who do not wish them to go out and risk being hurt or ridiculed. Community gossip may create shame for the family or may have a negative impact on the marriage prospects for other siblings. This "protection," or denial of opportunities to perform tasks and undertake risks, can render the disabled person passive, reduce self-esteem, and reduce opportunities for developing independence.

The enormous burden related to mental health problems in developing countries is being increasingly acknowledged. High levels of stigma, lack of access to services, lack of awareness of treatment options, and inability to afford medicines mean that many people with mental illness remain undiagnosed and untreated.

THE DISABILITY-POVERTY CYCLE

The cycle between poverty and disability is increasingly being studied and documented. The World Summit for Social Development, held in Copenhagen in March 1995, observed that disabled people, as one of the world's largest minorities, are often forced into poverty, unemployment, and social isolation. Disability leads to poverty by excluding people from working or accessing education or skills development. Family members, usually women and girls, are frequently required to care for the disabled family member, reducing time available for earning income, going to school, or supporting the development of other children. This further contributes to the family's poverty. In certain areas, having a disabled child is reason enough for a man to divorce his wife as it may be deemed that the child's disability was her fault. Cultural norms may prevent her from returning to her mother and father, and she may be unable to wed again, having been "soiled" by her first husband. This places the woman and child at significant risk.

Conversely, poverty can lead to disability through increased vulnerability to risks. Poor people are less likely to be able to afford firewood to boil water and may live in places where sewerage is not clearly separated from drinking water, increasing risk of disabilities related to malnutrition and water-borne diseases. They may be vulnerable to injuries from unsafe work practices—it is difficult to resist dangerous worksites when the site manager can easily employ someone else who is willing to take the risk. Inability to afford antenatal and perinatal medical services, or simply lack of ability to afford the transport to these services, increases the risk of disability to the child and mother.

APPROACHES TO DISABILITY

Approaches to addressing disability in developing countries have mirrored those in Western countries to some extent—beginning with medical and charity models, followed by adoption of social and rights-based models. Institution-based rehabilitation, typically within the medical model, is criticized as an expensive means of providing rehabilitation to relatively few, generally only in urban areas. It is seen as too isolating from normal life, Western in approach, and specialized. The social model of disability considers disabled people as members of communities with rights and responsibilities equal to all others; it states that the problem of disability is not in the impairment, but in society's response to the individual and impairment, and in the physical environment. Change must therefore happen within families, communities, and societies. This does not mean rejecting medical or rehabilitation services, but it necessitates that these be provided in the context of wider change, rather than solely focusing on improving individuals' function.

The Role of Specialist Rehabilitation Professionals

Health teams that include a range of trained therapists, such as those in many industrialized countries, are sparsely located and often found only in cities, or sporadically in rural sites. In many developing countries, therapist positions are not in the government staff structure, and the only therapists are those with nongovernment agencies. The relevance of using therapist-focused rehabilitation frameworks developed in Western settings has been frequently questioned in developing countries. The magnitude of disability and the shortfall in health infrastructure and funding often undermine the feasibility of this approach on a national scale. However, the role of qualified therapists is vital, albeit in different ways from Western health settings. Therapists are needed for training and providing technical advice and support to community-based rehabilitation workers, special needs teachers, and support workers; reviewing complex cases; training civil engineers and architects to ensure accessibility to public spaces; working alongside local artisans and disability organizations to ensure suitable and effective designs for appropriate technology; designing appropriate income generation training and adaptations to equipment; and providing evidence and technical support to advocacy campaigns.

Community-Based Rehabilitation

Community-based rehabilitation (CBR) was introduced in the 1980s in recognition of the fact that provision of rehabilitation services to the majority of disabled people was impossible through existing institution-based approaches. It was instigated by the World Health Organization (WHO) as a strategy for providing cost-effective and accessible rehabilitation services to people in their communities. The concept was that large numbers of midlevel rehabilitation workers would be trained, supervised, and supported by skilled rehabilitation professionals. The rehabilitation process was to be demystified and responsibility given back to the individual, family, and community. However, over the past two decades it has been recognized that the original model of CBR was not reaching adequate numbers of disabled people, nor was it having the desired impact, and that disabled people were still experiencing significant discrimination, marginalization, and poverty, even if they had managed to access services through CBR.

During the 1990s, the emphasis of CBR evolved. Instead of focusing on mitigating the impairment or disability, it is now seen as a strategy within community development for the rehabilitation, equalization of opportunities, and social integration of all children and adults with disabilities, taking into account social, cultural, and environmental factors and removing the emphasis on medical rehabilitation. By increasing accessibility and human rights sensitivity generally, it should benefit all people in the community, not just disabled people. Some examples of outcomes of CBR programs include providing or facilitating access to loans, community awareness-raising, providing or facilitating vocational training, facilitating formation of local self-help groups, parents' groups and disabled peoples organizations, training in mobility and daily living skills, facilitating contacts with different authorities, and facilitating school enrollment.

Rights-Based Approaches

Rights-based approaches to disability are rapidly gaining currency in many developing countries. Since the UN Decade of Disabled Persons (1983–1992), disability activists and disabled people's organizations (DPOs) have increasingly spoken out in international fora, playing a key role in promulgating this approach, which is in line with the rights-based approaches to development espoused by the United Nations. Key elements are accountability, popular participation, equality and nondiscrimination, expansion of people's choices and capabilities, and social integration. Increasing global access to information and communication has assisted networks of DPOs in gaining strength and solidarity. DPOs offer mechanisms for disabled people's voices to be heard so that fundamental human rights and self-determination can be achieved, legislative reforms enforced, and attitudinal and structural barriers removed. Self-help groups are enabling disabled people to access microcredit and income generation programs, facilitating economic empowerment for an increasing number of disabled people and their families, similar to the achievements by women's groups around the world.

UNESCAP's Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-Based Society for People with Disabilities in Asia and the Pacific sets the priorities for the extended Decade of Disabled Persons, 2003–2012. These are (a) self-help organizations of persons with disabilities; (b) women with disabilities; (c) early intervention and education; (d) training and employment, including self-employment; (e) access to built environments and public transport; (f) access to information and communication, including information and communication technology; and (g) poverty alleviation through social security and livelihoods programs. The framework's guiding principle is that disabled people are integral in all endeavors.

Inclusive Education

It is estimated that only 2 percent of disabled children in developing countries receive an education despite recognition over many decades that education is a basic human right. In 1994, the UN World Conference on Special Education produced the Salamanca Statement and Framework for Action on Special Needs Education. This was crucial in affirming the world's commitment to, and outlining the roadmap for, inclusive education (IE). The essence of IE is the improvement of education services so that all children can be enrolled in ordinary schools, regardless of differences or difficulties, unless there are compelling reasons for doing otherwise. Inclusive settings have shown benefits for disabled as well as for nondisabled students. Disabled children have shown better academic and social achievement, more appropriate behaviors, higher self-esteem and motivation, and greater likelihood of living independently, gaining employment, and becoming married. Students without disabilities in inclusive settings have been shown to have academic performance better than or equal to their peers in noninclusive classes and to have developed positive attitudes and meaningful friendships with disabled students. The self-concept, social skills, and problem-solving skills of all students have been shown to improve in inclusive settings.

Despite its potential benefits, IE has not been widely successful in the developing world. A number of developing countries have educational policies or legislation that recognize the value of IE; however, the implementation of this is generally unsatisfactory or functioning only at a "pilot project" level and has not been scaled up across countries. Some of the factors preventing the success of IE include lack of funding for relevant educational materials, inadequate training of personnel, lack of advisory or support services, and large class sizes. Successful IE requires the support of professionals who assist in diagnosis, referral, and treatment, for example, audiologists, speech pathologists, and occupational therapists. These professionals are rarely available in developing countries. It has been argued that a more realistic approach to IE in developing countries at this stage, rather than aiming for provision of equipment and facilities for special needs, is promotion of welcoming schools that recognize differences, support learning, and break down discriminatory attitudes.

A fundamental difficulty is that in many developing countries, there is gross underfunding of basic mainstream educational services. Within this milieu, the role of global lobby groups to pressure governments and donors for guarantee of resources specifically for IE as a fundamental human right of disabled people is critical.

PREVENTION OF THE CAUSES OF DISABILITIES

Prevention is integral to addressing disability in the developing world. Programs include immunization, de-mining, water and sanitation, peace building, occupational health and safety, road traffic accident prevention, neonatal care, nutrition, health promotion, medicines that prevent specific disabilities, and management of the causes of childhood fever. Many donors have justified their role in disability by citing prevention programs; however, disability activists argue that this ignores the 10 percent of the population who are already disabled and that prevention alone is an inadequate response.

DISABILITY IN THE DEVELOPMENT SECTOR

The "development sector" comprises various agencies working toward improving the situation in developing countries and includes multilateral agencies such as UN institutions, government-to-government funding, charities, trusts and foundations, nongovernment organizations, and private benefactors. Projects focus on issues such as infrastructure development, poverty alleviation, community development, education, health, women, children, human rights, agriculture, water, environment, governance, security, and many others. Efforts by the development sector to work with disabled people have largely been small scale.

Many argue that the development sector has ignored disability, allowing disabled people to miss out on the benefits of foreign assistance, and thereby further disadvantaging one of the most marginalized groups in the world. For example, in the wake of Hurricane Mitch in Nicaragua in 1998, not one foreign donor required that accessibility codes be applied to construction projects, and as a result entire towns, including schools, hospitals, and other public buildings, were rebuilt with barriers for disabled people. Water programs do not always ensure accessibility to the pumps; inappropriate choices of training venue or means of transport present barriers to disabled people participating in capacity-building programs; obstacles to accessing small loans exist, for example, applicants may be required to own land, which precludes many disabled people. The formulation of development agendas has seldom considered the needs of disabled people; representatives of the disability community have rarely been consulted in the design and evaluation of development programs; and many donors, aid agencies, and development organizations do not have, or practice, policies of disability equality.

There have been many reasons given by development agencies for not tackling disability: It is not raised as a priority by developing country governments or communities; it is too specialist, too costly; and it would be more cost-effective to fund prevention programs. Disability activists and analysts have argued strongly against these pretexts, contending that due to discrimination and ignorance, disabled people's needs are systematically ignored, which is why communities and recipient governments are unlikely to raise disability as a priority. Fatalistic assumptions often exist that nothing can be done about disability, and consultations with communities to elicit their priorities for development frequently fail to meet with disabled people. Specialist rehabilitation requirements do exist, such as aids, equipment, and particular rehabilitation exercises, but only for *some* disabled people. Evidence shows that the rehabilitation needs of at least 80 percent of disabled persons can be met by ordinary people and local communities who are given appropriate knowledge and skills. For many disabled people, access to basic human needs is all that is required.

Donor programs based on charity and medical models, in which small-scale specialist rehabilitation projects have been funded, have reinforced the belief that addressing disability is expensive and that the benefits reach only a small number. The move to more social and rights-based approaches to disability seeks to distribute the benefits more widely. Cost-benefit analyses have shown that long-term benefits of including disabled people in the economically productive sector far outweigh the initial costs of training, awareness-raising, and making services, environments, and transport accessible. The cost of disability prevention programs is indeed less than programs working with disabled people; however, disability cannot simply be eradicated through focusing on prevention—it will always exist and unless resources are applied to removing disabling barriers and supporting disabled people, human rights abuses will be perpetuated and the potential contribution of disabled people will remain underused.

Another reason why disability has been disregarded is the absence of, or limitations in, data enumerating disabled people. Compared to areas that can show strong evidence regarding estimates of people affected and potential beneficiaries of programs, for example, malaria, inconsistent definitions of disability, poor survey methods, and unreliable statistics have meant it is problematic to justify funding. There is a great need to improve consistency and reliability of disability data.

The World Programme of Action Concerning Disabled Persons was unanimously endorsed by UN member states in 1982, and its principles further sanctioned in 1994 with the UN General Assembly unanimously adopting the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which became the international legal standards for disability programs, laws, and policies. It states that opportunities equal to those of the whole population and an equal share in the improvement in living conditions resulting from social and economic development must be ensured for disabled people. During the 1990s, commitment to the rights of disabled people was demonstrated through UN policies and programs in areas such as social development, advancement of women, children, shelter, population and development, education, and environment. The development sector has acknowledged that by ignoring disability, not only are the rights of a huge number of people being systematically violated but the world's goals for economic and social development, known as the Millennium Development Goals, adopted at the UN General Assembly on September 8, 2000, can never be met without actively addressing disability in all programs and sectors.

Twin-Track Approach

A "twin-track approach" to disability in development is being suggested by various groups. It appreciates the need for disability-specific programs as well as consideration of disability in mainstream development projects. For example, if a man in a wheelchair undertakes vocational rehabilitation and successfully learns how to handle a welding machine but physical barriers prevent him accessing the workplace, then his disability-specific rehabilitation has been of little use. Or if a mother makes her daughter a special handle to help her hold her pencil and write but she is barred from attending the local school because of discriminatory policies, then her efforts have been of little use. Conversely, if a government ensures that teachers are trained in inclusive education, ramps are put in schools, and buses enable disabled children to board safely but a young child is lying at home rigid with contractures and unable to move, all the efforts at modifying the school environment have been of no benefit to him. Or if public documents are produced in Braille to enable the visually impaired access to information but no one knows how to read Braille, then those mainstreaming efforts are of little use to them. A combination of disability-specific programs and mainstreaming efforts are required.

To enable full realization of the rights of disabled people, consideration of disability must be actively undertaken by agencies across multiple sectors, not merely by health and social welfare departments or disability-focused nongovernment organizations. Disability must be mainstreamed into sectors including housing and infrastructure development, public transport, finance, telecommunication, information, legislation, urban planning, education, employment, tourism, rural development, poverty alleviation, statistics, agriculture, refugees and displaced persons, defense, and law enforcement.

Some of the many strategies for mainstreaming disability into development include involving DPOs in the design and evaluation of mainstream projects and on steering committees; ensuring that enumeration of people targeted to benefit from projects are disaggregated to include estimates of disabled; systematically screening project designs to identify and circumvent potential barriers; appointing disabled people as staff; appointing someone within each agency or department to be responsible for considering disability across the program of work; allocating a small proportion of each budget to mainstreaming disability; incorporating monitoring and evaluation tools within all projects to assess the extent to which project-related benefits are reaching disabled people in the target community; and supporting the creation of self-help groups of disabled people in target populations—for example, in a slum development project, a self-help group would work to ensure that the voices of disabled slum-dwellers are heard.

Agencies Working in Disability in the Developing World

There are numerous agencies engaged in addressing disability in the developing world. Each brings its own priorities, skills, and approaches. UN bodies most directly involved are the UN Global Programme on Disability, the WHO, the UN Educational, Scientific and Cultural Organization (UNESCO), the International Labour Organization (ILO), the UN Economic and Social Commission for Asia and the Pacific (UNESCAP), the UN Children Fund (UNICEF), and the World Bank. The United Nations Special Rapporteur on Disability is responsible for monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities*,* and reports to the Commission for Social Development.

The UN Global Programme on Disability, housed in the Division for Social Policy and Development at the Department of Economic and Social Affairs, is the lead program on disability within the United Nations. Its mandate stems from the World Programme of Action Concerning Disabled Persons and the Standard Rules on Equalization of Opportunities for Persons with Disabilities and it also serves as substantive secretariat for the General Assembly Ad Hoc Committee on a Comprehensive and Integral International Convention to Promote and Protect the Rights and

Dignity of Persons with Disabilities. The WHO, through its Disability and Rehabilitation unit, focuses on supporting member states in framing policies, developing appropriate services, strengthening community participation, and supporting integration of rehabilitation into primary health care through CBR. UNESCO has led the "Education for All" initiative and has worked strongly toward IE. It focuses on developing IE national policies, developing human resources in support of IE, and developing materials and disseminating information in support of IE.

The ILO promotes equal opportunities for women and men, including those with disabilities, to obtain decent work, which it defines as productive work in conditions of freedom, equity, security, and human dignity. It works to overcome the obstacles preventing people with disabilities from full participation in the labor markets; improve knowledge on disability-related matters concerning training and employment; provide advocacy, guidance, and policy advice to governments, workers, and employers' organizations; and improve occupational health and safety and workplace conditions. UNESCAP hosted the Asian and Pacific Decade of Disabled Persons (1993–2002) and is now under way with activities for the next decade (2003–2012). Activities thus far have focused on web-based networking for people with disabilities, awareness-raising of public administration personnel, and training in the promotion of nonhandicapping environments.

UNICEF has focused on early detection and intervention, mainstream education, and CBR; land mine awareness and education to prevent injuries; and child-based prevention and intervention, advocacy and public education, partnership and capacity building, and data collection. The World Bank's disability goals are access, inclusion, and poverty reduction of persons with disabilities. It uses an economic approach to examine the impact of disability on poverty and is committed to disseminating knowledge resources on good practice in development assistance for disabled persons.

There are many nongovernmental organizations (NGOs) actively working in disability. Some of these include Action on Disability and Development, ActionAid, Associazione Italiana Amici di Raoul Follereau (AIFO), Christian Blind Mission International, Disabled Peoples' International, European Disability Forum, Handicap International, Inclusion International, International Disability and Development Consortium, International Disability Foundation, International Save the Children Alliance, Landmine Survivors Network, the Leprosy Mission, Pan-African Federation of Disabled People, Rehabilitation International, South African Federation of Disabled, World Blind Union, World Federation of the Deaf, and World Network of Users and Survivors of Psychiatry. Many of these have websites with information and resources.

WHAT THE FUTURE HOLDS

It has been estimated that numbers of disabled persons in the developing world will increase by over 120 percent in the next 30 years, while numbers in OECD countries will increase by 40 percent. The critical need to address disability within the developing world has been powerfully asserted by many groups, demonstrated vividly through the lobbying that occurred to bring about discussions on the Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities.

The outlook for disabled people in the developing world is mixed. There have been many gains made in terms of legislative and policy improvement, programmatic understanding about what works and what does not, changing attitudes regarding rights and discrimination, the formation of strong networks of DPOs, multiple global statements indicating the priority that disability must hold in development agendas, and strategies for ensuring that the benefits of development are experienced by disabled people.

However, there are macro forces in the world affecting the situation for disabled people that are not easily controlled. Poverty levels in many countries are increasing, and economic gains that are made have tended to benefit the rich and not the poor. Trade rules enforced by the World Trade Organization continue to advantage richer countries and have increased pressure on developing countries, forcing prices down and reducing any profits that small growers or manufacturers may have made. This mounting financial pressure at individual, family, community, and government levels diminishes energy and funds that might have been used to improve the situation of disabled people.

HIV/AIDS continues to threaten economic security in an increasing number of developing countries and is costing the world many billions of dollars in prevention and treatment programs as well as losses to economies through sickness and death of large segments of the labor force. This diverts funding that may otherwise have been available to implement action plans for disability. The amount of money spent on armaments around the world completely eclipses that spent on health, and as armed conflicts and the focus on terrorism continue, this amount is increasing rather than decreasing.

Despite these substantial forces, the disability-in-development movement is visibly strengthening and making unequivocal progress toward equity and achievement of human rights for disabled people. Governments and development agencies are being urged and trained to mainstream disability into a wide variety of programs and to work toward universal accessibility; collection of data on disability is being steadily gathered to enable greater advocacy and evidence-based program planning; the push toward inclusive schools is moving forward; several donors are beginning to require consideration of disability and accessibility in grant applications; and increasing numbers of disabled people are accessing means of financial security through micro-credit and income generation programs. Perhaps most important, a rising awareness of rights generally among disabled people has enabled a change in the way they see themselves and their place within families, communities, workplaces, schools, religious institutions, councils, governments, and manifold other settings.

—Beth Fuller

See also Community-Based Rehabilitation; Economic and Social Development, International; Inclusive Education; Poverty; United Nations; United Nations Standard Rules; United Nations Declaration on the Rights of Disabled Persons.

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DEVELOPMENTAL DISABILITIES

Developmental disabilities (DD) is an umbrella term for multiple conditions emerging from anomalies in development. The essential feature of DD is onset prior to adulthood and the need for significant, life-long supports. Conditions commonly encompassed under the DD term are intellectual disability, autism, cerebral palsy, epilepsy, and hearing and visual impairments, among others.

BACKGROUND ON TERMINOLOGY

The DD concept and terminology were first formalized in the United States in the 1960s and were not widely used internationally until the 1970s. In its original incarnation in the United States, DD was used in place of "mental retardation" (MR) in the 1969 reauthorization of the Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L. 91–517). In response to advocates urging Congress to be more inclusive of other disability groups with similar service and support needs, the DD term was substituted for MR in the amended legislation, defined as a disability originating prior to age 18, attributable to MR, cerebral palsy, epilepsy, or "other neurological conditions." The federal definition has undergone a number of revisions since the original act. Autism was added to the roster of DD conditions in the 1975 amendment (P.L. 94–103), and a significant conceptual change was the adoption of a noncategorical approach in 1978. Rather than using diagnoses of, for example, MR or cerebral palsy, DD was defined in terms of limitations in major life activity areas. The criteria of severity, chronicity, and origination prior to adulthood remained in the definition. Thus, one could have cerebral palsy or MR but not be considered DD if substantial support was unnecessary.

SIGNIFICANCE OF THE DD DEFINITION

In practice, the U.S. federal DD definition serves more as a conceptual statement than as a diagnostic standard. In its various incarnations across the United States, the term is used interchangeably with, and across, diagnostic disability categories but most commonly as an alternative term for MR. State governments within the United States employ their own eligibility standards, using the framework of the federal guidelines but anchored primarily on the older diagnostic groupings of the original DD definition. International use of the DD concept is less formalized and equally variable in application. The term is used interchangeably to represent congenital disorders, conditions arising from trauma or other damage to the brain or nervous system, and other chronic disabling conditions emerging during infancy or childhood. Nonetheless, the development of the DD definition marked an important turning point in that it formalized growing consensus about the significance of reforming what were at the time largely custodial policies and services.

UNDERLYING CAUSES AND PREVALENCE

The underlying causes of DD represent the broad array of developmental risks that can impair neurological function—hereditary disorders, perinatal and neonatal complications, malnutrition, disease, and trauma. For the majority of persons labeled as having DD, the underlying causes are of unknown origin. Since risk is not randomly distributed, the causes of DD and the rate of occurrence are highly variable, across both populations and regions of the world. Though definitions vary widely, some approximations of population size can be made. Using the core concepts of severity, life-long support needs, and emergence during the developmental period of life (vs. acquired later in life), estimated rates converge in the range of 1 to 2 percent in the developed world.

Of the limited epidemiological data available from the less developed nations of the world, reported rates are consistently higher though they tend to vary widely, ranging from 5 to 25 per thousand in the general population. Such variations are not unexpected given the differences in sampling and screening methods used across studies as well as the dissimilar circumstances of risk in different countries. Nonetheless, important causes of DD such as trauma, infectious diseases, and malnutrition are more pronounced in the developing world and it is not unreasonable to assume that greater risk translates into higher prevalence.

DD IN CONTEXT: SERVICES, RESEARCH, AND POLICY

The study of DD during the past 50 years spans the breadth of human endeavors, from molecular genetics to civil rights. A useful organizing template is the

International Classification of Functioning, Disability, and Health (ICF), which describes the disablement process across multiple dimensions: (1) body function and structure, (2) activities and participation, and (3) environmental and social factors.

Body Function and Structure

Given the prominence of genetic and neurodevelopmental events in the etiology of DD, emphasis is traditionally given to biomedical concerns, with a primary focus on prevention. Basic biomedical research focuses on the identification of specific risk in the neurodevelopmental process and development of interventions to prevent or reduce their impact. A classic example is the genetic condition phenylketonuria (PKU), in which excess phenylalanine results in neurological damage. Knowledge of biochemical dynamics led to preventive interventions in the form of protein-restricted diets. Public health approaches target understanding of the causes and distribution of DD on a population-wide basis in an effort to develop large-scale prevention programs. Examples include lead abatement in the older urban areas of the United States and folic acid supplementation in third world countries to decrease the incidence of neural tube defects among newborns.

Activities and Participation

Activities in the ICF refer to the performance of specific tasks, while participation reflects more global involvement in life situations. These notions are consistent with the U.S. federal definition, which defines DD across domains of activities (limited ability in self-care, receptive language, expressive language, learning, mobility, and self-direction) as well as the participation-like dimensions of independent living and economic self-sufficiency. The evolution of the DD definition away from specific diagnoses served to shift attention toward methods for enhancing participation in the larger society, rather than emphasizing the "repair" of individual deficits. The years since the early 1970s witnessed a dramatic expansion of publicly and privately supported services in education, employment training, family support, health care, income supports, residential care, and other related support services. Across the developing nations of the world, lack of fiscal resources limits development of publicly supported services and a professionalized workforce. Nongovernmental organizations (NGOs) funded through a variety of international organizations and agreements form the bulk of what would be considered a formal DD service system. What limited services are available are in the form of specialized and segregated schools, institutional services, and in recent years, a movement toward locally developed and controlled community-based supports. Generally, little is know about the structure services or the degree of need among persons with DD in the developing world. In both the developed and developing nations, the vast majority of persons with DD live with their families.

Social Factors

Early in the legislative development of the DD concept, the focus of DD policy was shaped by the idea that the environment in large measure determined the extent of disability, thus the emphasis on "rights" in the authorizing legislation (P.L. 94–103). Indeed, the U.S. federal effort developed in parallel with the emerging human rights-based themes of disability advocacy through the United Nations in the 1970s, and both developments were indirectly influenced by the emerging Scandinavian concepts of integration and normalization.

Policy was and remains anchored on the ideal of inclusion: abandonment of segregated institutional care in favor of community-based housing, education in the local school, and notably, emphasis on civil and human rights through legal and other legislative means. While implementation lags far behind the ideal, the efforts dramatically transformed the options available to persons with DD. Within resource-poor nations, service models are anchored on similar themes of social integration, opportunity, and the reduction of stigma. The rise of community-based rehabilitation (CBR) models in the less developed economies of the world in the 1980s, in which local resources and family networks are employed in providing supports, represents acknowledgment of the person with DD as a member of the community fabric.

SUMMARY

Ironically, the two forces that have most changed the face of DD—the ethos of human rights and the rapid advance in our understanding of the basic sciences of human development—may create difficult and as yet not fully understood ethical challenges. The emergence of human and civil rights as a relevant agenda item for persons with severe disabilities in the post-World War II era dramatically altered the character of the DD dialogue. Humane care was replaced by human rights as a guiding force for shaping services and policy. Yet the logical extension of the great advances in the biological sciences is the elimination of impairments and prevention of perceived "defects." The fit of persons with significant DD in our societies is an issue yet to be resolved throughout the world, and it is very much anchored to the larger discussion of how humanity is defined. The juxtaposition of these two trends represents one of the great new challenges in the evolving conceptualization of DD.

—Glenn T. Fujiura

See also Autism; Cerebral Palsy; Epilepsy; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Mental Retardation, History of.

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▣ DIABETES

Diabetes mellitus is both remarkably ancient and thoroughly modern. A disease known for several millennia, the pathophysiology of diabetes has been radically altered over the past century by medical therapeutics, transmuted from an acutely lethal disease into a more stable but still-too-often debilitating condition. Concomitantly, the experience of having the condition has transformed from laboring under a "death sentence" to intensively managing this ever-changing chronic illness.

Earliest descriptions of the ailment's symptoms date to an Egyptian text written in the sixteenth century BC. In the second century AD, the physician Aretaeus of Cappodocia offered a compelling, vivid portrait, declaring that "diabetes is a mysterious illness . . . [where] the flesh and limbs melt into urine." Derived from the Greek word for siphon, diabetes made "life disgusting and painful; [and] thirst unquenchable," according to Aretaeus, "and one cannot stop [patients] either from drinking or making water," as though like a siphon all liquid entering the mouth ran through the body, exiting the bladder. In 1674, Thomas Willis noted how "the diabetes or pissing evil" rendered the patients' urine "wonderfully sweet as if it were imbued with Honey or Sugar." By 1776, Matthew Dobson had demonstrated the presence of "saccharine matter" in diabetic urine, theorizing that excessive sugar had built up in the bloodstream. A slew of dietary treatments ensued, from "animal diets" consisting of "plain blood pudding" and "fat and rancid old meats" at the end of the eighteenth century to the early-twentieth-century "starvation diets" that drastically restricted the amount of calories ingested.

Then in 1921—after a generation of previous researchers had failed—a team of investigators in Toronto isolated the hormone insulin, which proved to be a wonderful treatment but not a cure for diabetes mellitus. Frederick Banting, Charles Best, J. B. Collip, and J. R. R. Macleod managed (despite much squabbling and subsequent bitterness) to produce and test the wondrous pancreatic extract on people with diabetes by 1922, an achievement soon thereafter awarded the Nobel Prize. Since then, new formulations of insulin have been developed, some acting slower but longer, others more immediately but for shorter periods of time. All forms of insulin thus far have needed to be injected in order to work.

We now understand diabetes mellitus to exist in two major forms. Type 1 (previously referred to as juvenile-onset or insulin-dependent) diabetes arises from an autoimmune process that destroys pancreatic beta-cells, which are the producers of insulin, thus leaving the patients deficient of this vital hormone. Without adequate insulin, not only does the level of blood glucose rise but so too the levels of fats and acids produced by the faulty metabolism of fat. Type 2 (previously referred to as adult-onset or non-insulin-dependent) diabetes is due principally not to a deficiency of insulin (although this can happen as the disease progresses) but rather the impaired ability of the body tissues to respond to insulin appropriately. Resistant to the influence of insulin, the body permits the blood glucose level to rise along with fats (but not the acids that plague type 1 diabetes). The terms *type 1* and *type 2* are preferable to the older terminology because (among other reasons) sometimes type 1 arises in adults, the incidence of type 2 diabetes is increasing among children, and type 2 often requires the use of insulin. Type 2 diabetes is many-fold more prevalent than type 1.

The impairment of the diabetic metabolism poses both short- and long-term threats to health and function. The acids pose the most immediate threat to life, since as they accumulate the patient can slip into coma and die. High blood glucose also causes the kidneys to excrete excessive amount of urine, which can lead to life-threatening dehydration. If the disease is kept sufficiently in check so as to avoid these immediate problems, and time passes, the health hazards stem mostly from the damage that elevated blood glucose levels (as well as fats) wreak on the blood vessels throughout the body, especially the retina of the eyes, the kidneys, the legs and feet, and the heart. Nerve damage also occurs. These impairments of the blood vessels and nerves, in turn, account for the high risk that diabetes imposes for blindness, renal failure, gangrene and the need for amputations, heart attacks or heart failure, and ultimately death. Indeed, despite the truly miraculous power of insulin, diabetes remains one of the leading causes of disability and death in the United States.

Diabetes in the setting of pregnancy poses a particular set of problems for both the mother and the fetus. If the maternal blood glucose levels are elevated during the first part of gestation, the embryo may develop abnormally; if high blood glucose occurs later in pregnancy, the fetus may die in utero or grow so large that birth is dangerously difficult, and the baby subsequently can have grave difficulty adjusting to life outside the womb. These problems now are mostly prevented through more rigorous management of diabetes during pregnancy, and medical attention is increasingly focused on developing means to ensure that the mother's longer-term health is not compromised by the pregnancy.

Providing a telling example of physician-induced irony, the treatment of diabetes, with either insulin or (for type 2) oral drugs that increase the body's response to insulin, also poses the health hazard of low blood glucose or hypoglycemia, which, in turn, can cause giddiness, slurred speech, seizures, brain injury, or even death. For many people with diabetes, anxious concerns about how they will behave if they were to become hypoglycemic on the job or in public greatly curtails their performance in these realms.

The work involved in the self-care of diabetes can be substantial. A diet and regular mealtimes need to be followed. Regular testing—as often as several times a day—with a home blood glucose monitor is a mainstay of current regimens. With good evidence to show that "tight control" of diabetes (i.e., keeping the blood glucose level constantly in the normal range) markedly reduces the risk of secondary impairments, the ways in which insulin are used are become more sophisticated but also more complicated, with potentially several injections of insulin throughout the day or even having a tiny pump inject insulin continuously under the skin. Other technologies, such as laser treatment of the retinal disease of diabetes or renal dialysis for kidney failure, have improved the quality of life and extended life expectancy of people with diabetes, while treatments under development, such as pancreatic beta-cell transplantation, may cause even more dramatic change in the biology of the disease and the experience of the illness.

Diabetes long has had stigma attached to the condition. Famous people who had diabetes often kept this fact a secret, until the example of open disclosure was set by individuals such as the tennis player Bill Talbert and more recently the actress Mary Tyler Moore. Although public awareness and acceptance of diabetes have increased dramatically over the past century, children and adults with diabetes can still confront barriers to participation in activities such as sports, and discrimination regarding employment or insurance.

Much work remains to be done to diminish the impairments, disability, and handicaps associated with diabetes. Given the rising epidemic of obesity in the United States and the United Kingdom, and the parallel rise in type 2 diabetes, especially notable in children, the disease that is treated with one of the most phenomenal medical discoveries of the past century still awaits a lasting solution.

—Chris Feudtner

See also Health Promotion; Obesity.

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DIABOLIC POSSESSION

Belief in diabolic possession, the occupation and control of a human being by a demon, and in exorcism, its religiously effected cure, was an important part of the Christian cultural tradition for much of Western history. The vulnerability of individuals to demonic assaults of this kind was seen as representative of the general threat Satan posed to humanity; conversely, the Church's power to cast out devils symbolized (and anticipated) the final defeat of Satan by Christ.

The characteristic features of diabolic possession developed from those described in the New Testament came to include violent convulsions and contortions, paralysis, local anesthesias, the vomiting of foreign objects, hostile reactions to religious symbols, grotesquely distorted voices, memory loss, and even articulate demonic alter egos. Hard data on incidence rates are hard to come by for most of the early Christian era. What is known is that late sixteenth- and seventeenth-century observers were struck by the great increase in demonic activity in their own times. Possession cases across the Christian world in this period—a time of religious unrest and heightened eschatological anxiety—certainly numbered in the thousands. Many involved children or adolescents (both sexes), and were blamed on witchcraft. The "symptomology" of diabolic possession was relatively uniform; it was also, significantly, relatively well-known.

Modern notions of disability capture past attitudes toward possession only very imperfectly. Diabolic possession was terrifying in large measure because of the positive abilities it might confer on the sufferer, ranging from superhuman strength to prophetic knowledge. A possessed individual's intimacy with the spirit world, while fraught with physical and moral peril, was epistemically enabling; demonic pronouncements concerning the coming of the Antichrist and the (typically imminent) end of the world were often taken extremely seriously.

Unlike the more conventionally disabled, the diabolically possessed were never a marginalized group. On the contrary, they tended rapidly to become centers of religious and lay attention. Tales of possession and exorcism figure frequently in the religious propaganda pamphlets of the early modern period. The New Testament records possessing devils testifying to the divinity of Christ, and later writers were not beyond citing demonic authority to settle matters of true religion.

Diabolic possession is now a largely extinct phenomenon (though anthropologists continue to study spirit possession, a much broader category of behavior, in many non-Western cultures), and its proper interpretation is a matter of some controversy. In fact, it was controversial even at its height: Priests, doctors, and lay propagandists devoted much effort to the difficult task of distinguishing "genuine" demoniacs from the merely mad or the frankly fraudulent. The possibility of non-demonic forms of possession (e.g., by the Holy Spirit) further complicated matters; complete uniformity of opinion, then as now, was the exception rather than the rule. Some historians have sought to explain all recorded instances of possession—bar cases of conscious fraud—as misdiagnosed cases of epilepsy, schizophrenia, or hysteria. More recent scholarship has stressed the central importance of contemporary religious beliefs in molding symptoms as well as diagnoses; on this view, attempts to identify possession with the categories of modern pathology are unlikely to be successful.

—Nick Tosh

See also Folk Belief; Religion.

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DICKENS, CHARLES (1812–1870)

English author

Charles Dickens began writing fiction at age 21, and by 24 he was internationally known and appreciated. He was one of few nineteenth-century writers to remain financially viable and publicly popular during his life. When Dickens was 10, the family moved to London, where his father worked as a clerk in the navy pay office. Dickens's father had a difficult time managing money. His extravagant spending habits brought the family to financial disaster, and in 1824, John Dickens was imprisoned for debt.

As a result of his father's imprisonment, Charles, the oldest of the Dickens children, was withdrawn from school and sent to work in a shoe dye factory. It is likely that much of Dickens's sympathy with the working class, poverty, and child labor abuses is tied into this history.

There are many themes in both Dickens's life and fiction relevant to disabilities. He suffered from recurrent depression that was particularly severe toward the end of his life. He also had periods of intense, frenetic activity during which times he varied from being irritable to productive and at these times was seen walking down London streets acting out characters and dialogue in novels on which he was working.

Between 1837 and 1839, Dickens wrote three of his most famous novels, *Pickwick Papers, Oliver Twist,* and *Nicholas Nickleby.* Dickens himself acknowledged that he was mercurial in temperament and notes the accuracy of his son's recollection that he had moods of deep depression and irritability in addition to his energetic bursts of vitality. In the 1840s, he started to experience writer's block. He would spend days locked up in a room, unable to put words on paper. He wrote: "Men have been chained to hideous walls and other strange anchors but few have known such suffering and bitterness . . . as those who have been bound to Pens."

Dickens in response to material written about him in his lifetime says, "You might, I suppose, want to read this as a description of your 'manic-depression.'" It is very likely that Dickens did have bipolar disorder. But despite and sometimes because of this condition, he remained highly productive and creative most of his life, though he experienced more and more depression toward the end of his life.

Portraits of downtrodden and seriously depressed people recur through Dickens's fiction, as do many individuals with disfigurement, impairments, and disabilities. The character Tiny Tim, who hopes that "people saw him in . . . church, because he was a cripple, and it might be pleasant to them to remember upon Christmas Day who made lame beggars walk and blind men see," is arguably the most memorable literary image of physical disability in the minds of many twentieth-century people. It should be noted, however, that Tiny Tim is also a disabled character whom many literary critics and disability activists find objectionable as he quickly became emblematic of a crippled child who is supposed to accept his suffering, and appreciate charity from healthier, wealthier, nondisabled people.

—Joseph A. Flaherty

See also Novel, The.

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DIDEROT, DENIS (1713–1784)

French author

From the volume and diversity of Denis Diderot's writings—difficult even to suggest if account is taken of his editorial work on the *Encyclopédie* (1749)—his "Letter on the Blind for the Benefit of the Sighted" ("Lettre sur les aveugles à l'usage de ceux qui voient," 1749) and "Letter on the Deaf and Mute" ("Lettre sur les sourds et les muets," 1751) may be singled out as relevant to disability studies.

Beyond its numerous philosophical implications, which drew six months of imprisonment for Diderot, the first letter contains three important and novel ideas about disability: (1) The blind enjoy the integrity of human faculties (this in opposition to the prejudice that the loss of a sense cuts off the ability to reason); (2) as a consequence, their education is possible and desirable (this is the thrust of additions made to the letter in 1771 after the extraordinary success of Mélanie de Salignac); and (3) what the blind actually can accomplish must be shown (this explains the presence in the letter of Saunderson, the English mathematician, and of "the blind man from Puiseaux").

The "Letter on the Blind" had considerable influence, without which the establishment of education for the blind by Valentin Haüy would doubtless not have occurred. The "Letter on the Deaf and Mute" is more of a philosophical discussion of language, but nonetheless helped to call attention to sensory disabilities during the century of "sensualist" philosophy and to animate the education of the disabled by the invention of adaptive techniques.

—Henri-Jacques Stiker

See also Blind, History of the; Valentin Haüy.

DIDYMUS THE BLIND

(ca. AD 313–ca. AD 398)

Alexandrian theologian and scholar

According to Palladius, Didymus the Blind (not to be confused with an earlier scholar of the same name [63 BC–AD 10]) lost his sight from "ophthalmia" when he was about four years old. However, thanks to his superhuman diligence, he obtained the highest scientific education possible at the time and became a famous scholar and a most prolific writer. The fifth-century writer Sozomen says that, while attending schools and learning through listening, he first learned letters of the alphabet through touch by means of shapes engraved in depth on wooden planks, and he went on to learn syllables and names through listening and memory. This information is repeated by the fourteenth-century Byzantine scholar Nicephorus Callistus.

Didymus had a profound command of the philosophical, theological, and scientific theories of his time and was chiefly indebted to Platonic, Aristotelian, Stoic, and Neoplatonic thought. In addition, his learning embraced poetry, rhetoric, astronomy, grammar, music, mathematics, and medicine, in the last of which he was influenced chiefly by Hippocrates and Galen.

He was a pupil of Origen, and the condemnation of the latter by the second Council of Constantinople in 553 for favoring preexistence and apokatastasis of the human soul discouraged the preservation of Didymus' prolific writings. Manuscripts containing some of his writings were discovered at Tura in Egypt in 1941, but their authenticity has been debated. Didymus wrote both dogmatic and interpretative works, the latter consisting mainly of commentaries on the Old and New Testaments. He also defended the doctrine of the Holy Trinity against Arianism.

In spite of his considerable theological learning and asceticism, Didymus remained a layman. In recognition of his achievements, Bishop Athanasius appointed him director of the theological school of Alexandria, a post he held until his death more than 50 years later. His students included such famous Christian authors as Jerome, Rufinus of Aquileia, and Palladius Bishop of Helenopolis.

—D. P. M. Weerakkody

See also Blind, History of the.

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DIGESTIVE DISEASE

See Gastrointestinal Disabilities

DISABILITY AND CAREER DEVELOPMENT

People with disabilities are underrepresented in the workplace. This entry examines the issue of people with disabilities in the workplace through the lens of career development and makes recommendations. To that end, the following topics are addressed: (1) work and disability, (2) disability and career development, and (3) recommendations to facilitate positive career development.

WORK AND DISABILITY

Work is a central aspect of life. On the one hand, it provides marketable goods and services. On the other hand, it provides meaning and structure to life, economic support, identity, and social stature.

Unfortunately, people with disabilities are seriously unemployed and underemployed. National statistics and recent research suggest that the situation is getting worse despite the Americans with Disabilities Act of 1990.

An additional complicating factor is the changing nature of the workplace. There are now fewer manufacturing and more service jobs along with more temporary and contract work. In addition, due to the rapid pace of change and increased competitiveness resulting from the global economy, employers are looking for workers who are flexible and adaptable.

The recent changes in the workplace may present challenges for some individuals with disabilities. Specifically, the increase in temporary and contract positions, often without benefits, disadvantages people whose conditions require costly medical treatment. This is not just an immediate disadvantage but also a long-term one in that temporary positions often help build résumés and qualifications for more stable positions. In addition, the increased complexity and interdependence of some jobs along with the need for many workers to be flexible and adaptable may pose challenges for some individuals with cognitive or emotional limitations. Furthermore, the increased job stress in some organizations may cause or exacerbate some disabilities.

CAREER DEVELOPMENT

The concept of career generally refers to individuals' work experiences over a lifetime. This life pattern is influenced by a full range of factors. Numerous theories have evolved to explain how people navigate the world of work.

Over the years, there has been considerable discussion about the applicability of theories of career development to people with disabilities. However, my colleagues and I believe the wide variation among people with disabilities means that theories cannot be either fully applicable or fully nonapplicable. Nonetheless, disability, like minority status, is certainly a risk factor for career development.

To address the interaction of disability and career development, my colleagues and I developed an ecological model of vocational behavior that includes the basic concepts and processes from the major theories and serves as an organizing framework for discussing the impact of disability on career development. The model is made up of factors and processes that interact dynamically with each other over time to shape careers. The factors are individual, contextual, mediating, environmental, and outcome constructs; and the processes are congruence, decision making, developmental, socialization, allocation, chance processes, and labor market forces. The elements of the model are used to frame the discussion of disability and career development.

Clearly, individual differences can have an impact on career development. However, it is important to note that people with disabilities are a very diverse group. For example, career development challenges are very different for individuals with congenital disabilities than for those who acquire disabilities after an established career. Similarly, the challenges for someone with a visual impairment differ from those for someone with an orthopedic impairment. The basic issue here is the extent to which individual abilities or limitations interact with workplace requirements and the extent to which discrepancies can be accommodated through individual adaptation or job accommodation.

The context in which people live clearly influences career development. Some minorities, people living in poverty, and some people with disabilities may have limited opportunities for work or experiences leading to positive career development. Other contextual influences include the economy, types of industry, and disability-related policies and legislation. Each of these influences can hinder or promote career opportunities for people with disabilities.

Environmental factors present significant issues for the career development of people with disabilities. For example, physically inaccessible environments not only limit job possibilities for some individuals but also limit work-related learning experiences for some young people with disabilities. Accommodations can address some environmental barriers.

Mediating factors are beliefs (individual, societal, or cultural) that affect or mediate the interaction of individuals and their environments. Individual examples include self-concept, self-efficacy (i.e., individual beliefs about specific task-related abilities), and outcome expectations. Each of these can be affected by experiences, which may be limited or adversely affected by disability. Culture, worldviews, and acculturation can have an impact on how disability is perceived and how people with disabilities are treated. Similarly societal beliefs can form the basis of discrimination or stereotypes that can limit career opportunities for people with disabilities.

The interaction of all the career development constructs and processes can produce outcomes that include job satisfaction, job stability, and job stress. Interestingly, job stress is a particular concern for some individuals with disabilities. Individuals in service sector jobs that are monotonous and give them little control over their work are particularly susceptible to job stress. Unfortunately, many people with disabilities are employed in these secondary labor market positions.

As noted earlier, the congruence of individuals with their environments is an important consideration in career development. Good matches between individual abilities and job requirements contribute to positive outcomes for people with disabilities and their employers. It is important to remember that congruence can be enhanced by job modifications and accommodations.

Decision-making processes can be adversely affected by disability. This is because some people with disabilities may have limited learning experiences that may lead to a relatively flat profile of interests. Other individuals may unnecessarily rule out occupations because of limited knowledge of their own abilities or of the potential for accommodation. In addition, some individuals with cognitive disabilities may need assistance in learning how to make career decisions.

When considering developmental processes, it is important to recall that interests are not innate traits; rather, they are learned. To that end, it is critical that children and young adults with disabilities have a wide array of opportunities to learn about different types of work. It is also important to provide experiences that enable productive socialization into the role of worker rather than a “disabled” role. To that end, chores may be very important for children with disabilities.

Allocation processes are a particular problem in the career development of people with disabilities. Low expectations by teachers and counselors may limit educational and career preparation opportunities. Similarly, labor market forces, including a sluggish economy and the increased competitiveness of the global economy may limit employment opportunities for people with disabilities.

Finally, it should be noted that chance occurrences often have an impact on career development. If a disability or limited experiences compromises individual ability to cope with or profit from chance happenings, the individual may be disadvantaged.

RECOMMENDATIONS

The first and most important recommendation for professionals working with people with disabilities is to remember that people with disabilities are, first, people. The disability is not just an individual characteristic. Rather it is a complex phenomenon that affects the interaction of individuals and their environments.

A common error is to look only at the individual in planning career development. Environmental modifications such as architectural accessibility, ergonomics, and job accommodation must also be considered.

The second critical recommendation is to remember that interests are learned. People with disabilities and service providers often unnecessarily exclude career possibilities because they are not "interesting" at the time. This exclusion may result from limited experiences or from failure to consider job accommodation possibilities. For people with congenital disabilities, it is important to promote exposure to a wide range of job possibilities and to guard against premature narrowing of goals. Individuals with acquired disabilities will need assistance in reconsidering possibilities that they may have ruled out either due to perceived barriers that can be overcome or due to limited experiences.

Third, workers must maintain and expand their skills. Career development is a lifetime proposition. People tend to change jobs many times throughout their working lives. In addition, in the current economy, long-term stable employment with one employer is no longer very common. It is important for all workers, including people with disabilities, to continue to develop skills and experiences to ensure marketability. Similarly, for people with progressive or unstable conditions, it is important to seek positions in which there is flexibility. There is some evidence that higher-level positions offer individuals more control over their work and are thus more adaptable in the face of changing health status.

Fourth, career interventions must be empowering in the long run. They need to promote individual self-determination as well as long-term positive career growth. Specifically, interventions should facilitate independence, or, if appropriate, interdependence, promote maximum consumer control, and be the most natural and least restrictive for the given environment. In other words, it is not appropriate to provide services or supports that create dependence, are under the control of someone else, or call negative attention to the individual.

Fifth, career interventions must address upward mobility. Many people with disabilities start in the secondary labor market, in jobs that are temporary or may lack good benefits or working conditions. Although these jobs may provide necessary experience, it is very important for service providers to help people to move on from these jobs to better and more stable positions.

Finally, career development is a lifelong process in which we express and support ourselves through work. People with disabilities have unacceptable levels of unemployment and underemployment. It is important for professionals to be creative in helping both individuals and employers examine the many ways in which society can be enriched by tapping the talents of people with disabilities.

—Edna Mora Szymanski

See also Employment; Job Analysis and Placement.

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DISABILITY ARTS

The term *disability arts* emerged in the United States in the 1970s and generally refers to the artwork by people with disabilities that reflects a disability experience, either in content or form. Some restrict the term to artwork that is also intended primarily for audiences with disabilities. Most often, though, disabled artists create work that is intended for audiences that include both disabled and nondisabled people. Occasionally, the term is used to refer to any artwork created by a disabled person, whether referencing disability or not, but this usage is uncommon among members of the disability community.

A primary function of disability art has been to articulate for the disability community as well as for the mainstream what disability means—politically, personally, and aesthetically. As such, disability art is considered an integral aspect of both the disability civil rights movement and what is known as *disability culture*, a term that describes a subcultural community of diverse disabled people (in terms of impairment type, race, class, gender, and sexuality) who nevertheless share certain experiences, values, and perspectives. Disability art across media shares themes that have helped to shape disability culture: an engagement with political issues relevant to people with disabilities, a challenge to stereotypes, a focus on the lived experience of disability, and the development of alternative aesthetics based on the particularities of the bodies and minds of people with disabilities.

Gallery openings, theatrical performances, and film festivals that feature disability art draw large numbers of attendees with disabilities. These venues necessarily provide access (such as wheelchair ramps and accessible bathrooms) and accommodations (such as audio description and American Sign Language interpreters) unavailable in the larger community. If access and accommodation are not part of the event, then the featured artwork cannot be properly described as "disability arts," even if the work features disability themes or disabled artists.

Frequently, disability art has an explicit or implicit political edge, as its themes and aesthetics run counter to prevailing notions of disability. Disability arts can explicitly expose the marginalization and societal mistreatment of disabled people. Because of this tendency, disability art often finds audiences at events such as activist gatherings and conferences, and it is therefore considered integral to the disability civil rights movement. Disability art also forms the base of support for the emergence of disability culture. Disability art events provide an occasion for disabled people to gather and define themselves as a subcultural community.

Often disability art explicitly rejects, critiques, or complicates traditional representations of people with disabilities. These representations include stereotyping of disabled people as objects of pity, medical intervention, inspiration, fear, curiosity, or wonder. Artists use a number of techniques to engage with these stereotypes. They inhabit them through parody, thus disarming the stereotypes' power to shame through the use of humor. They call explicit attention to stereotypes and then compare them to the lived experience of disability. Or they simply offer alternative visions of their bodies and lives that run counter to stereotypical representations without explicit commentary.

Artists with disabilities often use autobiographical material, whether in individual or collaborative work. A sense of urgency is palpable in these pieces, a sense that the actual stories of disabled people have been ignored, silenced, or diminished and therefore must be told. Autobiography offers first-person testimony of life with a disability, a corrective to traditional stereotypical representations. This work helps to clarify pressing political issues and personal concerns for its audiences.

Artists also represent the lived experience of disability by making work from the lives of historical figures with disabilities in a nonstereotypical way. Another tactic is to focus on how disability influenced or informed a historical figure, when a figure's disability identity has been downplayed or omitted from the historical record.

Disability art often fosters disability pride by embracing a politicized disability identity, celebrating bodily difference, and consciously participating in the building of a distinct disability community. Theater artist and scholar Victoria Ann Lewis suggests that such work exhibits "disability cool," a term the disability community uses to describe a revaluation and resignification of the very markers of disability and impairment that traditionally connote shame.

Traditional arts have evolved and become conventionalized over time according to bodies considered appropriate to each artistic medium. The body appropriate to perform ballet, for example, is different from the body considered appropriate to painting. The ballerina must be extremely thin, petite in stature, and symmetrical, with a long neck and strong limbs. While painters may not have such extreme physical requirement, they are generally assumed to have full use of their arms, hands, and eyes. Therefore, a ballerina in a wheelchair or a painter who uses his mouth to hold a paintbrush necessarily alters the aesthetics of her or his media. The particularities of these bodies transform the media in which they work. Disability artists that are most successful take advantage of the transformative potential of difference rather than trying to fit their nonstandard bodies into standardized conventions. The sometimes startling and innovative results of these artistic experimentations are known as disability aesthetics. Such aesthetics can also include an aestheticizing of assistive devices—such as canes, guide dogs, and interpreters—into the artwork itself. This inclusion runs counter to the tendency to consider such devices "add-ons" that are not part of the artwork itself.

Disabled artists must continually struggle to have their work taken seriously by art establishments, to be considered "professional." Few disabled artists have had access to quality training programs due to discriminatory admissions practices and rigid, unimaginative curricula that do not accommodate a variety of abilities. In addition, art therapy programs were often the only art training available to disabled people. These programs are not intended to provide professional training for its participants. The lack of access to training and the medicalization of disability arts have led to a stigmatization of disabled artists as amateurish, lacking in sophistication. Conversely, artists with disabilities can be branded "outsider" artists, especially when their work focuses on the subject matter of impairments or people with disabilities. This stigma remains despite the increasing numbers of professionally trained disabled artists and the increased visibility of disability art in mainstream venues. These pioneering artists have a long way to go until their work is considered a legitimate and regular part of the art world's multicultural mosaic. Nevertheless, disability art reflects the move toward self-determination in the cultural arena; disabled artists are consciously reshaping the media that have always shaped them in the public sphere.

—Carrie Sandahl

See also Aesthetics; Disability Culture; Drama and Performance, Representations of Disability; Stigma.

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DISABILITY ASSESSMENT/ EVALUATION, EUROPE

An important element with regard to disability is the evaluation of work disability as a percentage of loss (of working capacity or earning capacity) or as a category (e.g., severely disabled, partly disabled). These evaluations are the crossroads for people in the journey from work through sickness to disability or reintegration and open (or do not open) the way to social rights.

We believe it is important for readers of this encyclopedia to acquaint themselves with practices of disability evaluation in different countries. Knowledge of different practices may help those concerned to gain insight into the evaluation process. Moreover, it may offer suggestions to further improve the evaluation process.

Disability evaluation is thought to be as old as humankind itself, the first indications being found in Hammurabi's codex in which an indication is given of how to compensate the loss of parts of the body. In ancient Europe, the Romans and the Germanic people had sophisticated ways of weighing the social impact of damage to the body. The principles the Romans developed to pay for damaged slaves still rule the public programs of disability, whereas the Germanic principles live on in liability and professional risk. By the end of the nineteenth century, modern, state-governed disability insurance started to develop in Europe, first in Bismarck's Prussia, quickly followed by the other countries, each country developing its own specific arrangement.

In this entry, findings of an international comparison of disability evaluation are briefly presented and discussed. We made this international comparison in 2002–2003. We present information on the following issues:

The main characteristics of the arrangements for long-term disability in European countries

The main actors involved in the assessment

The characteristics of the assessment and the process steps

Quality control

In describing our findings, we use the term *assessment* to refer to the assessment by a professional, most often a medical assessor. The term *disability evaluation* refers to the whole processing of the claim up to the decision, involving other people, such as case managers and administrative staff.

MAJOR CHARACTERISTICS OF LONG-TERM DISABILITY ARRANGEMENTS

Legal Definition of Disability

The core characteristic of the long-term disability arrangement is the legal definition of disability for work. Although we found some variation in the legal definitions, we could generally discern the common elements of the handicapped role. These elements are as follows:

- Clients' (in)abilities to do work that can reasonably be asked of them
- Health conditions that explain these (in)abilities
- Chances and opportunities of improvement/ reintegration

Whereas the legal definitions in all countries investigated contain the first two elements, only in Norway and Spain is the element of reintegration explicitly stated in the definition of disability. In some other countries, this element is tied to the law on disability in connected regulations.

Operationalization of Disability

It is obvious that all three elements of the definition represent diffuse borders between being disabled or not. In individual cases, it can be a dilemma where to draw the line, a dilemma in which social norms and cultural values apply in an implicit manner. To achieve efficiency and uniformity, the legal definition of disability for work is translated into a more detailed concept for assessors. In this entry, we use the term *operationalization of disability* to refer to this process of translation, which can occur in various ways.

- A medical operationalization is characterized by an emphasis on medical findings, such as diagnosis of symptoms and impairments, and these findings in themselves justify the making of a decision regarding disability.
- A functional operationalization is characterized by an emphasis on (restriction of) activity, and these findings lead, by themselves or through job matching, to a decision on disability.
- An operationalization of rehabilitation is characterized by an emphasis on the possibilities of, and experiences with, rehabilitation, and these findings lead to a decision on disability.

We found the following operationalizations in the countries we studied:

- Purely medical (Belgium, Italy, the Russian Federation, the United States, and probably Hungary as well)
- Medical combined with functional (Ireland, Slovenia, Spain, and the United Kingdom)
- Medical combined with rehabilitation (France, Norway, and Germany)
- Medical combined with functional and rehabilitation (Denmark, the Netherlands, Slovenia, and probably Spain as well)

Other Characteristics of the Arrangement for Long-Term Disability

There is considerable variation in other characteristics of the arrangement for long-term disability. For instance, the number of levels of disability varies between countries. In some countries, there is only one level, "fully disabled"; in the Netherlands there are seven. The length of time that elapses from the onset of sickness to application for a disability benefit varies from 26 weeks (United Kingdom) to 5 years (Denmark). In many countries, this period is flexible with a maximum.

ACTORS INVOLVED

An important element with respect to the organization of disability assessments pertains to the actors that are involved. The assessments are always carried out by medical doctors, single or several, sometimes in multidisciplinary teams of varying composition. In some countries, such as the United Kingdom, a screening of applications takes place on evident cases of incapacity, carried out by non-medical assessors.

It is believed by some that assessments take place only in the "black box" of the medical doctor's consulting room. Consequently, it is thought that these doctors are the only ones who control the assessments. However, there are various actors that are involved in assessments. There is an intricate interplay between the assessors, the organization that contracts them, curative health care, the courts, the external supervisory organism (if there is one), the former employer of the claimant, and of course the claimant him/herself. The influence of the involved parties varies considerably, notably with regard to the role of curative health care. Curative health care is sometimes closely (Norway) and sometimes rather distantly (e.g., Italy, the Netherlands) involved in the individual assessment process. Moreover, the structural influence of curative health care on medical assessors, through professional education and in the setting of medical norms, is possibly much larger.

ORGANIZATION OF THE ASSESSMENT PROCESS

Primary Goal of the Assessment Process

The goal of the assessment may not only be to check the entitlement of the claimant to the benefit but also to promote rehabilitation/reintegration. The goals of the assessment process that we found in the different countries were as follows:

- Check of entitlement (Belgium, Finland, Ireland, Italy, the Netherlands, Norway, Spain, and the United States).
- Check of entitlement plus promotion of rehabilitation/reintegration (Denmark, France, Hungary, Slovenia, Russian Federation, and the United Kingdom). In Germany, it is decided following assessment whether a benefit will be granted or if rehabilitation should take place first.

Combining the check of entitlement with the promotion of rehabilitation/reintegration has advantages, but it also presents disadvantages. An obvious advantage is that reintegration is promoted. Limiting assessors to focus on the disability claim may result in insufficient attention for helping individuals to recover. However, the separation of rehabilitation and the assessment of disability may ensure a more "pure" assessment, in which empathy resulting from a "curing or caring" relationship is likely to be limited.

Process Steps

The process steps followed in the various countries investigated show quite some variation. In general, the evaluation of disability is preceded by a period of sick leave in which certification takes place and in which effort is put to rehabilitation. In some countries (e.g., France, the Netherlands) this period is supervised by Social Insurance. After this period, an application is made for a disability benefit. That claim is to be evaluated on file (e.g., Germany) or in an encounter of claimant and assessing professional(s). The actual decision is generally taken by the administrative staff, relying heavily on the professionals' advice. The time to reach a decision, often with help from health care institutions, is 5 days in the Russian Federation but up to 3 or 4 months in most countries. The actual time for processing varies considerably: In most countries it is around 1 hour, but in the Netherlands it is almost 7 hours. These periods are difficult to compare, however, because part of the work may be done by health care institutions. After admission, in general reassessments are scheduled periodically. In case of refusal, several ways of appeal are open to the claimant.

The process steps are described in greater detail in the publication of our comparative study.

Method of Assessment

We found the following methods of assessment in the countries under study:

- Face-to-face assessments supported with file information (Belgium, Denmark, Finland, France, Ireland, Italy, the Netherlands, Norway, the Russian Federation, Slovenia, and Spain)
- Assessments based on paper file, if necessary completed by face-to-face examination (Finland, Germany, the United Kingdom, and the United States)

Judging (some) cases on paper may be attractive for reasons of efficiency. Furthermore, assessors may feel less empathy for cases on paper than for claimants who are met during face-to-face examinations. This might contribute to a more objective assessment. However, the fact that the information present in the file stems from a personal encounter between the claimant and some kind of assessor should not be discounted. The robustness of the file information depends on this encounter in a comparable way as it does in countries that rely on face-to-face assessments.

Medical Assessors

The number of medical assessors involved in the assessment varies between countries:

- One medical assessor (France, Germany, Ireland, Italy [local level], the Netherlands, and the United Kingdom)

- Several medical assessors (Finland, Italy [specialist unit], the Russian Federation, Spain, and Slovenia)
- Number dependent on specific case (Hungary, Belgium, Denmark, and Norway)

The employment of several medical assessors seems to be primarily dictated by reasons of reliability and may in this way serve the quality of the decision: Additional assessors may correct each other. To our knowledge, however, it has not yet been empirically tested to what extent the use of several assessors increases the accuracy of the assessment.

Labor Experts

In some countries (Germany, the Netherlands, Slovenia, and Spain), labor experts are involved and routinely consulted. As labor experts are specialized in labor market conditions and job demands, they are used for establishing the relationship between disease, impairment, or functional limitation and participation in labor.

Decision-Making Process

What knowledge and what information is processed and in what manner? We found it particularly difficult to grasp the exact reasoning for determining disability for work. The decision-making process seems to rely on undefined professional knowledge applied in unique and individual cases. Moreover, the values of a specific country come into play. In some countries, such as France and Norway, factors like age and labor market are to be taken into account. In other countries, only medical aspects of the individual count in the assessment. This shows that the concept of disability for work is a relative concept, relative to values of that specific country.

Technically, evaluations should be organized in a manner that complies with the requirements of validity and reliability. It is probable that many of the practices and instruments described below are intended to enhance this part of quality, but it is unclear how the relationship between instruments and validity and reliability is viewed.

Instruments

The Netherlands is unique in using interview protocols and a computer program for selecting jobs a claimant could do. The medical decision is expressed into a list of functional capacities that are matched with existing jobs. This matching points out suitable work for the claimant and his or her earning capacity therein. The earning capacity is compared with the claimant's previous earnings and in this way a loss of earning capacity is calculated.

In the United Kingdom and the United States, we found lists that state which conditions entitle a claimant to a disability. The list used in the United Kingdom is more limited than the one used in the United States and focuses on serious conditions that do not require a personal capacity assessment. In none of the investigated countries did we find a list of diseases that do *not* entitle a claimant to a benefit.

In several countries, notably Germany and Italy, professional guidelines have been developed for specific diseases. Furthermore, in some countries (e.g., the Netherlands), guidelines have been developed with respect to the assessment process itself.

Factors Influencing the Decision Making

Several factors influence the decision making, some of which seem interrelated. These factors encompass the following:

Time pressure

Compassion for the claimant

Aggression/pressure from the claimant

Political pressure/climate

Claimant's age and prospects in the labor market

Although, formally, many of these factors should not influence the decision making, it appears to be difficult to rule out their influence. These findings hint at the importance of factors beyond the legal criterion that influence, or rather distort, the decision-making process in the assessment of disability. In many cases, these factors indicate differences between theory and practice.

QUALITY CONTROL

Knowing that disability evaluation is a vulnerable and important process, one might expect a well-established management circle in every organization so as to monitor and correct the process of evaluation. The input into the process, the process itself, the professionals, the output, and the outcome all offer possibilities to control quality. However, this is only partly done. Nevertheless, as described in the publication of our international comparison, there are a great many possibilities that may serve as inspiration to enhance existing quality management.

Criteria, Indicators, and Norms

In many of the investigated countries, quality control with respect to the assessment process is not in a very advanced phase. Criteria, indicators, and norms for the quality of the assessment process are generally not defined in a very precise, detailed manner. We have the impression that this is particularly true for the quality of the decision. Furthermore, it appears that the quality of the decision is generally controlled only by file inspection. The effectiveness of file inspection as a method for evaluating the quality of the assessor's decision is questionable. This is particularly problematic if files do not have to be very elaborate, as is generally the case.

Other Procedures to Control Quality

In some countries, quality is promoted by the specific design of the assessment process. For instance, in some countries, the quality of the assessment is promoted by using additional assessors or additional boards. This may be particularly effective when additional assessors/boards not only inspect files but also perform medical examinations.

Various other procedures to control the quality of the assessment exist. These procedures vary from intercolleague consultation, professional and continuous education, and coaching to using forms, protocols, guidelines, books, and magazines. In Slovenia, appeals are used to improve the quality of the assessment.

Individual feedback appears to be common practice in the majority of the examined countries. Moreover, in some countries (Belgium and Hungary), the assessor's performance is compared with the performance of other assessors (i.e., benchmarking).

Scientific Foundation of Disability Evaluation

As the evaluation of disability seems to be a particularly difficult task, one would expect a large scientific tradition to exist with regard to checking the validity and reliability of the evaluations. Such a scientific tradition barely exists. This is not to say that the evaluations are done in an inappropriate manner, but it is astonishing to see that such an important social activity seems so poorly funded with specific knowledge. Furthermore, if a country decides to change the organization of the assessment process, the lack of insight into the validity and reliability of assessments would make it difficult to predict the effects of these changes.

EPILOGUE

In sum, there is a large variation with respect to the organization and practice of disability evaluation in the countries under study. The exact reasoning to determine disability for work proves difficult to grasp. Furthermore, it seems that quality control is on the whole more implicit than explicit and systematic. This finding is particularly surprising because many systems of social insurance seem to be faced with problems: The volume of disabled people is in many countries considered to be too high; there are a number of people with health complaints of which the severity is difficult to establish; in many countries getting back to work from a benefit situation is very hard; and the transaction costs of the systems are high. In such a situation, a robust and tightly controlled system of disability assessments is of utmost importance.

A common framework of terms would be desirable as a first means to develop more robust practices. The World Health Organization's International Classification of Functioning, Disability, and Health (ICF), as far as the condition of the claimant is concerned, might offer such a frame although many other aspects of the disability evaluation are not addressed by ICF. Likewise the development of a taxonomy of functional assessment might offer a frame for identifying instruments of assessment. Moreover, the value of the instruments in social insurance needs to be empirically tested. In addition, research should be conducted into the validity and reliability of practices in disability evaluation. This kind of research would foster the development of more robust practices of disability evaluation, in particular with respect to quality control.

—W. E. L. de Boer, V. Brenninkmeijer,
and J. J. M. Besseling

See also Disability and Career Development; Functional Measurement.

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DISABILITY CONVENTION (UNITED NATIONS)

See United Nations Disability Convention

DISABILITY CULTURE

A universal definition of *culture* is the sum total of behaviors, beliefs, ways of living, and material artifacts characteristic of a particular group or society. Particular definitions of culture—such as *disability culture*—take many different forms and are *context bound* (dependent on the cultural and geographic context in which they are formed). Three common ways of thinking about disability culture are historical, social/political, and personal/aesthetic. Historical definitions of disability culture focus on art, poetry, language, and social community developed by disabled people. Social/political definitions of disability culture focus on a minority group distinction with common values of social and economic justice, radical democracy, and self-empowerment. Personal/aesthetic notions of disability culture emphasize a way of living and positive identification with being disabled.

Although concepts of culture vary as much as concepts of disability, one concept does seem clear. The experience of disability is embedded in culture and the social relations of culture. These relations influence the ways in which the importance and meaning of disability are defined, and the relation of disability to notions of functional impairment. To begin, it is important to recognize the distinction between impairment and disability, or *disablement*. Impairment is generally recognized as a loss or limitation of physical, mental, or sensory function on a long-term or permanent basis. Disability or disablement is generally understood as the loss or limitation of opportunities to take part in the life of a community on an equal level with others due to physical and social barriers in the environment.

Two dominant models of disability have been developed in the popular and scholarly literature on disability in relation to this distinction between impairment and disability. The social model of disability focuses on environment and assumes that impairment is not as significant as the disability that is constructed by social attitudes and cultural mores that underlie the structural environment. In the social model way of thinking, the environment disables the individual and needs fixing. The second model of disability has been termed the medical model. This model assumes that the individual needs fixing in order to adapt to the environment—either by therapy, medicine, surgery, or special treatment. A third model comes mainly from developing countries and is not as well-known as the social and medical models. This model has been termed the traditional model of disability and asserts that disablement is created specifically by traditional religion and culture. In this traditional model, people with impairments may be regarded as unfortunate, different, or blemished in some way, and as a consequence, they are sometimes perceived as having inhuman or nonhuman traits because they are considered unable to perform traditional social roles due to this difference.

All of these models relate directly to culture and provide a starting point for understanding how culture, and specifically disability culture, is developed or enacted.

To begin to understand how disability and culture might interact, and the importance of the distinction between impairment and disability, consider this example. In a particular culture, a girl child with an impaired finger might be considered unmarriageable and education therefore unnecessary. On the other hand, a boy child with severe multiple impairments might be offered comprehensive support services in school and technological communication aids that greatly minimize his functional impairment and allow him full access to social and cultural interactions. Although the girl child's impairment is strictly minimal in terms of her ability to function, the impact on her life chances and opportunities for interaction are significant compared to the boy child's in this example. As a result, it should not be assumed that the severity of an impairment equates with severe functional limitation or disablement. From this example, impairment exists, but its meaning and significance derive from treatment of the individual in the broader cultural context within which the individual lives.

DISABILITY CULTURE: THE BEGINNINGS

The notion of disability culture began to develop in the latter part of the twentieth century. Those who ascribe to a disability culture challenge the meaning of functional limitation in its broader cultural contexts, just as Deaf people have recognized Deaf culture since at least the beginning of the twentieth century. Although medical and traditional models of disability consider loss or limitation in hearing as a substantial impairment, regardless of cultural context, many Deaf people across different cultural contexts consider their deafness not as an impairment but as a linguistic difference from *phonocentric* language norms (language that relies on sounds rather than gestures). Deaf people who consider their deafness as a linguistic difference, rather than an impairment or even a disability, have self-identified as a linguistic minority and have developed a Deaf culture they consider distinct from disability culture or majority culture. Their notion of culture is primarily built on their distinctive language and associated sociocultural practices and beliefs, rather than that of a dominant or majority (mainstream) culture. As a result, Deaf people who embrace a Deaf culture claim their inalienable right to exist apart from "mainstream" society.

Deaf individuals who experience a Deaf culture do so from the experience of a lived community. It seems likely that what is commonly referred to as Deaf culture emerged from attempts to institutionalize Deaf people and to segregate them from hearing people. It is in segregation that communities—institutionalized or not, imposed or not—develop a "culture."

Institutionalization and segregation from mainstream society have also been attributed as the impetus for creating disability culture. For example, in the 1970s, young disabled people in Zimbabwe were institutionalized in residential missionary schools. Isolated from their families, and geographically removed from society-at-large, young people with impairments formed strong ties with each other and a support system among themselves. At one school, Nguboyenja, the "inmates," as they called themselves, held discussions among themselves and decided to start a social organization that they called Kubatsirana/Ncedanani (which means to help each other). They organized excursions, and through a combination of discussion and action, began to *conscientize* themselves (become aware of their solidarity and the common injustices they experienced). They launched a countrywide campaign and membership drive. Eventually, they established clubs in every district of Zimbabwe and a headquarters in the city of Bulawayo that they called Freedom House, where they could congregate as a community and develop a shared group identity.

By the same token, people with impairments in other countries who were institutionalized or excluded from mainstream activities and rights afforded to non-impaired citizens began to organize in similar ways. In the United States and other countries, communities of disabled people such as those in Zimbabwe's Freedom House began to mushroom in the 1970s. From the centers for independent living in the United States to the sanghams in India and the working cooperatives in South Africa, disability communities sprang up and have multiplied exponentially over the past 30 years. These communities have spawned what has become known today as *disability culture*.

The beginnings of disability culture have varied in different countries and regions of the world. In the United Kingdom and parts of Western Europe, for example, organizational groups of disabled people raised the consciousness of their members and brought them together to form a social movement for change. This social movement emphasized structural inequalities in society and focused on economic and institutional discrimination. In the United States, organizations of disabled people built on the momentum of the Black civil rights movement, focusing on litigation and legislation connected to civil rights. The U.S. disability rights movement, as it is called, developed an essentially political movement that emphasized identity as citizens and individual rights. In developing countries such as India, and several African countries, disabled people's organizations were influenced by fundamental human needs (shelter, food, education) that were largely taken for granted in more industrialized countries. The need to eradicate extreme poverty in these countries led disabled people to organize a movement that coupled disability with development, or the idea of their ability to make contributions to needed social and economic development in society as a whole. In Latin American countries and in Asia, organizations of disabled people tended to focus on liberation from basic forms of institutionalized political and social oppression as well as on individual human rights and basic needs. Their agendas tended to be more broad based and all-encompassing than in other regions of the world.

From these beginnings of political and social organization to confront injustices in mainstream society and to advocate for basic needs and rights, notions of a disability culture began to be talked about and embraced. People with impairments who had been "conscientized" to think of their impairments as disabilities constructed by societal practices and norms began to develop a disability pride. Through their collective political association and social interaction with other "disabled" people, they began to realize their individual strengths and abilities and to seek ways to celebrate them. Their initial focus on external oppression that manifested itself in segregation, social injustice, and discrimination led to a realization of the ways in which they had internalized this oppression. Negative societal attitudes, discrimination in institutional practices, and cultural beliefs that dehumanized them began to be challenged at a personal level.

Supported by their disability communities (political and social), and beginning to be socialized through these communities to a different way of thinking about themselves in relation to society at large, disabled people began to create an internal revolution of unique thought, action, and beliefs. This revolution manifested itself cross-culturally in unique expressions of literature, poetry, dance, film, theater, and music.

EXPRESSIONS OF DISABILITY CULTURE

At the present time, numerous individuals who identify as disabled express disability culture as artists, poets, and actors and in theater groups and can be found in all regions of the world. Their cultural expressions of pride in a disability culture include artwork such as the Disability Historical Quilt created by Amy McWilliams; Count Us In, an artistic women's cooperative in Zimbabwe; performance poetry groups in Britain such as Frank Bangay's Survivors' Poetry; dancers such as Bruce Curtis and the AXIS Dance Troupe; and musicians such as Canada's Jane Field, England's Johnny Crescendo, and Jeff Moyer in the United States. Writers and poets in fiction and oral history include Jenny Morris's popular book *Pride against Prejudice;* Allen Sutherland's *Disabled We Stand; No More Stares,* profiles of disabled people created by the Disability Rights Education and Defense Fund; and Sibongeleni's *Through Sibo's Eyes.* Many of these individuals are increasingly supported by institutions such as the more than 26 creative art centers in various countries, the Institute on Disability Culture, and the National Institute of Art and Disabilities in the United States. These few examples represent the tip of the iceberg in expressions of disability culture.

At the same time, in academia (higher education institutions at postsecondary and university levels), the field of disability studies was born. Disability studies scholars worldwide are currently supported by their own networks of academic communities such as the Society for Disability Studies, the Disability Research Unit (University of Leeds), and the Association of University Centers on Disabilities (based in Hawaii). Over the past 30 to 40 years, disability studies scholars have challenged perceived knowledge in such wide-ranging fields as anthropology, sociology, feminist epistemologies (study of the origin and limits of knowledge concerning gender), history, arts and humanities, and education, as well as medical fields of public health, bioethics, genetics and genome research, and rehabilitation.

Cultural representations of disability in disability studies have taken many forms within these fields. Examples include genealogical histories such as the French scholar Henri-Jacques Stiker's *Corps infirmes et sociétés* (1982), in which changing images of disability are recorded and analyzed across time. In the arts and humanities, disability studies scholars such as Paul Longmore, Mairian Corker, David Mitchell, and Sharon Snyder have traced negative images in mainstream (broader society) literature, art, and film, uncovering and exposing these images as inadequate, distorted, and contrived. These critiques have focused on culture as discursive practice (the codified, visible representations of culture), and in the process have developed the subversive potential of a disability culture as a reactionary transgressive response to these negative images. Performing artist and poet Cheryl Marie Wade (1997:408) vividly expresses the transgression that is characteristic of this genre in one of her poems:

> I am not one of the physically challenged—
> I'm a sock in the eye with gnarled fist
> I'm a French kiss with cleft tongue. . . .
> I'm the Gimp
> I'm the Cripple
> I'm the Crazy Lady
> I'm the Woman with Juice

Other examples of culture as discursive practice include those from anthropology. Numerous ethnographies and narrative stories from all regions of the world provide detailed descriptions of the lived experience of disability. These stories and ethnographies provide in-depth cultural images of personhood that capture the wide variety of individual experiences of disability. Examples include Crapanzano's *Tuhami* (South Africa), Mariana Ruybalid's *A Pattern of Silent Tears* (Costa Rica), and Irving Zola's *Missing Pieces* as well as Robert Murphy's *The Body Silent* (United States).

At the same time, the Third Estate (popular media such as newspapers and magazines) has begun to preserve and record the history of disability and to disseminate cultural knowledge of disability. In the year 2000, the United States' National Telability Media Center collected documentation of 3,000+ newsletters, 200 magazines, 50 newspapers, 40 radio programs, and 40 television programs dedicated to disability in the United States alone.

Finally, expressions of disability culture often take the form of special events such as commemorations of the Holocaust, recognizing the annihilation of more than 200,000 disabled people in Hitler's Germany.

Today, celebrating difference has become the mantra and visible manifestation of disability culture in all regions of the world. These visible and codified (recorded in texts or other means) manifestations of a fast-growing disability culture have created noncorporeal (nonphysical) manifestations of disability culture: shared values such as an acceptance of difference, tolerance for ambiguity, highly developed problem-solving skills, and "dark" humor among them.

DIFFERENCES IN DISABILITY CULTURE

Both the rise of disability communities through social and political movements and the development of academic communities through disability studies have contributed to notions of disability culture. The first, disability movements, conceive of disability culture as primarily social and political. The second, academic communities, view disability culture from predominantly historical, discursive, and linguistic perspectives. A third notion of disability culture underlying both of these approaches is the notion of a personal and aesthetic disability culture. In this third notion, a disability culture is constructed through concrete and specific encounters that are linked to a mind/body consciousness of disability. This notion of disability culture focuses on individual identity and identity formation—or how culture is produced. One concrete expression of this notion is the statement "I was born colored and crippled. Now I am Black and Disabled."

From this view, Kay Gainer's (1992:31) statement "Now I am Black and Disabled" says something about the culture within which she experiences life, its values, and norms. But her statement also reveals that she constructs her identity—not only in relation to her cultural environment—but in resistance to the broader cultural norms inherent in this environment. Others see her as colored and crippled, but she understands that she is Black and Disabled. In a similar way, Cheryl Marie Wade describes being a cripple as not one of those physically challenged but as a "French kiss with cleft tongue."

The process through which Gainer and Wade transform their identities gets at the heart of the multiple meanings that can be ascribed to disability culture. Some writers, particularly in countries of the North, have described the notion of pride inherent in these statements as an aesthetic expression of culture. One disability studies scholar, Harlan Hahn, for example, has asked the question, "Can disability be beautiful?" In his writing, he has developed the notion of impaired bodies as a potentially subversive source of sensualism with an intrinsic appeal because impairments provide a kaleidoscope of beauty beyond those embodied in cultural norms. This aesthetic pride in the impaired body represents one aspect of personhood related to disability culture.

Casting disability culture in relation to constructions and interpretations that individuals make of their experiences creates the possibility for multiple expressions of cultural identity. It has been argued that social and political disability movements have not allowed individuals room for these expressions. On the one hand, various disability movements have been challenged on the basis of their notions of disability as dichotomy (Us vs. the "Other" and social vs. biological). On the other hand, disability movements have brought disabled people of all stations and backgrounds together through a consciousness-raising process that has created and embodied notions of disability culture.

However, the underside of this growing disability culture is that disability pride is not typically created in isolation. It is most often created within disability communities, but also shaped by the wider majority cultural context. First, disability pride is generally developed through membership in a disability community. But the focus on unity against societal oppression within disability movements has been criticized as exclusionary and oppressive in itself. For example, for some individuals with impairments, personal experiences of racism are more immediate and significant than being disabled. For others, being blind is more important than being disabled. Still others with no visible markers of impairment or disability have expressed the feelings that they are marginalized by those with more visible traits. To complicate the issue further, People First (an international organization of those with developmental disabilities/cognitive impairments) by and large rejects the notion of disability as the primary marker of personhood.

Second, considering personhood further complicates the notion of disability culture in the ways that identities are created, transformed, or resisted in relation to majority culture. For example, although concepts of beautiful bodies have changed over time and vary greatly across cultures, the concept of the body beautiful—a svelte athletic figure—has been particularly emphasized in Western cultures. Pride in individual identity, as it refers to the body, may be a particularly Western concept. In contrast to Western notions of personhood as connected to "the body beautiful," many other regions of the world emphasize notions of "the body functional." As an example, for the Songye of Zaire being human is to live communally and carries with it social responsibilities. For the Songye, a woman with a physical impairment that inhibits fetching water or cutting wood becomes virtually unmarriageable and thus socially incompetent and a nonperson. The Punan Bah of central Borneo also equate personhood with concepts of social competence. A person in Punan Bah society is defined primarily by age, sex, and marital status. However, young children with impairments may be assigned daily tasks, such as caring for younger siblings, that allow them to demonstrate social competence. For disabled people who do not marry and lack offspring, it is considered the moral duty of their siblings to make a gift of one of their own children so that the disabled person can maintain a social status as societal members.

Constructions of disability in different cultures may cast disabled people as heroic or autonomous and capable. Those mutilated as a result of political, ethnic, or civil wars in such countries as Nicaragua, Vietnam, Sierra Leone, and East Timor have resulted in a heroic class of disabled people identified as "living martyrs." Many famous blind poets and writers in

Iranian literature attest to the image of disabled people as autonomous and capable.

In Islamic countries such as Iran and Pakistan, religion plays a central role in cultural formation. The Qur'an teaches that serving "handicapped" people is like being in the service of the prophets of God. Qur'anic teaching also stresses family ties and loyalty. In rural areas of Iran, a high number of genetically transmitted disabilities exist because all families are blood related. As a result, disability becomes an expression of honoring strong family foundations. By contrast, marriage of blood-related individuals is strongly discouraged in many parts of China, where Confucianism also stresses a perfectionist view of mental health. In these different cultures, a disabled child may be seen as a gift of God or as divine punishment (the will of Allah).

All of these different cultural practices and beliefs influence the process of developing a positive disability identity and of identifying with a disability culture. For those who do not identify as disabled, for those who have no knowledge of or who have not experienced a disability community or culture, or for those whose primary identity lies in alternative cultural connections, disability culture remains marginal to their sense of personhood.

DISABILITY CULTURE: A SUMMARY

To summarize, expressions of disability culture take three generally distinct forms. First is the notion of disability cultures as historical, discursive, and linguistic. This notion is based on the idea of culture as depicted (e.g., in art and poetry) or received (e.g., through a common language, historical lineage, or social community). This notion reflects traditional anthropological studies of culture.

The second notion of disability culture is based on social/political dynamics of group interaction. This notion is based on sociological notions of culture that look at minority groups and their solidarity and common goals of fighting oppression. The notion also includes common values of social/economic justice. From this way of thinking, disability culture stands *in resistance to* mainstream cultural expressions of disability as pathological and unproductive and stands *for* radical democracy and self-empowerment. In making disability a social/political issue, disabled people affirm the validity and importance of disability and represent a disability culture of dissent and struggle that includes material (economic) and temporal (body) dimensions.

The third general form that disability culture takes is personal and aesthetic. In this notion, culture is created from individual experience. The disabled person is an interpreter of cultural identity. The mind/body consciousness has the capacity to resist and transform values about disability in mainstream culture. Disability culture as personal/aesthetic is what disabled people acknowledge when they say, "I am proud to be Black and Disabled."

These three forms of disability culture take expression simultaneously. The boundaries between personal disability identity pride and notions of disability community are blurred. Identities forged from personal experiences may be supported and further developed by identity with a particular disability community—whether social, political, or academic. Disability culture as social/political coexists with personal values of disability pride. All of these forms of disability culture are expressed through textual, discursive, linguistic, and artistic forms.

LOOKING TOWARD THE FUTURE

Understanding disability culture offers several possibilities for future thinking, study, and practice. These possibilities might include (1) study of changes in the way disability and difference are defined and understood; (2) changes in thinking about disability identity in relation to society as a whole, as well as in relation to disability movements; and (3) changes in the ways we think about and develop supportive communities. These three possibilities open the way for furthering current notions of disability culture.

Defining Disability and Difference

Disability, disablement, and impairment are universal. They know no national, societal, or cultural boundaries. Anyone can become disabled—regardless of age, class, race, or gender—through birth, accident, illness, war, poverty, or advanced age. Most individuals, at some point in their lives, will experience disability, disablement, or impairment. The vast majority of the current 600 million disabled people worldwide live in developing countries. Most of these individuals live in rural areas and experience their cultural identity in traditional agrarian societies. It has been estimated that in some regions of the world, as much as 25 percent of the population have impairments. In fact, in some countries such as Mali, blindness is not considered a disability but just one of the many conditions of everyday life that all Malians experience in one way or another. Under these conditions, disability and impairment are not merely the experience of a minority group, but rather the normal condition of humanity. From this perspective, distinctions between disabled and nondisabled individuals that have formed the basis for developing disability culture become problematic. When all individuals are included—because they are frail, limited, mortal—there will be no distinct identity.

Study of disability culture also shows us that people who have impairments often define themselves not by their impairments, but in relation to disablement in cultural contexts, whether political, social, or aesthetic. These cultural contexts show us that different cultural beliefs and practices make biological impairment difficult to define (consider the example of deafness) or to separate from disablement. Notions of the impaired body shift and change, depending on the cultural context and historical times. Definitions of disability culture and the processes of enacting this culture (identifying as Disabled, or not) suggest a future in which *embodiment* (the experience of disability) may be a more effective way of understanding impairment than attempting to refine or develop universal descriptions and categories of impairment. Seeing disability and impairment as embodiment recognizes the historical and cultural aspects of impairment that are inseparable from the biological aspects.

Embodiment as a line of thinking in relation to impairment characterizes a small but growing number of recent scholarship in disability studies. Two examples are the books *Embodied Rhetorics: Disability in Language and Culture* (edited by James C. Wilson and Cynthia Lewiecki-Wilson) and *Semiotics and Dis/ability: Interrogating Categories of Difference* (edited by Linda J. Rogers and Beth Blue Swadener).

Recognizing Multiple Identities

Disability culture has been associated with identity politics because of its emphasis on collective identity to work for social change. This collective identity is based on an understanding of shared oppression and has the principle goals of forging positive images and changing society to meet the requirements of social justice and equity. Notions of disability culture that emphasize a collective identity have been criticized as the paradox of disability culture by disability activists and by disability scholars. The paradox lies in the argument that claiming unity against oppression is actually a source of oppression in itself. In other words, claiming unity leads to simple dichotomies of "Us" (Disabled) and "Them" (Nondisabled), ignoring and devaluing differences among disabled people.

All people have multiple identities. Gainer's statement "Now I am Black and Disabled" points to this fact. These identities take on different meanings and importance in different contexts. As an example, for many disabled people, being a woman, being gay or lesbian, or being Black is more disabling in relation to societal discrimination than having an impairment.

One of the core values of disability culture is acceptance of difference. At the same time, the social model of disability aims to fix the environment so that differences no longer make a difference. The paradoxes of unity and difference inherent in these values and goals need to be addressed in the future—both at a practical level and in theory.

Developing Communities

In industrialized countries of the North, the rule of thumb for counting the prevalence of disability is 10 percent of the population. In developing countries of the South, this number may be greater, due largely to conditions of poverty. All in all, disabled individuals the world over arguably represent one of the largest minority groups in the world. In today's globalized world, coalescing (coming together) as an oppressed minority—whether group membership is based on discrimination from full rights as citizens or on exclusion from social roles that define personhood—has become imperative.

The rise of disability culture has depended primarily on community building, either as a result of physical exclusion from society (as in Zimbabwe) or to resist social, political, or economic exclusion from basic human rights, employment opportunities, or from social roles and responsibilities connected to personhood. The social and political movements that have developed from community building have been composed largely of middle-class individuals from industrialized countries. These movements have also created social and political agendas within a disability culture that is based on Western assumptions about disability. The growing movement in developing countries exposes the limitations and narrow vision of these earlier movements.

The challenge for the future is to develop a broader cross-cultural and comparative vision of disability culture. This vision would take into account notions of personhood and "the body functional," as well as traditional models of disability and the broad vision of disability and development.

Globalization has brought with it advances in computer technologies and other scientific advances that have greatly benefited disabled people. For example, electronic devices for blind individuals, physical mobility devices, and opportunities for communication via the Internet have greatly contributed to the expansion of disability culture. At the same time, these technologies are not available to the majority of disabled people living in poverty. For this reason, globalization carries opportunities as well as dangers. The opportunities lie in including greater numbers of disabled people with access to disability culture. The danger occurs when these numbers represent mainly the privileged, creating a greater divide and exclusiveness in disability communities.

Whether disability culture is a state of mind, a place, or membership in a community, the ultimate goal of disability culture is for all disabled people everywhere to be at home in their country. Playwright and poet Neil Marcus (n.d.) puts it this way:

> If there was a country called disabled,
> I would be from there.
> I live disabled culture, eat disabled food,
> make disabled love, cry disabled tears,
> climb disabled mountains and tell disabled stories. . . .
> If there was a country called disabled,
> Then I am one of its citizens.
> I came there at age 8. I tried to leave . . .
> But found myself, in the end staying and living there . . .
> In my life's journey
> I am making myself
> At home in my country.

—Susan J. Peters

See also Aesthetics; Deaf Culture; Disability Pride; Disability Studies; Global Inequities; Globalization; Oppression.

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DISABILITY DISCRIMINATION ACT OF 1992 (AUSTRALIA)

See Disability in Contemporary Australia

DISABILITY DISCRIMINATION ACT OF 1995 (UNITED KINGDOM)

The Disability Discrimination Act 1995 (DDA) (as amended by the Special Educational Needs and Disability Act 2001), together with the Disability Rights Commission Act 1999, constitutes the primary source of antidiscrimination legislation for disabled people in the United Kingdom.

The campaign for antidiscrimination legislation in the United Kingdom began in earnest in the late 1970s, as a result of the emergence of the disability movement in the United Kingdom. This movement—a loose coalition of disabled individuals and organizations (influenced by disabled people and organizations in other countries and by other liberation movements both in the United Kingdom and abroad) with a common understanding and consciousness—developed a new way of understanding disability through what became known as the social model definition of disability. The term *social model* was coined by Mike Oliver in 1983 to reflect the growing demand by disabled people and their allies for “nothing more fundamental than the switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations on certain groups or categories of people.” In summary, the social model sought to understand the concept of disability as the result of the relationship between people with impairments and an oppressive society, as opposed to what became known as the medical model of disability, which placed disability within the framework of medicine. Accordingly, disabled people reframed the discourse so that their experiences and lives were explained as a reflection more of discrimination and oppression than of their impairments (their medical or quasi-medical condition). As a result, in 1981, the first attempt at antidiscrimination legislation for disabled people in the United Kingdom was made by Alf Morris MP. That attempt, together with the next 16, all failed. However, over the next 15 years, the campaign for antidiscrimination legislation grew, particularly with the passing of the Americans with Disabilities Act in 1990.

THE DDA

Until the DDA, disability legislation in the United Kingdom was primarily aimed at providing welfare support in the form of financial benefits or services and by establishing special homes and schools. The DDA, however, established requirements on employers, service providers including those disposing of or managing premises, transport providers, and (since September 2002) education providers to end less favorable treatment of disabled people and make “reasonable adjustments”: amend policies, practices, and procedures; provide auxiliary aids and services; and remove physical and other barriers.

Who Is Covered?

The act limits the protection afforded to those with impairments that have a substantial and long-term (which means at least 12 months) adverse effect on at least one of eight prescribed day-to-day activities. These activities are mobility; manual dexterity; physical coordination; ability to lift, carry, or otherwise move everyday objects; speech, hearing, or eyesight; continence; ability to concentrate, learn, or understand; and perception of the risk of physical danger. In addition, the act covers those who have had (but no longer have) such an impairment, those with severe disfigurements, those with symptomatic progressive impairments, and those with impairments that would have a substantial effect on one or more of the prescribed activities were it not for the fact that the effect is controlled or corrected by the use of prostheses, medication, or otherwise. On the other hand, drug addiction, hay fever, and certain mental illnesses that have antisocial consequences (such as pyromaniacs, kleptomaniacs, and voyeurs) are excluded. In total, more than 10 million people are covered—about 17.5 percent of the UK population. Those not currently covered by the legislation include those with impairments that do not have a substantial effect on a prescribed activity, those with short-term impairments, those with a genetic predisposition to impairment, those with impairments that have yet to manifest themselves symptomatically, those assumed to have an impairment, and those associated with or related to people with impairments.

The Employment Provisions

The DDA gives a general duty on employers to treat disabled applicants for jobs and employees no less favorably than they would treat nondisabled applicants and employees. In addition, the act requires that employers make what are known as "reasonable adjustments" to remove obstacles that substantially disadvantage disabled people. Such adjustments may be physical adjustments to premises to make them accessible or, for example, altering working hours or providing training. Discrimination is, however, lawful if it is for a reason that is both "material to the circumstances of the case and substantial." However, the employment provisions of the act do not currently cover certain categories of employment including the police service, fire service, prison service, armed forces, and partnerships.

The DDA abolished the quota system established by the Disabled Persons (Employment) Acts of 1944 and 1958. Until the DDA was brought into force, large employers—those with more than 20 staff members—were obliged to ensure that at least 3 percent of their workforce consisted of registered disabled people. That duty no longer remains. In any event, most large employers never met the 3 percent target. The rationale behind abolition of the quota system was, essentially, that with antidiscrimination measures, quotas were no longer necessary. In addition, even those companies that did meet the quota tended to employ disabled people at junior levels and the fines levied on those employers that failed to meet the quota were derisory. However, abolition was not universally supported as some believed that it provided a rare opportunity for a disabled applicant to be given an advantage over a nondisabled applicant in recruitment. It is hard to tell whether abolition has itself (without the DDA) affected employment opportunities for disabled people.

Discrimination in the Provision of Goods, Services, Facilities, and Premises

The DDA also affords some protection to disabled people in the provision of goods, services, and facilities. These include access to and use of any place that members of the public are permitted to enter (including shops, churches, courts, railway stations, and public parks); access to and use of means of communication; access to and use of information services (including advice agencies); accommodation in hotels and boarding houses; facilities by way of banking and insurance and for grants, loans, credit, and finance; facilities for entertainment, recreation, and refreshment (including bars, restaurants, theaters, and leisure centers); facilities provided by employment agencies; and the services of any profession and trade (including doctors, lawyers, and hairdressers) and any local and public authority. The act requires providers of such services not to treat disabled users less favorably than they would a nondisabled person and also to make such adjustments as may be reasonably required to remove or reduce obstacles for disabled people. Adjustments may be to policies, practices, and procedures to provide alternative means of communication (such as text phones, Braille, extra staff, and other equipment) and (from September 2004) to the physical environment and buildings. Discrimination is, however, permitted if it is related to health and safety, capacity, the need to be able to provide services to others, or additional expense unrelated to the duty to make reasonable adjustments. The provisions do not apply to aspects of the general environment (such as street furniture), some private clubs, the design or manufacture of goods, or anything related to national security.

There are similar obligations on those disposing or managing premises save that there is no duty to make any adjustment.

Transport

The act establishes time frames for meeting minimum requirements for access to public service vehicles (buses and coaches), trains, and licensed taxis. However, there are currently no directly enforceable antidiscrimination provisions.

Education

Until September 2002, most education was expressly excluded from the antidiscrimination provisions of the DDA. However, amendments brought by the Special Educational Needs and Disability Act 2001 extended the DDA into the provision of education in schools and colleges. Schools must not treat a disabled applicant or pupil less favorably than they would a nondisabled applicant or pupil and must make adjustments to policies, practices, and procedures (though not, necessarily, in the provision of auxiliary aids and services—which is dealt with by separate, education legislation—or in physical adjustments to premises). Colleges must also not treat a disabled applicant or student less favorably than a nondisabled applicant or student and must make adjustments to policies, practices, and procedures; in the provision of auxiliary aids and services; and (from September 2005) to physical features. Discrimination is, however, permitted in order to comply with permitted forms of selection, to protect academic or other standards, and where it is "material to the circumstances of the case and substantial."

Two key recent cases have illustrated the extent of the effect of these new provisions. In *Ford Shubrook v. St Dominic's 6th Form College* (2003)*,* the Court held that the refusal of a college of further education to permit a 16-year-old student with cerebral palsy to commence academic studies, because of concerns about his ability to access parts of the building, was, having regard to all of the circumstances, unlawful. The Court issued an injunction requiring the college to admit the student. In *Buniak v. The Governing Body of the Jenny Hammond Primary School* (2003)*,* a Tribunal held that a school acted unlawfully in discriminating against a six-year-old student in a variety of ways at school, including in excluding him from school activities and in refusing to secure adequate staffing support for him.

CHANGES FOR 2005

Recently, the government passed the Disability Discrimination Act 2005. The changes extend the protection against discrimination in job advertisements, group insurance, transport services, public authorities, and private clubs, among others. The changes also deem people with HIV infection, multiple sclerosis, or cancer to be disabled for the purposes of the DDA at the point of diagnosis (not simply at the point that the impairments become symptomatic).

—David Ruebain

See also Air Carrier Access; Communication: Law and Policy; Housing: Law and Policy.

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DISABILITY IN CONTEMPORARY AFRICA

Africa is the second largest continent in the world with 40 countries and a population of 800 million people. Geographically, it is often divided into northern Africa and sub-Saharan Africa. Northern Africa is mostly Muslim, while sub-Saharan Africa is mainly Christian. Africa is a continent of contrasts—geographically, economically, and culturally. Geographically, Mount Kilimanjaro in northeastern Tanzania (the highest mountain in Africa) stands at 20,000 feet, while the Sahara Desert in Egypt sinks 436 feet below sea level. African countries range in size from Togo with a land area of 21,927 square miles to Sudan with 967,495 square miles. Economically, Africa is generally a poor continent—some of the poorest countries in the world are in Africa—and yet it hosts some very rich coastal trading countries and some of the wealthiest individuals. Add to these contrasts the extensive varieties of languages and ethnic groups; the South African government alone recognizes 11 official languages in the country.

What this means is that Africa has a mosaic array of cultures within which disability exists. It is important to understand disability in Africa within this context. Rich cultural heritages—indigenous, traditional, and modern—provide an essential context for understanding disability. Within this context, poverty and its implications are the major problems in Africa—both as a cause and as a consequence of disability. Nevertheless, disabled people and their organizations in Africa are pursuing a rich path to development that provides strength and spiritual force for economic self-determination and political empowerment at the individual and collective levels. They will need these forces for the "long journey towards inclusion in development as a contribution to the transformation of the African continent" (Lorenzo 2003:776).

CULTURAL CONTEXT OF DISABILITY IN AFRICA

Traditionally, disability was viewed suspiciously and negatively in Africa, but as Chimedza, Mpofu, and Oakland (2000) observed, the situation is changing to a certain degree. Africa today is made up of a rich cultural heritage, both indigenous traditional and modern. The majority of the millions of citizens of Africa live in rural areas, and in the main they hold indigenous traditional worldviews. A minority of Africa's citizens live in towns and cities, and in the main most of these people subscribe to modern scientific worldviews as a result of the continent's colonial heritage and modernization (Mpofu forthcoming). This affects the African people's understanding, definition of, and interaction with disability. For example, indigenous traditional African societies view or define disability as "a limitation in social role functions resulting from physical, sensory or emotional abnormalities and is of a spiritual nature" (Mpofu and Harley 2002:27). This view is reflected in the proverbs that are used in relation to disability (Devlieger 1999) and in the nature of the words they use to describe and to define disability (Burch 1989; Devlieger 1998; Mpofu 1999). Thus, the Bantu languages in sub-Saharan Africa, for instance, have the suffix *-rema* or *-lema* (i.e., becoming heavy, to fail, to experience difficulty or foolishness) in words that refer to disability. The implicit meaning is that having a disability makes one incapable of many roles. Moreover, in many of these languages the word *rema* or *lema* is prefixed by the object or animal referent *ki*, *chi*, or *isi* (for "it") as in *kilema* (e.g., in Lebe, Sanga, Songye languages: Angola, Congo, Zambia); *chirema* (Shona language: Zimbabwe, Mozambique); or *isilima* (Ndebele, Nguni, Zulu: Malawi, South Africa, Tanzania, Zimbabwe). Therefore, the traditional African view of disability places a person with a disability somewhere between a human being and an animal or object. This view is demeaning and pejorative even in those cultures and yet continues as acceptable everyday practice. Unfortunately, it promotes wrong messages, attitudes, and stigmas against people with disabilities by dehumanizing them as objects, things, and animals.

Generally, proverbs in the African cultures are used mainly as words of wisdom to advise and warn each other on topical issues and situations. Proverbs on disabilities in the African languages serve a similar function. Kisanji (1995) argued that

> in traditional Africa, proverbs generalize a community's experience and that each proverb was accompanied by a parable which provided a sketch of the original situation . . . understanding proverbs to do with disability in African languages helps understand the attitudes towards disability and persons with disability in the society.

It is therefore important to understand the nature of disability as portrayed in the African proverbs. Several themes tend to run across most proverbs in eastern and southern Africa (Devlieger 1999). There is fear by people without disabilities of becoming disabled. One sees a sense of insecurity related to disability in many of these proverbs. For instance, there are several proverbs that send strong warnings against laughing at disability or at persons with disabilities. The proverb "Tosepanga lemene, Efile kiakupanga" (Don't laugh at the disabled person, God keeps on creating you) is widely used among the Songye people. The theme is also expressed in many other countries in Africa, for example, Zimbabwe (Shona): "Seka hurema wafa" (Laugh at disability after you are dead); Tanzania (Swahili): "Cheka kilema, uzae kilema" (Laugh at a deformed person, and you will bear a deformed person); and Zambia (Chitonga): "Haaseka bacembele bulema buzya buseka" (To him who laughs at old people, a crippled state comes laughing). The implications of laughing at persons with disabilities make clear the insecurity of any person's life. This insecurity is obvious for the persons with disabilities, but the possibility of becoming disabled is emphasized as a possibility to everyone. The message "it can happen to you one day in life" is very clear.

The other theme that seems to characterize proverbs on disability in Africa especially in sub-Saharan Africa is that there seems to be a general acceptance of the limitations of disability. For instance, this acceptance is clearly illustrated not only concerning the vulnerability of being blind but the acceptance of the limitations of that condition. Examples of this can be found in Zimbabwe (Shona): "Bofu harimemi hunza" (A blind man does not inspect a game pit) and Senegal (Wolof): "Gumba du jiite yoon" (A blind person should not lead the way) (see Devlieger [1999] for more examples). These proverbs offer a different way of thinking in contrast to the rehabilitation approach to disability, according to which the disadvantages of disability may be reversed or compensated.

By contrast, the third theme shows that there appears to be a general acceptance of people with disabilities as a source of integrity and family connectedness in some of the proverbs. The point these proverbs make is that although persons with disabilities can face negative attitudes and laughter elsewhere, the family is one source of consideration and respect. People cannot laugh at or look down on a member of their family who has a disability. It is unacceptable. Examples of this can be found in Tanzania (Swahili): "Mama hawezi kumkana mtoto, hata akiwa na vilema" (A mother cannot repudiate her child, even if it has defects); Zambia (Chewa): "Mako ndi mako usamuone kuchpa mwendo" (Your mother is your mother even if she has a deformed leg); and Zimbabwe (Shona): "Benzi kunge riri rako, kudzana kwaro unopurururudza" (If an idiot is a member of your family, you applaud his dancing).

One of the major challenges of understanding disability is to address the meaning of disability in a cultural context. Such meanings are no doubt situated in the tensions between language and the experience of disability. Language is the vehicle of our thoughts, feelings, attitudes, and ideas toward objects, ideas, and people. The language that people use to describe other people if negative shows the enshrined negative attitudes and stigmas that have been accepted as normal in that society. Through its language, the African traditional society perpetuates a mixed culture that generally looks down on people with disabilities. People with disabilities then continue to experience significant social stigmas. For example, studies in schools have revealed that students with disabilities are discriminated against by their peers and teachers and are more likely to be ascribed more negative characteristics (e.g., dirty, lazy, useless, dishonest) than their other classmates (Chimedza et al. 2000; Mpofu 1999; Barnatt and Kabzems 1992).

At the same time, it is important to note that in some traditional African communities disability is accepted as a positive attribute. People with disabilities are revered in some communities in Africa. Some disabilities are viewed as having extraordinary powers that influence the community (Mpofu 2000; Ingstad 1995). In such cases, positive attitudes and beliefs about disability exist. However, such communities are few and limited to specific disabilities (e.g., a one-eyed person is believed to see better than a two-eyed person and to possess extraordinary vision-based powers; some psychiatric disabilities are viewed as spiritual gifts). For instance, among the Chagga people of eastern Africa, children with disabilities are regarded as hosting evil spirits, thus guaranteeing the safety of the whole community from the same spirits (Devlieger 1995). In such situations, some African people with disabilities seem to enjoy much more acceptance among their community than elsewhere.

In contrast to these indigenous, traditional views of disability, modern African views of disability are emerging, largely influenced by the West—particularly through education and modernization. For example, a modern Zimbabwean definition of *disability* is "a physical, mental or sensory condition which gives rise to physical, cultural or social barriers inhibiting an individual from participating at an equal level with other members of society in activities, undertakings or fields of employment that are open to other members of society" (Government of Zimbabwe, Disabled Persons Act 1994, p. 51). Such definitions conform to modern worldviews of disability.

THE PROBLEMS OF DISABILITY IN AFRICA

Of the 800 million people living in Africa, estimates of the prevalence of disabled people range from 3 to 18 percent, or approximately 50 million individuals. The DISTAT (United Nations Disability Statistics Database) figures (as reported by Elwan 1999:6) provide high estimates of 18 percent of people under 15 years of age in Ethiopia, to low figures of 3 percent in Malawi, with several other African countries falling within the range of 10 to 15 percent. In some areas, this number may be higher, as in some villages in Zaire, where more than 30 percent of the population may be affected by river blindness (Coleridge 1996:106).

Poverty and disability are linked. Limited access to adequate health care, education, and employment increases the risk of illness, injury, and impairment. Perhaps one of the most dramatic examples is the AIDS pandemic. Worldwide, 39.4 million people are infected with HIV/AIDS. The World Health Organization (WHO) reports the highest rates of infection in Africa and estimates that disabled people—especially those with hearing and visual impairments—are two to three times at higher risk for infection than other groups because of their lack of access to education and health care. Disability is thus a life-and-death survival issue in many parts of Africa (Disabled People South Africa 2000). By world standards, the situation is bleak.

The main cause of disability in Africa today is poverty. Unlike developed countries, diseases that are otherwise preventable such as polio, measles, tuberculosis, and meningitis continue to cause impairments and disability in Africa. This situation exists because governments are too poor to afford preventive measures for these diseases, or they have not prioritized prevention in their development agenda. Another cause of disability that is poverty related is malnutrition. Both severe malnutrition and undernutrition cause disability. Children either die or become disabled due to malnutrition and starvation simply because there is no food to eat. This situation is more common in wartorn parts of Africa. Wars in such countries as Rwanda, Burundi, Angola, Congo, and Sierra Leone have resulted in significant numbers of injuries and disabilities. Because of wars, children and women suffer and become victims of death and disabilities. The United Nations estimates that 45 million land mines are buried in 11 African countries with Egypt, Angola, and Mozambique the most affected (Onasanya 2004). This situation will cause more disability if not managed properly.

Lack of resources due to poverty and war, in combination with cultural values, means that service provisions for people with disabilities in most African countries are very limited. For example, less than 1 percent of the approximately 6 million children with disabilities in sub-Saharan Africa who are school age attend school (Chimedza, Mpofu, and Oakland 2000). Until recently, the education of people with disabilities was left to missionaries, charitable organizations, and individual philanthropists with minimal support from governments. It is only recently that governments are beginning to participate in providing services to people with disabilities but still in a very limited way. Yet the education of people with disabilities in Africa has come a long way. In precolonial Africa, children with disabilities were educated with the rest of the community in the village under the tutorship of the elders. There were no special sessions or special institutions to educate children with disabilities. Everyone was integrated within the learning community. However, with the advent of postcolonial formal education, children with disabilities began to be educated in special schools isolated from the rest of the community. These usually were boarding mission schools. For a long time, this was the only model of special education available in Africa. Whereas special schools still exist and are used in most countries in Africa, most current practices favor the integration and inclusion models of special education.

It is important to note that the concepts of integration and inclusion as used in various countries in Africa may not necessarily mean the same both within and outside of Africa. For instance, the concept of integration in general suggests bringing the student with disabilities into the mainstream of the school system so that the student learns together with the regular students. Hence in the United States, the same concept is called mainstreaming. In integration—whether it be in schools or in communities—the focus is on changing the person with disabilities to fit into the mainstream of the system. Persons with disabilities are assisted to adapt and function so that they can cope with the system by provisions of back-up support and training. However, in real terms, in countries in Africa such as Zimbabwe, integration has often meant a geographical process of moving a child with disabilities physically into the mainstream school. This process ignores issues of whether the child with disabilities is learning or not.

Most African governments have accepted integration as the best form of education for people with disabilities without considering the implications. The issue of the integration of people with disabilities is one that has to be considered with care and detachment. Many teachers have expressed reservations about integration of people with disabilities despite its advantages. Some scholars have pointed out that the integration of children into ordinary schools has many implications for teachers and planners. For example, integration requires attitude change, additional teaching materials, resource teachers, and modification of infrastructure (Peters 2004). Placement of students with disabilities into ordinary schools without the relevant provisions is frustrating to both the school authorities and the student.

The other concept that is commonly used in the education of children with disabilities that needs unpacking for Africa is inclusion. Inclusion should not only be a policy but a practice. Inclusion should include inclusive schooling, inclusive education, and inclusive societies. Most African societies' inclusion practice is limited due to negative attitudes and stigmas that are prevalent in these communities. Inclusion should not aim to change the person with disabilities to fit the environment. Instead the aim is to change the environment to accommodate the needs of the person. In practice in most African countries such as Uganda, the inclusion of children with disabilities in schooling means all children with disabilities must go to the school nearest to their home. This is the school where their siblings, friends, and neighbors go irrespective of the accessibility and pedagogic appropriateness of the school. In other words, inclusion may mean placing the person with disabilities into the community with or without support. Unfortunately, most Africa economies are not able to support and sustain inclusion in the same manner as in the West. The idea therefore is to adapt these concepts to fit the sociocultural and economic contexts of Africa.

Governments' services and support to their citizens for education and other services are generally facilitated or enabled through legislation and budget allocations. This support is critical to ensure that the citizens get the required services. Most countries in Africa do not have legislation on disability. There are no acts of Parliament that give comprehensive attention to disability. This situation affects the funding of disability supports, and in most cases does not become part of the national budget. Disability issues are then funded through an external donor project or become a sidelined peripheral issue within a Ministry allocation. Generally, almost all national constitutions guard against the discrimination of their citizens on any grounds. Some of these constitutions (e.g., Zimbabwe) go on to enumerate the basis on which people should not be discriminated against (e.g., race, color, tribe, gender, poverty, political affiliation) and in the process they usually fail to include disability. While one can argue that disability is implied, the omission causes problems.

Finally, in terms of employment, the situation of people with disabilities in Africa is fraught with significant problems. In general, there are high rates of unemployment in the formal sector in Africa and people with disabilities are worse off than their nondisabled counterparts with regard to employment opportunities. In the past, the practice was to train people with disabilities in basic trades such as shoe mending, basketry, leatherwork, pottery, weaving and crocheting. Such trades are no longer viable. Moreover, some people with disabilities now have professional and higher academic qualifications to compete in the current professional job market. There is no country in Africa that has an affirmative action system of employment whereby people with disabilities have a certain number of jobs reserved for them in employment. Although some people with disabilities have been employed in professional and other high-level jobs, generally they are unemployed or underemployed, and they get very little promotion once they are hired. Some turn to begging for survival since there are no state "social security" benefits. The only social security for most of Africa is the family support system.

THE NEW AFRICAN RENAISSANCE

> Nothing about us without us.
>
> *Friday Mavuso*

Despite the problems, the disability rights movements in Africa have organized and grown, over the past 25 years, at a rapid rate. The activities of disabled people's organizations (DPOs) and their leaders provide much hope and lessons to learn for other regions of the world. Every country in Africa has organizations of disabled people that are growing in numbers and in power. In South Africa, Friday Mavuso (who became a paraplegic as a result of a gunshot fired by a police officer) became legendary in the township of Soweto for his charisma and political savvy. The organization that he founded during South Africa's struggle for liberation from colonial rule—Self Help Association of Paraplegics (SHAP)—became a model for bringing about economic empowerment and social transformation for disabled people throughout sub-Saharan Africa (Laclave 2004). The well-known slogan "Nothing about us without us" was popularized by Friday Mavuso and has been adopted by DPOs worldwide. Disabled People South Africa (DPSA) grew out of efforts like SHAP and now enjoys membership of more than 12,000 disabled people and is influential throughout Africa and the world. DPSA currently holds special consultative status with the Economic and Social Council of the United Nations. Disabled Peoples' International (DPI), one of the leading DPOs at the international level, benefited for several years from the leadership of another well-known African disability activist, Joshua Malinga of Zimbabwe.

In its 2002 Annual Review, Action on Disability and Development reported that in Burkina Faso alone, memberships of DPOs increased by 21 percent in that year. From the National Union of Disabled Peoples of Uganda, to the South African Federation of Disabled People, to the Federation of Disability Organizations in Malawi, much is happening at the country level in Africa. As a result of these groups' advocacy and development efforts, persons with visual impairment in Ghana and Sierra Leone now vote with tactile ballot guides, and most governments have developed not only accessible voting standards but a wide range of legislation and policies that address the basic rights of disabled people to quality of life and active participation in their communities. Some African countries now include disabled representatives in government at the national level. South Africa's 1997 *White Paper on Integrated National Disability Strategy* now guides government policy in all sectors of national initiatives.

In addition, UNESCO and UNICEF report growing numbers of community-based rehabilitation programs and inclusive education programs that seek to improve the quality of life of disabled people through education, employment, and access to health care.

The African Decade of Persons with Disabilities (2000–2009) was adopted by Declaration of the Organization of African Unity in July 2000, with its secretariat based at the South African Human Rights Commission in Johannesburg. Decade activities and Plan of Action are the responsibility of the Africa Rehabilitation Institute and are coordinated and monitored by the Pan-African Federation of Disabled People (PAFOD). Regional federations have been formed in the South, East, West, North, and Central Africa to oversee work at the regional level. The overall goal of the African Decade of Persons with Disabilities is full participation, equality, and empowerment of people with disabilities in Africa. Eight objectives have been formulated for the African Decade: (1) contributing to poverty alleviation; (2) combating causes of disability; (3) strengthening the African voice; (4) awareness raising and sensitization; (5) putting disability on the social, economic, and political agenda; (6) spearheading the implementation of the UN Standard Rules; (7) addressing issues pertaining to children, youths, and women with disabilities; and (8) using the UN Standard Rules as a basis for policy and legislation. The Plan of Action for the Decade, developed in Addis Ababa in 2002, targets 12 specific objectives, including (1) support of community-based service delivery; (2) programs to alleviate poverty; (3) ensuring representation of disabled persons at national levels; and (4) addressing the needs of the most vulnerable—women and children.

While it is impossible to adequately report the range and scope of activities related to the African Decade declaration and Plan of Action, some examples are illustrative. First, the plight of disabled women has received special attention. In Beijing, for the World Congress on Women's issues, disabled African women participating in the World Congress initiated the African Network of Women with Disabilities (WWD) formulated in 2001. The initiative focuses on reproductive health and HIV/AIDS for women with disabilities. Various disabled women's support groups throughout Africa have been formulated and have generated a variety of economic, health, and social support systems that address their specific needs.

The CBR Africa Network (CAN) was established in 2001 to promote community-based rehabilitation (CBR) as a participatory strategy in Africa (reported in *Disability World*, Issue No. 21, Nov.-Dec. 2003). CBR as a philosophy and practice has been in existence since at least the early 1970s. CBR is a "strategy within community developed for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education and social services" (ILO/UNESCO/WHO 1994 as reported in Ingstad 2001:781). However, early CBR efforts focused on the individual rehabilitation component. The new wave of CBR efforts, as envisioned in Africa, focuses first and foremost on collective equalization of opportunity and social integration of disabled people. In Kenya, for example, itinerant CBR workers conduct an "open education" program in rural areas. These workers visit blind children in their homes and work with the parents to provide early stimulation activities that will assist them in entering school. The workers also provide Braille lessons in schools, and attend teacher staff meetings to assist in planning and curriculum adaptation. Tanzania uses a similar model of itinerant CBR workers in schools, funded by the Tanzanian Society of the Blind (Peters 2004:30).

However, CBR in some African countries has met with cultural problems. For instance, CBR is based on the concept of volunteerism. This concept rarely exists in African communities in the same manner as it does in the West. People do not just volunteer to work for nothing, especially when their families do not have enough to eat. Traditionally, they worked in the village or the chief's field for free because when there was hunger the chief used the produce from that field to feed them. They volunteered to assist in the fields of a neighbor because there was a beer-drink at the end. After all, in most of Africa, disability is a family and not a public issue. This view is one reason why early CBR foreign workers complained that African families were hiding their children with disabilities. The reality is that the families were protecting their children with disabilities from these outsiders. The situation changed once the families understood the mission of CBR. A case is given, for instance, in Botswana, where a daughter-in-law who was looking after her blind mother-in-law refused to have her trained in mobility and orientation so that she could move independently around, since her husband and his relatives would view her as very irresponsible to let the mother-in-law wander around guided by a stick.

In charting the way forward, the Office on the Status of Disabled Persons in Africa has targeted economic empowerment, social services, capacity building and empowerment of DPOs, and reinforcing policy and legislative frameworks for disability rights throughout Africa. Overall, the African renaissance approach to problems of disability and African solutions to the problems hold the promise of models for the rest of the world to learn from.

—Robert Chimedza and Susan J. Peters

See also Experience of Disability: Sub-Saharan Africa; Inclusive Education; "Nothing about Us without Us"; United Nations.

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DISABILITY IN CONTEMPORARY AUSTRALIA

According to a 1998 national survey of disability conducted by the Australian Bureau of Statistics, there are more than 3.6 million Australians with disabilities. This number corresponds to 19 percent of the

Australian population. The census also found that there were another 3.1 million Australians who had an impairment that did not restrict them in their daily lives. This means that over one-third of all Australians live with some form of impairment. The vast majority of disabled Australians do not rely on government assistance. There were 658,915 Australians on the Disability Support Pension in 2002, of whom 406,893 (or 61.75 percent) were men and 252,022 (or 38.25 percent) were women. The most common primary medical conditions reported by people on the Disability Support Pension were musculoskeletal, psychological/psychiatric, and intellectual/learning impairments. The most commonly reported problems facing disabled Australians were a need for assistance with mobility, property maintenance, health care, self-care, and transport.

The overall rate of labor force participation for the entire Australian population is 76 percent, but only 53 percent of people with a disability are in the labor force (Australian Institute of Health and Welfare [AIHW] 2000). Disabled Australians are entitled to many different forms of government assistance, including income support (such as the Disability Support Pension, Sickness Allowance, and Mobility Allowance). State and federal governments also provide funding for employment programs, home and community care programs, aids and appliances programs, and other services. Work-related disability programs are also provided by the Commonwealth Rehabilitation Program, which receives more than $100 million in funding.

According to a study by the AIHW (2003), 1,737 800 people, or 48 percent of disabled Australians, used some form of aid in 1998. The sorts of aids used by disabled Australians include wheelchairs (both electric and manual), scooters, canes, crutches, walking sticks, seating and bedding aids, incontinence aids, nebulizers, dialysis machines, ventilators, and hearing aids. The AIHW reported that the use of aids was particularly prevalent among people with sensory, speech, and physical disabilities.

The commonwealth government first began providing financial support for disabled people in 1908, when it introduced the Invalid Pension and Old Age Pension. In 1944, the commonwealth government felt a need to establish a social security system that would protect citizens from the extremes of a market economy and began providing Sickness Benefit Payments and Unemployment Benefits. The period from the 1950s to the 1970s was characterized by economic and political stability, as well as full employment, and the idea of a comprehensive social security system was consolidated at this time.

Australia's modern disability policy took shape after the International Year of Disabled Persons in 1981. The 1980s saw a shift away from placing disabled people in institutions; the introduction of the Commonwealth Disability Services Act, which provided a framework for the provision of disability services; and the formation of a large number of disability organizations. In 1991, the federal Disability Reform Package was introduced, which aimed to maximize the employment of disabled Australians and a 10-year Commonwealth-State Financial Agreement clarified the roles of respective governments with regard to the provision of disability supports and services.

A number of legal mechanisms have been developed to protect the human rights of disabled Australians. The Human Rights and Equal Opportunity Commission is the main body charged with protecting the rights of disabled people and advocating on their behalf. It administers the Disability Discrimination Act, which was introduced in 1992 and which aims to eliminate discrimination against people with disabilities and to promote equal opportunity for disabled Australians. The Disability Discrimination Act covers a wide range of areas, including work, accommodation, education, and access to premises, clubs, and sports, and it prohibits both direct and indirect discrimination on the grounds of disability. There are also Disability Discrimination Act Standards, which specify in more detail rights and responsibilities about equal access in particular areas, such as employment, public transport, education, accommodation, and in the administration of commonwealth laws.

The Commonwealth Disability Strategy, first introduced in 1994 and revised in 2000, is designed to provide equal access to commonwealth government services for people with disabilities. It encourages organizations to provide information in flexible formats, purchase accessible services, employ disabled staff, and consult with people with disabilities to find out their needs.

National, regional, and local disability advocacy organizations are funded under the National Disability Advocacy Program. Some of the more influential disability organizations in Australia, which are represented in the Australian Federation of Disability Organizations, are Blind Citizens Australia, Deafness Forum Limited, the National Ethnic Disability Alliance, Women with Disabilities Australia, National Council on Intellectual Disability, Physical Disability Council of Australia, Head Injury Council of Australia, and the Australian Association of the Deaf.

A major review of Australia's welfare system (including the Disability Support Pension) was announced by the minister for Family and Community Services, Senator Newman, on September 29, 1999. The review was prompted by concern over the growth in spending on welfare payments and services (to a point where it had reached a third of total budget outlays). Also, the number of Australians in receipt of welfare had grown rapidly from 1.5 million people in 1989 to 2.6 million people (one in five Australians) in 1999. In particular, the number of Australians on the Disability Support Pension had grown from 300,000 in 1989 to 600,000 in 1999, and it was predicted to rise to 750,000 in 2006. This level of "welfare dependency" had created the urgent need for reform, Senator Newman said.

Despite the presence of this significant social welfare system, significant unmet needs have been identified within the Australian disability community. In 1998, the Australian Bureau of Statistics reported that more than 24,000 people with a profound or severe disability received no assistance at all, and more than 41,000 carers received no assistance or support. Also, many of the services that were designed to provide respite care are not able to perform those functions because they are being used by people in need of long-term solutions who cannot be housed elsewhere. An acknowledgment of this problem can be found in the 1998 report by the New South Wales Community Services Commission, which estimated that 40 percent of respite beds are not being used for this purpose.

Another of the major disability issues in Australia over the past five years has been the inappropriate placement of young disabled people in nursing homes. Approximately 6,000 disabled people under the age of 65, including 1,100 under the age of 50, currently reside in Australian nursing homes. The majority of these people have acquired brain injuries, multiple sclerosis, and other neurological conditions. A national summit on young people in nursing homes attracted 180 people in May 2002, and 500 people attended a national conference in 2003 titled Unlocking Potential: From Vision to Reality.

In recent years, a number of Australian disability rights groups have taken up the issue of discrimination against disabled immigrants and refugee seekers. Sometimes, lawsuits have been instigated around these cases. For instance, in the case of *Inguanti v. Minister for Immigration and Multicultural Affairs* (2001), a man with an intellectual disability was denied a visa that would have allowed him to live with his brother in Australia. His brother was his legal guardian, and the man had significant financial resources to support himself. However, the decision of the Migration Review Tribunal was that the man's intellectual disability was likely to require the provision of health care or community services that would result in a significant cost to the Australian community, and on this basis he was denied a visa. This decision was subsequently set aside after an appeal to the Federal Court of Australia.

The circumstances of this case were similar in some respects to another federal Court case, *Minister for Immigration & Multicultural Affairs v. Seligman* (2001). In this case, an application for a visa by a successful South African businessman and his family was denied because the family included a 22-year-old son who has a borderline intellectual disability. The son's intellectual disability was also deemed as "likely to require the provision of health care or community services which would result in a significant cost to the Australian community," even though a substantial trust fund had been established to support him, and he had an offer of employment as part of the Community Services provided by the Australian Jewish Welfare Society. The initial denial of a visa was subsequently overturned. Not all of the appeals in this area have been successful, however. The case of *Blair v. Minister* *for Immigration & Multicultural Affairs*, for instance, upheld the refusal of a visa to a 9-year-old boy, Michael Courey (who has a mild intellectual disability, hypothyroidism, and a hearing impairment), on the grounds that he would be likely to require health care or community services in Australia.

In recent years, the National Ethnic Disability Alliance (the peak body in Australia for disabled people from non-English-speaking backgrounds) has been advocating on behalf of the rights of disabled children in refugee detention centers. There were 16 children identified as disabled who were in detention centers in 2002, with impairments including cerebral palsy, hearing impairment, vision impairment, acute dwarfism, Perthes disease, and Fragile X syndrome. The National Ethnic Disability Alliance also suggested that the numbers of children with invisible disabilities may be much higher than these figures indicate. It has argued that keeping disabled children in refuge detention centers amounts to a fundamental violation of their human rights and is highly inappropriate. It also places this situation in the context of broader patterns of disadvantage and discrimination, suggesting that three-quarters of disabled people from non-English-speaking backgrounds do not receive any commonwealth-funded disability services.

Australian women with disabilities are particularly disadvantaged. Women with Disabilities Australia reports that although women make up half of the overall population of people with disabilities, they experience labor market marginalization and poverty at much higher rates than other Australians, including men with disabilities. More than half of all women with a disability in Australia earn less than $200 a week. Also, the rates of employment for disabled women are almost half those of disabled men. Entry into vocational rehabilitation programs is also more difficult for women with disabilities. However, the open employment services funded by the commonwealth government largely assist men rather than women: In 1997–1998, these services provided two-thirds of their services to disabled men. Compounding these vocational barriers, women with disabilities are also less likely to receive appropriate health services than nondisabled women, are more likely to be institutionalized than disabled men, experience higher rates of violence and abuse than other Australians, and are more likely than other Australians to experience barriers in access to telecommunications (Frohmader 2002).

The continuing, unlawful sterilization of women with intellectual disabilities is another major human rights issue in Australia. Some of the reasons given for the sterilization of women with intellectual disabilities include the need to prevent pregnancy, manage menstruation, and improve personal care. The unlawful nature of these sterilization procedures has been recognized in a number of reports from state and federal governments, as well as other organizations including the Human Rights and Equal Opportunity Commission. In 2000, a resolution was passed in the Australian Senate that called for a review into the legal, ethical, and systemic issues surrounding this issue.

Indigenous Australians have many unique experiences with regard to disability. Many Aboriginal and Torres Strait islander communities have different definitions of *disability* from those used by Western professionals. The difficulties measuring the extent of disability in Aboriginal and islander communities is compounded by the fact that there is a dearth of literature on this topic. However, one study in New South Wales conducted by Thomson and Snow (1994) found that Aboriginal people were more than twice as likely to be disabled than other Australians. This study reported that sensory impairments were most common, followed by musculoskeletal impairments, circulatory system disorders, and respiratory disorders.

—Mark Sherry

See also *Scott and Disabled Peoples' International (Australia) v. Telstra.*

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DISABILITY IN CONTEMPORARY CHINA

China is a land of contrast and change. The world's most populous nation (1.3 billion) is in the throes of rapid development, enjoying the benefits and suffering the stresses of integration in the world economy, with widening disparities between rich and poor, rural and urban, disabled and nondisabled. Communist China's transition to a market economy has increased the marginalization of already vulnerable individuals through dismantling the "iron rice bowl" of a job and basic security for life, introducing a competitive labor market, and the gradual weakening of nonprofitable primary care services. Partly in response to this, the Chinese government has initiated a series of laws and programs to improve the life chances of disabled people. The driving force has been Deng Pufang, president of the China Disabled Persons' Federation (established 1988), a wheelchair user and son of the late Chinese leader Deng Xiaoping. The benefits have mostly been felt in large cities, where access to education, employment, high-tech medical services, and community-based rehabilitation has increased for those with money, good social connections, and less severe impairments. In rural areas where most Chinese disabled people live, access to such services is severely restricted and in some areas, millions of disabled people live below the absolute poverty line. With per capita gross domestic product in 2001 of US$4,020 (compared to US$34,320 in the United States), China is still a developing country.

BRIEF HISTORY

The People's Republic of China was founded in 1949. Mao Zedong, leader of the Chinese Communist Party, propelled China toward his vision of a self-reliant socialist state. The Mao decades were characterized by upheaval: organizing the masses into collectives and work units, exhorting them to rapid industrialization and repeated revolution, with some devastating effects. Even so, when Mao died in 1976, China had higher levels of adult literacy, life expectancy, and living standards and a more stable economic base. Isolationist in relations with the West, China seemed a model of socialist development.

The Cultural Revolution (1966–1976) left a deep scar and a readiness for new direction. Deng Xiaoping responded with far-reaching reforms embracing market economics and opening China's doors to the world. Deng legitimized personal profit and ownership to achieve a prosperous China: What difference if the cat is black or white, so long as it catches mice? Collective farms were divided and allocated to individual households. Town and village commercial enterprise was encouraged. In cities, state work units gave way to a competitive labor market. Special Economic Zones to attract and control foreign investment powered economic growth in southern and eastern coastal regions.

The demise of work units marked the end of the so-called iron rice bowl of a job and basic security for life. Millions saw their standard of living rise. More experienced job insecurity and relative poverty. The potential for social instability, compounded by large-scale rural-urban migration, strengthened the government's resolve to restrict population growth. The one-child policy was a response to fears of endless poverty due to overpopulation. The policy became less draconian over time but it remains, in modified form, part of Chinese life. China's economic and social landscape had been transformed again, but political reform was absent, as shown by the repression of pro-democracy demonstrations in Tiananmen Square on June 4, 1989.

Since Deng's death in 1997, China has become more liberal economically, socially, and culturally, but the Chinese Communist Party still represses those who speak openly against the government, seek independence (Tibet, Xinjiang), or may threaten social order (Falun Gong). The third generation of political leaders (Hu Jintao succeeded Jiang Zemin as president) has continued to focus on economic growth and social stability. Integration into the world economy has been accelerated by accession to the World Trade Organization. Economic growth has now averaged 10 percent for two decades. Urbanization is predicted to reach 45 percent by 2010. In some cities, population pressures and resource shortages mean that per capita availability of water is among the lowest in the world. Environmental degradation and industrial pollution are cause for global concern. The 2003 United Nations Human Development Report ranked China at 104 out of 175 countries, yet vast tracts of western inland China would rank with the world's least developed countries. In 1997, there were 58 million people estimated to be living below the international absolute poverty standard. The aging pyramid structure of China's population (one child supporting two parents and four grandparents) is a constant anxiety. China has a vibrant economy and a dynamic population, but it faces some of the world's most daunting social, economic, and environmental challenges.

DISABILITY ON THE AGENDA

There are 60 million disabled people in China (5 percent of China's population). They are disproportionately represented among the poor and unemployed. Yet since the 1980s, and compared with countries with higher gross domestic product per capita, there has been a demonstrable attempt to raise awareness and increase life chances. The most important legislation and initiatives are the 1991 Law on Protection of Disabled Persons (promoting the comprehensive rights of disabled people to participate in all aspects of life); 1994 Regulations on Education of Disabled Persons (making education for all disabled children compulsory mainly through special education schools and classes, also promoting adult, further and higher education); and a series of National Work Programs for Disabled Persons (1988, 1991, 1996, 2001), integrating disability into the government's Five Year Plans for national development.

Enforcement of antidiscrimination legislation in China is difficult (although there have been pioneers such as the Centre for Protection of the Rights of Disadvantaged Citizens at Wuhan University). Official evaluations of progress against national program targets suggest that China's disability initiative has affected hundreds of thousands of disabled people. For example, there was an 800 percent increase in the number of disabled children in segregated (special education schools or classes) or mainstream school in 1995 compared to 1980 and a 400 percent increase in the number of segregated schools over the same period; provision of speech and hearing training to 60,000 deaf children and surgery to limit impairment from polio for 360,000 children and young adults.

Deng Pufang has spearheaded China's disability initiative. Born in 1944, eldest son of the late Chinese leader Deng Xiaoping, he became paralyzed during the Cultural Revolution. Following his father's political rise, Deng Pufang went to Canada for medical rehabilitation, where he glimpsed a different future for China's disabled people. In 1984, he set up the China Welfare Fund for Disabled Persons. In 1988, he founded the China Disabled Persons' Federation (CDPF). The CDPF is a national government agency (a quasi-ministry) and has branches at provincial, municipal, country, and township levels. It is not a membership organization. The degree of activism varies; it has been described as having a strong dragon's head and a weak dragon's body. It incorporates numerous agencies including the China Deaf Association, China Blind Association, and the China Association of Friends and Relatives of People with Mental Disabilities. CDPF aims to serve and represent disabled people. It receives government budgetary allocations and raises funds from donors inside and outside China. Deng Pufang is a well-connected figurehead for the organization: In 2003, he received the United Nations Prize in the Field of Human Rights.

Aside from Deng Pufang, two other factors have helped put disability on the agenda: statistics and international collaboration. Matthew Kohrman's illuminating analysis of the 1987 First National Disability Sample Survey reveals a complex of anxieties, pressures, and motivations relating to categorization, scientific caliber, and national self-image. The final survey comprised 1,579,314 people and covered household characteristics, self/family-identified disability, and medically certified disability. The medical survey had six categories: speech/hearing, intellectual, visual, physical, mental health, and multiple impairments. It found that 4.9 percent of individuals living in 18.1 percent of households were disabled. The statistics were sufficiently striking to legitimize a unique program of social development.

Credible statistics also enabled Deng Pufang and CDPF to participate internationally. None could have predicted the extent of China's participation in the United Nations Decade of Disabled Persons (1983–1992) or the Asia Pacific Decade of Disabled Persons (1993–2002), which China initiated. There have been numerous collaborations with UN agencies (rehabilitation pilots, training programs, publications on Western medical rehabilitation, and more recently, on practical advice for legal and social workers), not to mention the 1994 Far East and South Pacific Games for the Disabled in 1994 and forthcoming 2007 International Special Olympics in Shanghai and 2008 Beijing Olympics. Such collaborations strengthen the capacity of China's disability initiative to survive the passing of Deng Pufang's powerful father in 1997.

DISABILITY POLICY AND PROVISION

China has a long history of disability policy and provision. Fiscal and administrative disability classifications date at least to the Tang Dynasty (618–907). Ordinances on emergency relief date to the Han Dynasty (206 BC to AD 220). In the nineteenth century, foreign missionaries established schools for blind and deaf children. Under Mao, disability provision included some vocational segregated schools, mental asylums, welfare institutions (institutional provision was minimal), and Soviet-inspired welfare factories providing sheltered employment. Data on numbers and scale vary and reflect the upheaval of the Mao years, but it is likely that hundreds of thousands of disabled men and women were employed in welfare factories with larger factories operating like other state work units, providing housing and basic health services.

The economic reforms of the 1980s had a severe impact on disabled people. In urban areas, the demise and profit-orientation of work units led to unemployment, cutbacks, and shutdowns of welfare factories. In rural areas, the dismantling of collective farms seriously disadvantaged households with one or more disabled person. Free access to school and health care has been replaced by school fees, fee-for-service medical care, private medical insurance coverage (unaffordable for most), and erosion of nonprofitable primary care services.

Reversing the decline of already limited provision as well as increasing and improving services has been the task of the CDPF and the Ministries of Public Health, Civil Affairs, and Education (brought together with other government agencies in the National Co-ordination Committee on Disability, headed by a vice prime minister). The relationships between these agencies have at times been fraught and competitive. Nonetheless, CDPF has produced successive National Work Programs for Disabled Persons (1988, 1991, 1996, 2001) in line with national Five Year Plans. Key elements have been prevention, rehabilitation, education, employment, poverty alleviation, facilities, leisure, and sports. (Official statistics on progress are provided by the CDPF.)

There are continuities with the past: welfare enterprises, vocational segregated schools, minimal institutional provision, reliance on families, and limited emergency relief. There are also new developments, although many of these have been unpopular, have struggled to get beyond pilot phase (especially in rural areas), or meet only a fraction of need and demand. Examples are an unpopular employment quota of at least 1.6 percent disabled employees (many employers prefer to pay the fine, which in turn funds vocational training and support for disabled people); rural poverty alleviation programs (80 percent of disabled people live in rural areas, half of whom live in poverty); community-based rehabilitation (which has remained largely limited to a few urban areas despite its potential in rural areas); and professional training in Western medical rehabilitation and social work. Among the defining characteristics of China's disability initiative are self-reliance, population, and visibility.

SELF-RELIANCE

Disabled people are exhorted to show self-respect, self-confidence, self-strengthening, and self-reliance. Self-reliance is about earning a living and becoming a national economic asset rather than a liability, in line with the emphasis on individual and household responsibility—the touchstone of the post-Mao reforms, and on work as the central signifier of adult personhood in China. For dependent adults and children, families are expected to carry full responsibility. Welfare provision is minimal and patchy, often one-time payments to coincide with festivals, if available at all.

Employment options are self-employment, welfare enterprises (tax relief with a workforce of 35 percent disabled people, mostly run by local governments including in towns and villages) and employment under the quota system for government agencies, commercial enterprises, and nonprofit organizations (comparatively few gain genuine employment under this system).

National targets for education also feed into the goal of self-reliance. Education for disabled children is highly vocational, often linked to a specific welfare enterprise or stereotyped profession. There has also been a concerted effort to set up adult vocational training centers, retraining those who lost their jobs when some of the welfare factories closed, and assisting disabled people to find a trade for self-employment. Restoring function and enhancing employability, based on exacting notions of normalcy, lie behind some of the national targets for medical rehabilitation (speech and hearing training for deaf children, remedial surgery for children with polio), while imparting a vocational skill is seen as a central component of medical rehabilitation.

POPULATION

In 1990, the Law on Protection of Disabled Persons became China's first comprehensive piece of disability legislation (implemented in 1991). Reflecting the UN World Programme of Action, it asserts disabled people's rights to participation in social, economic, cultural, and family life. The law has been promoted extensively although enforcement through legal channels is very difficult. The law provides a framework for the development of legal, social, medical, educational, and vocational services, initiatives to reduce disabling barriers in the environment, and to limit the incidence and impact of impairment (e.g., reducing easily preventable intellectual impairments caused by iodine deficiency). More controversially, the 1994 Law on Maternal and Infant Health Care promoting better prenatal and postnatal care also includes a requirement for a premarriage medical examination to identify serious genetic, infectious, or mental diseases and, through restricting childbirth, reduce congenital impairments. The measure is repressive, even eugenic. It is consistent with government efforts to "reduce population quantity, raise population quality" and the construction of disability as a social problem (*shehui wenti*). The solution is seen as two-fold: reduce the number of disabled people, and ensure that those who are disabled can contribute to the economy.

VISIBILITY

Since its inception, the CDPF has used the media to raise public awareness of disability, to combat negative treatment and verbal abuse of disabled people, and to encourage disabled and nondisabled people to volunteer their services and raise funds (in 2003, CDPF announced 50,000 liaison centers for volunteers and 1.69 million registered volunteers). This use of national and regional media has been part of a careful and strategic approach to ensuring the long-term sustainability of China's disability initiative, and particularly of the CDPF itself, beyond the passing of Deng Pufang's powerful father in 1997 and the future passing of Deng Pufang himself. Other components of the strategy have been the National Disability Sample Survey of 1987, high-level and well-publicized international participation and collaborative programs, and the regular showcasing of individual disabled men and women who exhibit qualities commensurate with China's construct of a modern and progressive state. The need to demonstrate clear success and make a mark on China's modern landscape has also influenced decisions to pursue high-tech, high-cost urban rehabilitation centers, such as the flagship China Rehabilitation Research Center (set up in 1988 under the CDPF). The center and its equivalents in other large cities are a visual reminder of the CDPF and of what China should aspire to in line with advanced economic countries. Traditional Chinese medicine (acupuncture, *qigong*, massage) is used alongside Western medical rehabilitation, social and vocational rehabilitation, but the emphasis is on importing and developing scientific and technological rehabilitation. The handover of Hong Kong in 1997 and increased international collaboration have facilitated this, although the approach has been strongly criticized by agencies interested in expanding the access to services of poor and rural disabled people.

PROSPECTS

The current rehabilitation target of full access to rehabilitation services for all disabled people, including in rural areas, by 2015 seems remote. Imported models of community-based rehabilitation have great potential in China, but the reforms of the 1980s have weakened service infrastructures and the capacity of government at all levels to implement top-down, extensive, and nonprofitable services.

Among urban educated élites, there are signs of a discourse of rights and respect, demand for services and opportunities, and an emerging civil society of charitable and self-help groups (many led by parents of disabled children and some by disabled adults). In an authoritarian state, the capacity and sociopolitical space for genuine community-led approaches are weak and contested. The challenges for the CDPF are to empower such social enterprise, without seeing it as a threat; to continue to keep disability on the agenda in the face of growing social development pressures (including an aging population and projected exponential increase in people living with HIV/AIDS); and to expand the benefits of the disability initiative to reach the poorest of China's disabled population.

—Emma Stone

See also Experience of Disability: China.

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DISABILITY IN CONTEMPORARY INDIA

The subcontinent of India lies in southern Asia, between Pakistan, China, and Nepal. To the north, it is bordered by the world's highest mountain chain, where foothills and valleys cover the northernmost of the country's 26 states. Further south, plateaus, tropical rain forests, and sandy deserts are bordered by palm-fringed beaches. The population of India as of 0:00 hours on March 1, 2001, stood at 1,027,015,247 persons. With this, India became only the second country in the world after China to cross the one billion mark. India is home to 16 percent of the world's population, who occupy 2.42 percent of its land area, which is 3.3 million square kilometers. It has a coastal length of 7,600 km.

DIVERSITY

India's significance lies not only in its physical attributes but also in the fact that it is the world's largest functioning democracy, with regular and freely contested elections. India serves as an excellent example of facing challenges of fostering the development of plural communities and multiple identities. It is a country in which there are 15 official languages, more than 300 minor languages, and some 3,000 dialects. Twenty-four languages have more than 1 million speakers each. The most widely spoken language is Hindi, but this is the mother tongue of only about 40 percent of the population. Often Indians cannot understand each other, and they frequently use English as a link or administrative language. About 80 percent of the population is Hindu. But Hinduism is an amalgam of pluralistic beliefs and forms, often containing conflicting elements. An additional 12 percent are Muslims, deeply aware of their Islamic faith. Hindu, Urdu, Bengali, Marathi, Tamil, Telegu, Punjabi, and other languages create minorities of their own. Tribal and neoaboriginal peoples number almost 40 million. No contestant for political office can be successful without an awareness of these constituencies. This mosaic is culturally extraordinary. However, it is also a source of divisiveness in a nation where particular loyalties have a deep meaning, both spiritually and physically. Given this diversity, it is remarkable that India has remained and grown, and continues to grow, as one nation. The consciousness of the great past and the newness of the present sometimes produce an abrasive reaction.

The very word *India* implies a unity, which exists more as a tentative political form than as a human and sociocultural reality. For many in the West, India is considered as a torpid and remote conglomerate of people, which represents a combination of the exotic and tragic, a land of both poverty and plenty, a nation both powerful and weak, ancient and modern. The history of India is the history of colliding cultures—agrarian and industrial, masculine and feminine, national and imperial. Gaining independence after 200 years of colonial rule, India's progress into modernity has been fraught with all manner of fascinating entanglements, beginning of course with its knotty caste system and its ambivalent relationship with Pakistan. It seems fair to say that the identity of this great and ancient nation is at least partially defined by conflicts between the identity it wants and the one history has thrust upon it.

In all its diversity, India presents a revolutionary argument about the subtle nuances of progress and its fluid relationship with tradition. Both historically and in modern times, India has been an animated and vivacious society with a vibrant internal psyche as well as an influential relationship with the world. Modern India is home both to the tribal with his anachronistic lifestyle and to the sophisticated urban jetsetter. It is a land where temple elephants exist amicably with the microchip. Its ancient monuments are the backdrops for the world's largest democracy where atomic energy is generated and industrial development is rapidly making India a world industrial and technological leader. It is not uncommon to find fishermen along the country's coastline with simple fishing boats in a centuries-old tradition while, a few miles away, motor vehicles glide off conveyor belts in state-of-the-art factories.

Internationally, modern India has represented a middle ground in the international politics. Believing as it does in nonalignment in international politics, India has attempted to create a balance that demonstrates a viable route for nations that did not want to take sides in local conflicts. India's significance has to be understood in context of the geopolitics of South Asia. Bordering the Indian Ocean into which the Persian Gulf flows, it is a key location in an era of oil logistics. Add the proximity of Russia, Afghanistan, Pakistan, and China, and India's situation becomes critical to the tensions and interactions of current global politics.

INDIA IN A GLOBALIZING WORLD

In the past decade and half, India's economic policies have also broken new ground. They were the first large-scale test of the modern mixed economy. While these policies did usher in spectacular hopes and optimism, and assisted in the market reforms, they have also created a resurgence of ethnic politics around cultural identity, which appears poised to threaten the present world order. In India, the rise of radical Hindu nationalism, represented by Hindutva resurfaced with the integration of India in the global market. Divisive forces, in the name of religious and political ideology, have wreaked violence, chaos, and destruction violating the aspiration for a more humane order. As Indian society has moved along the road to modernity, it has led to a paradoxical scenario by creating two distinct worlds within India. There are the cities of India, where 28 percent of the population lives, and rural India, where about 600,000 villages contain the rest of the population.

Urban India is the India of modern industry, national politics and foreign policy, government planning, the national media, the major universities, business, the armed forces, science and technology. Its products are rated as some of the best in the world. This India has shopping malls, amusement parks, bowling alleys, and large department stores that seem to be drawing on the boom in the new economy sector. On the other hand, there are both urban and rural belts in which clean drinking water and electricity are not available. The onslaught of private media with innumerable private satellite channels does not fail to raise the aspiration level.

However, the drive toward upward mobility is not contained within the developing fabric of both economic and social life, creating dilemmas and discontent. With the euphoria of globalization and “high-tech civilization,” concerns about poverty, hunger, and inequality are virtually dismissed as an obsession of ideologists. This attitude has generated dangerous consequences. Both first-generation and second-generation reforms overlook various crucial issues and objectives such as eradication of poverty, prevention of concentration of economic power in private hands, avoidance of regional imbalances, and promotion of small-scale industries and village crafts. Economic development actually ran counter to these objectives. While India does and must take pride in its information technology (IT) professionals and cyber cities, it has had to recognize that there are tragic deaths by the hundreds of farmers and weavers, besides starvation deaths, in the wake of neoliberalization policies. The story of modern India is thus not simply the story of well-fed, well-clothed men; it is also the story of intense agony—loss of self and communication and relatedness. The urgent task before the government and civil society is to recover these myriad relationships so that democracy can be transformed into a rights opportunity for multiple identities and communities if a more equitable world order is to emerge.

BLEND OF MATERIAL AND THE SPIRITUAL

The most significant feature of Indian culture has been its belief that life cannot be viewed solely in terms of materialistic realities. True actualization is possible only when the attempt is made to look within, and India at its core quests for spirituality as the ultimate search. The desire to know life through, for example, yoga, art, and philosophy, persists despite the country’s modernity. Thus, an ingrained and dominant spirituality, a creative zest for life, and an intelligent combination of the rational, ethical, and aesthetical mind characterize Indian culture.

GENDERED CHARACTER OF INDIAN SOCIETY

In terms of gender issues, historically, the dominant ideologies in Indian culture have continued to operate paradoxically. While in principle they might be postulated as complementary, their actual meaning/working is oppositional. Thus, there is a strong cultural belief that while the female is opposed to the male, female is at the same time encompassed in male. This is symbolized in the figure of lord Shiva called Aard Nareshewar, where the left side is depicted as female and the right side as male. Yet the lives of women do not reflect this inclusion; large sections of women are among the most underprivileged in India. While some women from the upper classes head political parties and command large followings, women’s representation in Parliament and in state legislatures has not been more than 10 percent. There are several clear indicators of the fact that Indian women continue to be discriminated against: The sex ratio is skewed against them, maternal mortality is the second highest in the world, more than 40 percent of women are illiterate, and crimes against women are on the rise. Yet the women's movement, which gathered strength after the 1970s, has led to progressive legislation and positive change, spurred on by the participation of women in local self-government.

The most serious issue of modern India is the changing sex ratio. An alarming drop in the number of girls born in India is being blamed on a strong cultural preference for sons—coupled with cheap and widely available medical tests that can tell parents the sex of their unborn child. Data from India's 2001 census show the sex ratio for 0- to 6-year-olds fell from 945 females per 1,000 males in 1991 to 927 in 2001. The new figures give India one of the world's lowest ratios of women to men; the statistical norm is 1,050 females for every 1,000 males. The drop is largely due to the widespread but illegal practice of using ultrasound scans to identify female fetuses and then aborting them. In 1994, the Pre-Natal Diagnostic Technologies (PNDT) Act banned the practice. But it has proved toothless—seven years after enactment, not a single conviction has taken place. This is yet another indicator that technological advances may not always denote progress and growth.

CASTE SYSTEM

According to the Indian Constitution, there is a separation between religion and state. Caste discrimination is thus legally forbidden. However, in modern India, caste identity has become a subject of political, social, and legal interpretation.

Affirmative action programs in education, employment, and other spheres have been undertaken. Yet it is doubtful whether these steps have resulted in the social uplifting of the marginalized categories as there is a backlash from the communities that were high in the social hierarchy. Caste thus remains a site of contest for modern India.

DISABILITY SCENARIO

India has approximately 70 million disabled people. The unwillingness of the government to include the domain of disability in the 2001 census to obtain a conclusive idea about prevalence reflects the attitudinal barriers in acknowledging the disabled identity. Disability issues have no space in the political agenda or the most forward-looking social movements of the country. Consequently, within the dominant Indian cultural ethos, labels such as "disability," "handicap," "crippled," "blind," and "deaf" are used synonymously. The assumption of the label's naturalness is unquestioned. The roots of this assumption lie in the ideology that conceives of disability as inherent in the mind or body. This corresponds with the idea of lack and inability that is associated with these conceptions. In a culture that valorizes perfection, all deviations from the perfect body signify abnormality, defect, and distortion. Conveying feelings of inability and uselessness, disability epitomizes "failure" and is conceived of as a personal tragedy. The common perception views disability as a retribution for past karmas (actions) from which there can be no reprieve. The popular images in mythology attest to extreme negativity associated with disability in India. While sex selection is a cause for concern for social activists, killing imperfect children will not even count as a crime. The general response of the nondisabled world ranges from pity and charity, to hostility, anger, banter, and ridicule. Within this pessimistic situation, a silver lining comes in the form of disabled people themselves and their struggles to resist the system. Along with their families, their strivings to chart out a different destiny saw the first legislation for equal opportunities being passed in 1996.

Notwithstanding the different realities of education and employment, the discourse of disability activism in India itself constitutes a meta-narrative that universalizes disability. The leaders of the movement are middle-class urban men who have been educated in public schools and are representative of an "elite" background. Their fight for "disability rights" is borrowed from their Western counterparts without any clear analysis of the inherent biases. Consequently, the imported packages of "nothing about us without us," while perfectly appropriate in some contexts, are universal solutions that ignore the specifics of the Indian dilemma.

Academic and social reflection on whether these programs borrowed from the West have the potentiality of understanding and responding to the diversity of

Indian culture and concomitantly is practically nonexistent within disability activism. The fight for rights thus ends up paying lip service to the needs of diverse groups, whereas in actuality the agenda remains dictated by the understanding/needs of the leaders. While poverty exacerbates the disabled existence, the leaders fight for agendas that are their own.

India, while having a specific interpretation of disability, still has lived with values of interdependence and reciprocity. While it has a lot to learn from the West, it can contribute by becoming a role model in negotiating with diversity. It has a history of a freedom movement and struggles for land, language, and gender rights. These approaches have maintained a separate identity while keeping a unity of spirit and purpose intact. India in this sense is a perfect example of highlighting the limitations and strengths of identity politics. It demonstrates that a lot can be gained from a revitalization and reformulation of culture and tradition. India can thus contribute to disability studies a viewpoint that emphasizes a closer look at how communities mobilize locally to create a grassroots movement that initiates a culture of resistance to oppressive practices. These agendas of resistance connect local, regional, and global efforts toward the ideal of not an independent, but an interdependent, existence. India can demonstrate to the global disability movement as well as to disability studies that research and practice have to work at these interconnected levels. While according the highest priority to the rights of disabled people, it continues to adopt a sensitive, reflexive, and critical approach, thus rendering a careful interrogation of traditional values.

—Anita Ghai

See also Developing World; Disability Policy: India; Experience of Disability: India.

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DISABILITY LAW: CANADA

In 1982, the rights of persons with disabilities were given constitutional protection in the Charter of Rights and Freedoms, part of Canada's Constitution. As constitutional legislation, the charter applies to governmental action and legislation, including provincial and federal human rights statutes. The direct impact of the charter on the day-to-day lives of individuals is relatively limited. Indirectly, however, it has a significant impact, since it provides the framework within which provincial and federal human rights statutes operate. These statutes are considered quasi-constitutional and prohibit discrimination on a number of grounds, including disability, in areas such as housing, employment, education, and the provision of goods and services to the public.

The equality rights of persons with disabilities derive from Section 15 of the charter: "15**.** (1) Every individual is equal before and under the law and has the right to the *equal protection and equal benefit* of the law without discrimination and, in particular, *without discrimination* based on race, national or ethnic origin, colour, religion, sex, age *or mental or physical disability.*"

The charter does permit governments to implement programs that specifically help people in those groups protected by the charter. The rights of persons with disabilities are given the same degree or protection as other enumerated grounds such as religion and race.

If a statute or governmental action is found to be contrary to Section 15 of the charter, it may continue to operate if the government can demonstrate that it is justifiable in a free and democratic society. Section 1 states: "The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society." The onus is on the government to demonstrate that there is a significant societal justification for a distinction. A discriminatory provision may also stand if the government invokes Section 32 of the charter. That section states that Parliament or a provincial legislature may enact a declaration declaring that a statue or part of a statute will remain in effect despite the fact that it has been found to be contrary to

Section 15 of the charter. To date, no government has invoked this power.

The charter protections are enforced through individual actions brought in court. Administrative tribunals, including labor arbitration boards, also have the authority to interpret the charter where necessary to carry out their adjudicative functions.

Remedies available to the court under the Charter of Rights and Freedoms include declaring a statute or part of a statute invalid and therefore of no force and effect. Often when this is the result, the courts will give the government time to amend the legislation so that it complies with the charter. The court can also "read in" language to the statute so that it complies with the charter. Courts may also award damages for discriminatory treatment.

As constitutional legislation, the charter must be interpreted broadly and consistent with its overall purpose. The interests of society must be taken into account and the interpretation flexible rather than rigid. The broad purposive interpretation of the charter also extends to provincial and federal human rights legislation, which is considered quasi-constitutional.

One of the most important concepts running through recent decisions relating to discrimination on the basis of disability is the use of dignity and respect as fundamental interpretive principles. This is reflected in the duty to accommodate, the definition of disability, and the determination of undue hardship in both charter and human rights litigation. Starting with the decision of the Supreme Court of Canada in *Law v. Canada,* the courts have articulated the rights of persons with disabilities in relation to dignity. This applies not only to the underlying purpose of the charter, but it is used as a measure in determining appropriate accommodation. In *Law,* the Supreme Court of Canada set out the following steps to use in analyzing claims under Section 15 of the charter: Does the law specifically make a distinction between the individual and others or does it fail to take into account the individual's differences that may lead to disadvantage if the person is treated exactly like everyone else? Is the distinction based on a characteristic that falls within the grounds under Section 15 either those that are listed or that are considered to be analogous? Does the different treatment either impose an additional burden on the individual or does it deprive them of a benefit that others obtain from the legislation in a way that suggests that the person is a less worthy or valuable as a person or member of society or that they are less deserving of respect than others?

Some factors that may determine whether a person's dignity has been demeaned are the following: Does the individual belong to a group that has been subject to prejudice or stereotyping or is historically disadvantaged? Does the law take into account the person's own situation and needs or does it provide benefits based only on categories? Is the purpose of the law to improve the situation for people who are disadvantaged? How serious is the impact of the law and how defined is the group affected by it?

A second major aspect of charter litigation involved distinguishing between direct and indirect or adverse effects discrimination. Direct discrimination was described as intentionally treating people in one of the equality-seeking groups differently. Adverse effects discrimination in the employment context was said to occur when an employer had a policy or practice that was not intentionally discriminatory and did not treat people from equality-seeking groups differently, but nevertheless resulted in differential treatment creating a disadvantage for the individual.

In *British Columbia Government and Service Employees' Union v. Employees' Union (B.C.G.S.E.U.) (Meiorin),* the Supreme Court of Canada eliminated the distinction between the two types of discrimination in determining whether or not there was a duty to accommodate. In moving away from the bifurcated approach, the court in *Meiorin* wrote: "The distinction between a standard that is discriminatory on its face and a neutral standard that is discriminatory in its effect is difficult to justify, simply because there are few cases that can be so neatly characterized."

The Supreme Court of Canada set out a three-part test to determine whether a standard or policy is discriminatory: Is it rationally connected to the performance of the job? Was it was adopted in good faith with an honest belief that it is necessary to fulfill a work-related purpose? and Is it reasonably necessary to accomplish the work-related purpose?

The effect of *Meiorin* has been to move the inquiry from the question as to the type of discrimination to the duty to accommodate. In recent years, the Supreme Court of Canada has also expanded and clarified its approach to the duty to accommodate. The duty to accommodate is considered a significant human rights obligation. The obligation is on all parties to fully participate in the process. This includes the employer, the employee, and, where applicable, the union. The courts have been clear that unions have an obligation to participate in the process and to support accommodation measures.

An increasingly important component to the duty to accommodate is the process of determining accommodation itself. The employer has the primary responsibility because the employer controls all aspects of the work environment. However, the employee must also participate.

Accommodation must be provided to the point of undue hardship. The issue of undue hardship, however, does not arise until appropriate accommodation has been determined. The employer may not raise financial or other constraints during the initial process of deciding on the most appropriate accommodation. The onus is on the employer to demonstrate that an accommodation would result in undue hardship. What constitutes undue hardship depends on a number of factors including the jurisdiction in which the case is brought. In some jurisdictions, such as Ontario, the human rights legislation sets out specific factors that can be considered. In other jurisdictions the scope is broader. Among the factors that have been considered are the impact on a collective agreement, employee morale, the size of the employer's operation, and the operational requirements of the workplace.

In recent years, the courts have become much more demanding of the employer in terms of providing evidence of undue hardship. Concrete evidence must be provided; speculation is not sufficient. The courts have been clear that in terms of increased costs, such as insurance, there must be evidence from the insurer that the rates will in fact increase. The courts have also refused to consider the potential cost that may arise if others in the workplace seek similar accommodation, whether because of a disability or other enumerated grounds.

More recently, however, the Court has recognized that disability discrimination does not occur in isolation and that the social context and other factors must be taken into account. In *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City),* known as *Mercier,* the Supreme Court of Canada considered three related cases involving stereotypical assumptions about disability that resulted in discriminatory treatment. The discrimination in these cases arose not because of their underlying medical condition, but because of the perceived disability in the minds of their employers.

As with the interpretation of Section 15 of the charter, and related human rights provisions, the definition of disability in Canadian jurisprudence is also broad. There is no definition of disability in the charter, and provincial human rights legislation defines it broadly. The prohibition against discrimination also applies to perceived disability, temporary disability, past disability, and association with a person who has a disability. In some jurisdictions, such as Ontario, the inclusion of these related concepts is explicit, while in others, the definitions are being expanded through the broad interpretation of Section 15 of the charter, particularly after the decision in *Mercier.*

Although there is no set list of conditions, diseases, or disorders that constitute disability, the courts have determined that alcoholism, drug addiction, smoking where it is a significant addiction, and obesity fall within the definition of disability. In determining whether a disability exists, the court is is increasingly looking at whether the condition complained of arises out of a perceived limitation, whether or not that limitation exists.

—Patti Bregman

See also Ontarians with Disabilities Act of 2001 (Canada).

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British Columbia Government and Service Employees' Union v. Employees' Union (B.C.G.S.E.U.) (Meiorin), 1 S.C.R. 497 (1999).

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▣ DISABILITY LAW: EUROPE

Disability has finally become a human rights issue in Europe. There is now a developing base of legislation in many European countries that sees its goal as the elimination of discrimination against people with disabilities, taking individual human rights as its baseline philosophy. In three countries (Austria, Finland, and Germany), the right not to suffer discrimination because of a disability is enshrined in the constitution itself, although this by no means guarantees the right is upheld, in the absence of meaningful enforcement machinery. Three constitutions provide for the general right of disabled people to be integrated into their society and place a concomitant responsibility on the state to ensure that all barriers to such integration are removed (Austria, Greece, and Italy). A number of other national constitutions also refer to the rights of disabled people in more specific, more narrowly defined contexts, for example, a constitutional right to social welfare/social security (Finland, Italy, and Portugal) or a constitutional right to appropriate education and financial support (Italy, Finland, Greece, and Portugal). In a number of countries (Austria, Finland, Greece, and Italy), the special needs of disabled people are addressed primarily through social and economic policy and associated welfare legislation, rather than through antidiscrimination laws. In other countries (Belgium, Ireland, Germany, the Netherlands, and the United Kingdom), substantive national laws have been passed developing legal rights for disabled people to equal opportunities in education, employment, or other settings. This latter trend will continue to develop apace within the European Union, at least in the context of employment and training, as EC Directive 2000/78/EC requires all member states to have introduced antidiscrimination laws in the fields of employment and training by the end of 2006 at the latest (see below), thereby marking a decisive shift within the European Union toward using the language and the tools of civil rights in the disability context.

If we look beneath the superficial modeling of legal approaches to human rights for people with disabilities, to search out the underpinning philosophy, a clear picture emerges. While all the legal approaches preach equality, and all have the potential to move toward a notion of equality, clear differentiation nevertheless exists. The basic model is premised on the concept of equal rights. This “equal rights” model ignores difference. It states that everybody has equal rights and should therefore be treated the same; for example, Article 3 of the German Basic Law states that “no person shall be disfavoured because of disability.” While it has proved a useful political tool for disability activists as a means of overcoming the medical model of disability, which remains particularly predominant in Eastern Europe, the equal rights model has severe limitations as a practical tool for reform, if only because granting equal rights to all citizens requires taking a look at difference and understanding that different people have different needs. To ignore differences helps to prevent stereotypes and stigmatization but at the price of failing to do justice to the reality of difference.

A more sophisticated model starts with equal rights and adds equal opportunities. This “equal opportunities” model accepts that where people with disabilities are at a disadvantage, for example, in their quest for employment, granting them formal equal rights without providing equality of opportunity to exercise those rights is an empty gesture. A typical manifestation of an adherence to the equal opportunities model is the requirement that employers make “reasonable adjustments” or “reasonable accommodations” to their workplaces, policies, and practices to ensure that a person’s disability does not reduce his or her opportunity to participate in the workplace on the same terms as the person’s nondisabled colleagues. Article 5 of EC Directive 2000/78/EC requires employers to make reasonable accommodations in the form of “appropriate measures where needed in a particular case” to ensure that disabled employees are not prevented from performing the essential functions of their job purely because of their disability. The directive also expressly permits these accommodations to be accompanied, if necessary by special measures or affirmative action policies, thereby recognizing that merely imposing minimal standards of nondiscriminatory conduct on employers may not be sufficient to promote equality in practical terms. Several European countries (Denmark, Finland, Ireland, Spain, and the Netherlands) have legislation in place permitting special measures of this nature to be taken in the context of employing people with disabilities. Others may follow.

The fully developed model of legal approaches to human rights for people with disabilities, which comes closest to achieving genuine equality, can be described as the "tripartite" model. This model combines equal rights with equal opportunities but adds a third and final ingredient of equal outcomes. This model recognizes, for example, that an employee with a disability who receives the same pay, and equality of opportunity, as his or her nondisabled colleagues remains disadvantaged so long as the person has to bear a disproportionate further burden of costs to support his or her personal needs. Another example is a young club-goer who uses a wheelchair and who is granted access to a nightclub at the same price, and through the same entrance, as fellow clubbers without wheelchairs but remains disadvantaged unless the dance floor itself is as safe and welcoming to the person using the wheelchair as it is to the other dancers. "Equal outcomes" builds in a redistributive balancing of resources to compensate individuals for their extra expenditure, whether it be in time or money or overcoming "attitude." By this tripartite commitment to rights, opportunities, and outcomes, the model can truly be said to have embraced a full conceptualization of equality.

The fully developed tripartite model can be deemed successful, however, only if it achieves a balance of all three factors, that is to say, rights, opportunities, and outcomes. To concentrate on equal outcomes, without equality of rights and opportunities, could lead to an undesired result that shackles other freedoms. For example, while a child with disabilities may achieve higher academic results ("outcomes") in a segregated special school, he or she may as a result have been deprived the right and the freedom to choose integrated education, notwithstanding the possibility of a lesser scholastic "outcome." Regrettably, it cannot be said that, at present, any European country has embraced the tripartite model approach to disability in any meaningful way.

EUROPEAN UNION

Article 13 of the European Community (EC) Treaty establishing the European Community (as amended by the Treaty of Amsterdam) gives the countries of the European Union (EU) powers collectively to take all necessary measures to combat discrimination. Article 13 also provides the first specific reference to *disability discrimination* within the EC Treaties. On November 27, 2000, the EU passed Directive 2000/78/EC, which seeks to establish a general framework for equal treatment in employment and occupation and to render unlawful discrimination on a number of grounds including disability. Directives reconcile the dual objectives of (1) securing the necessary uniformity of community law and (2) respecting the diversity of national traditions and structures. The goal of a directive is more that of harmonization than unification. A directive is binding on the member states as to the objective to be achieved, but it leaves it to national governments to decide how the agreed community objective set out in the directive will be incorporated within their own legal system. Each directive lays down a set time frame by which the directive must be transposed into the national law of each member state. Member states are liable to pay damages where loss is sustained by reason of their failure to transpose a directive in whole, or in part, into their national system of law (see *Joined Cases C-6 Francovich and 9/90 Bonifaci 1991, ECR 1–5403*).

By December 2003, the Non-Discrimination Directive should have been transposed into the national domestic laws of all 15 members states, although individual countries can opt to wait until 2006 before achieving full implementation. In addition, the *acquis communitaire* underpinning the accession of new countries to the EU (known as the "candidate countries") requires a specific undertaking that they will transpose directives into their national laws as a condition of entry. As a parallel initiative, the EU has established a six-year Community Action Programme (CAP), ending on December 31, 2006, aimed at promoting measures to combat discrimination. In addition, the EU Social Policy Agenda, adopted in June 2000 by the Social Policy Council, is committed to monitoring implementation of the *Communication from the Commission to Council, European Parliament, Economic and Social Committee, and Committee of the Regions. 2.05.2000COM: Towards a Barrier-Free Europe for People with Disabilities.*

The CAP to combat discrimination has three main objectives:

1. To foster a better understanding of issues relating to discrimination by improving knowledge of the problem and assessing the effectiveness of policies and practices
2. To develop the capacity to prevent and to tackle discrimination effectively, particularly by strengthening organizations' means of action and supporting the exchange of information and best practice across Europe
3. To promote and disseminate the values and practices underlying the fight against discrimination, including the use of awareness-raising activities

To achieve these objectives, the program is supporting a number of activities. First, it has established Groups of Independent Experts who assist the commission and the member states in monitoring the transposition of the antidiscrimination directives into national law. The groups, consisting of experts from all member states, meet on average twice a year and provide an annual report to the commission. The Group of Independent Experts on disability has produced a major report on the states of anti-disability discrimination legislation across the 15 member states, which became available in 2005 (European Commission 2005). In addition, the group has carried out extensive research into the particular problems associated with reasonable accommodation and its practical operation in the discrimination field, pre-employment medical testing including genetic testing, and reconciliation of health and safety measures. In 2004, the specialist groups working on each of the discrete areas of discrimination covered in the directive (religion or belief, age, sexual orientation, disability) were merged into one "supergroup" monitoring antidiscrimination legislation as a whole, across the enlarged EU. It was a major task.

Second, the program is supporting a range of sophisticated data collection initiatives to measure the extent and impact of discrimination in Europe (European Commission 2003d). Third, the program is sponsoring independent studies of the effectiveness of the various national bodies already established to promote equality and fight discrimination, looking also at the measures to combat discrimination in countries that have applied to join the EU (European Commission 2003c). These studies will focus particularly on additional steps that may need to be taken in order to take on board the provisions of EC antidiscrimination legislation. A feasibility study, on the establishment of indicators to measure the cost-effectiveness of diversity in companies, has also been carried out by the Centre for Strategy and Evaluation Services (European Commission 2003a). This study seeks to identify new ways of measuring diversity and the benefits it can bring to business and thereby makes a valuable contribution to promoting diversity programs and measures in companies and help to make EU law a reality on the ground. Other studies on barriers to access to assistive technology and other forms of obstruction to employment progress have also been carried out. Finally, the program is promoting a range of initiatives designed to strengthen the capacity of nation-states to build their own programs, independent of EU support.

The candidate countries that gained accession to the EU in 2004 (Cyprus, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia, and Slovenia) and those expected in 2007 (Bulgaria, Romania, and Croatia) are all moving slowly toward a rights culture similar to that which is developing within the EU. Many of the initiatives that form part of the CAP include candidate countries. The majority of the candidate countries already have specific legislation dealing with disability discrimination, although in these countries the predominant concept of disability is based on a narrowly defined medical model. There are "quota" systems (arrangements whereby employers must ensure that a percentage of their workforce have specified disabilities, or suffer financial penalties) of varying kinds in the Czech Republic, Cyprus, Lithuania, Malta, Poland, and Romania and specialized or sheltered employment programs in operation in Bulgaria, Cyprus, Hungary, Romania, and Slovakia. Enforcement machinery for discrimination claims is scant across all the candidate countries, with only Romania possessing a special body for hearing discrimination cases. Sanctions for noncompliance either with quotas or with antidiscrimination measures are also weak, and largely unenforced, although the directive requires that effective enforcement machinery is in place.

The European Union Charter of Fundamental Rights sets out in a single text, for the first time in the EU's history, the whole range of civil, political, economic, and social rights of European citizens and all persons resident in the EU. The Cologne European Council (June 3–4, 1999) entrusted the task of drafting this charter to a specially convened convention. The convention held its constituent meeting in December 1999 and adopted the draft on October 2, 2000. The Biarritz European Council (October 13–14, 2000) unanimously approved the draft and forwarded it to the European Parliament and the commission. The European Parliament gave its agreement on November 14, 2000, and the commission on December 6, 2000. The presidents of the European Parliament, the council, and the commission signed and proclaimed the charter on behalf of their institutions on December 7, 2000, in Nice. The rights set out in the charter are divided into six sections:

Dignity
Freedoms
Equality
Solidarity
Citizens' rights
Justice

They are based, in particular, on the fundamental rights and freedoms recognized by the European Convention on Human Rights (see below), the constitutional traditions of the EU member states, the Council of Europe's Social Charter (see below), the Community Charter of Fundamental Social Rights of Workers, and other international conventions to which the EU or its member states are parties. The issue of the charter's legal status—that is, whether to make it legally binding by incorporating it into the treaty—was raised by the Cologne European Council, which originally launched the charter initiative. The convention drew up the draft charter with a view to its possible incorporation, and the European Parliament voted in favor of incorporation. When the charter was proclaimed in Nice in December 2000, Romano Prodi, president of the commission, stated that "in the eyes of the EC, by proclaiming the Charter of Fundamental Rights the EU institutions have committed themselves to respecting the Charter in everything they do and in every policy they promote."

Disability is included in the charter's general nondiscrimination clause (Article 21), and Article 26 specifically states that the Union recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.

COUNCIL OF EUROPE

The Council of Europe (COE) is a political organization, founded in 1949. Its aims are to guarantee democracy, human rights, and the rule of law and to develop common responses to political, social, cultural, and legal challenges in its member states. There are currently 43 states that are members. The COE's main instrument, the European Convention on Human Rights and Freedoms, is the core treaty with enforcement powers through which the COE influences policy on human rights across Europe. Although disability discrimination is not specifically protected by the convention, Article 2 ("the right to life"), Article 3 ("no-one shall be subjected to torture or to inhuman or degrading treatment or punishment"), Article 8 ("everyone has the right to respect for their private and family life"), and Article 14 ("prohibition of discrimination") have been used in a number of creative ways to come to the assistance of people with disabilities whose rights to equal treatment are not being respected. For example, the case of *Botta v. Italy* (1998) established (see para. 32) that the right to a private life, guaranteed and protected by Article 8 of the convention, included the need for a state or public authority to protect a person's physical and psychological integrity. The Court held that Article 8 was primarily intended to ensure the development, without outside interference, of the personality of each individual in his or her relations with other people, a statement that has far-reaching implications for disabled people who are denied such development. The duty on the state or a public authority is clearly a positive duty.

Article 8 was argued in another case against the government of Italy, *Marzari v. Italy* (1999), where the applicant, who suffered from a series of complex disabilities, filed an action against the government for failing to provide him with accommodation suitable for a person with his disabilities. The applicant was unsuccessful, because the Court decided that the state had taken all reasonable steps to provide him with suitable accommodation, which he had rejected, notwithstanding the fact that an independent tribunal had determined that the accommodation was suitable, with modification. Although the applicant lost his case on the facts, the Court nevertheless left the door open for a different outcome, had the facts been more compellingly in favor of the applicant, holding that a state has obligations of this type where there is a direct and immediate link between the measures sought by applicants and their private life.

The European Social Charter (ESC) is a COE treaty, signed in 1961, which also is designed to protect the human rights of individuals including those with disabilities. In 1996, a revised and updated charter was opened for signature. It entered into force on July 1, 1999, and will progressively replace the 1961 Charter. Article 15 of the ESC 1961 deals with the right of physically or mentally disabled persons to vocational training, rehabilitation, and social resettlement, stating that with a view to ensuring the effective exercise of the right of the physically or mentally disabled to vocational training, rehabilitation, and resettlement, all state parties undertake the following:

- To take adequate measures for the provision of training facilities, including, where necessary, specialized institutions, public or private.
- To take adequate measures for the placing of disabled persons in employment, such as specialized placing services, facilities for sheltered employment and measures to encourage employers to admit disabled persons to employment.

Article 15 has been now amended as follows: With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration, and participation in the life of the community, the state parties undertake, in particular:

- To take the necessary measures to provide persons with disabilities with guidance, education, and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialized bodies, public or private.
- To promote their access to employment through all measures tending to encourage employers to hire and keep in employment persons with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability. In certain cases, such measures may require recourse to specialized placement and support services.
- To promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities, and leisure.

Article 15 therefore no longer applies only to vocational rehabilitation but also to the right of persons with disabilities to independent social integration, personal autonomy, and participation in the life of the community in general. The words "effective exercise of the right to independence" contained in the introductory sentence to the provision imply, inter alia, that disabled persons should have the right to an independent life. Under this provision, state parties must aim to develop a coherent policy for people with disabilities. The provision takes a modern approach to how the protection of disabled people shall be carried out, for example, by providing that guidance, education, and vocational training be provided whenever possible in the framework of general schemes rather than in specialized institutions, an approach that corresponds to that of Recommendation No. R (92) 6 of the Committee of Ministers of the Council of Europe. It not only provides the possibility but, to a large extent, obliges state parties to adopt positive measures for people with disabilities.

An international monitoring system is in place to monitor the extent to which COE member states respect the articles of the charter. Governments must submit reports on the application of the provisions of the charter that they have accepted. Copies of the reports can be viewed and downloaded at http://www.humanrights.coe.int/cseweb/GB/GB1/GB1.htm. The reports are all examined by the Committee of Social Rights, comprised of independent experts, which examines the reports and gives a legal assessment of their conformity with the charter. In the light of this assessment, the COE Committee of Ministers can issue recommendations to any governments appearing to be in default. An Additional Protocol providing for a system of collective complaints was opened for signature on November 9, 1995, and entered into force on July 1, 1998. Its purpose is to improve the efficiency of the supervisory machinery of the Social Charter, by enabling collective complaints alleging violations of the charter to be dealt with, in addition to the existing procedure for examining governments' reports. A number of international organizations of employers and trade unions, and other international nongovernmental organizations (NGOs) with consultative status within the COE, are entitled to raise collective complaints. For a full list of those bodies entitled to raise a collective complaint, see http://www.humanrights.coe.int/cseweb/GB/GB3/GB31.htm. Collective complaints are examined by the Committee of Social Rights, which must first decide on their admissibility in the light of criteria listed in the protocol. In practice, the committee, after having collected information from the complainants, from the state concerned, from the other contracting parties to the charter and from both sides of industry, draws up for the Committee of Ministers a report containing its conclusions as to whether the contracting party against which the complaint is directed has, in a satisfactory manner, ensured that the provision of the charter which is the subject of the complaint is applied. It is then the task of the Committee of Ministers to address a recommendation to the contracting party concerned, in the event that the Committee of Social Rights finds that the charter has not been satisfactorily applied, or, should this not be the case, to adopt a resolution to that effect.

Finally, it should be noted that independent, state-financed bodies with a clearly defined role to educate, reform, and enforce legislation in the field of disability discrimination are an increasingly important phenomenon across the whole of Europe (European Commission 2002).

EUROPEAN DISABILITY FORUM

Created in 1996, the European Disability Forum (EDF) is now the largest independent, trans-European organization that exists to represent disabled people in dialogue with the EU and other European authorities. Its mission is to promote equal opportunities for disabled people and to ensure disabled citizens' full access to fundamental and human rights through their active involvement in policy development and implementation in the EU. EDF has national councils in 17 European countries, together with approximately 45 disability NGO members, and a number of associate group and individual members. One of the most important campaigns of the EDF in recent years has been to argue for a disability-specific directive, that covers a far wider range of discriminatory activities. EDF argues that discrimination does not occur in the field of employment only, as employment is closely linked to several other areas such as education, transportation, and access to services and goods. Therefore, a directive aimed only at employment is insufficient. For a disabled person to be an active member of society in all areas and to enhance a broad nondiscrimination approach, a new disability-specific directive is needed. EDF has prepared a draft for such a directive. For the full text of this draft directive, go to http://www.edf-feph.org/en/policy/nondisc/nond_ pol.htm.

—Jeremy Cooper

See also Council of Europe Disability Policy; European Commission Policy.

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▣ DISABILITY LAW: GERMANY

Written in 1994, Section 3, Paragraph 3, Sentence 2 of the German Constitution (Grundgesetz) forbids the discrimination of people based on their disability. The concept of disability in Germany, however, is not uniformly regulated in legal documents. The most comprehensive definition can be found in Section 2 of the Sozialgesetzbuch IX-Rehabilitation und Teilhabe behinderter Menschen (SGB IX; Social Security Code IX-Rehabilitation and Participation of Disabled People, in effect since July 1, 2001) and is defined in an identical manner in Section 3 of the Behindertengleichstellungsgesetz (BGG; Disability and Equality Law, in effect since May 1, 2001):

> People are disabled if their physical function, cognitive ability, or psychological health significantly deviates from that of the typical, age-appropriate condition for longer than six months, and therefore interferes with their participation in society.

The German laws provide various instruments to prevent the discrimination of people with disabilities. Section 81, Paragraph 2 of the SGB IX, for example, forbids the discrimination against severely disabled people (*Schwerbehinderte*) at the workplace. Employers may not discriminate against people with disabilities in hiring, promotion, or termination practices. If an employee makes a believable argument that discrimination has occurred, the employer must use objective reasons to prove that the unequal treatment is or is not justified. Individuals who have an officially recognized disability can be terminated only upon approval of the Integrationsamt (Integration Office). Larger businesses are required to employ a fixed quota of severely disabled people or pay the state a specific lump-sum penalty. The regional income from this so-called Ausgleichsabgabe (equalization tax) is used to help support the gainful employment of the severely disabled.

The Behindertengleichstellungsgesetz (Disability and Equality Law) of the Federal Republic of Germany and the corresponding equality laws of individual states prohibit direct and indirect discrimination within state institutions. Official information must also be available for people with sensory disabilities. Hearing-impaired and speech-impaired individuals have the right to use sign language and communication help. The regulations also include guidelines for barrier-free new construction, public streets, paths, and public transportation and for equality in primary and secondary education. In addition, disability associations have the right to negotiate and bargain with economic enterprises for their services and products. The enterprises are not, however, obliged to come to a consensual, contractual agreement (a so-called Zielvereinbarung [target agreement]).

As yet, there has been no explicit legal sanction regarding the exclusion or discrimination against disabled people with respect to the purchase and use of economic goods and services. When private insurance companies, landlords, tour operators, airlines, restaurants, or other private businesses refuse disabled people as customers, individuals may claim illegal discrimination on a case-by-case basis. So far in such situations, however, disabled people have had to prove that they have been discriminated against. As of the beginning of 2004, a comprehensive civil antidiscrimination law had not yet been adopted. Access to medical, occupational, and social rehabilitation; nursing programs; pension payments; and social security benefits are regulated in various laws (e.g., Sozialgesetzbücher [Social Security Codes] III, V to IX, XI, as well as the Bundessozialhilfegesetz [Federal Public Welfare Law] and the Grundsicherungsgesetz [Basic Income Law]). The decision as to which benefit applies in individual instances is delegated in the German social law to various öffentlich-rechtliche Körperschaften (Official Statutory Corporations), semi-national organizations like the Gesetzliche Krankenkassen (Statutory Health Insurance Companies). The service provision is provided through social welfare organizations and private companies, for example, private nursing services, and nursing homes with ecclesiastic or associational sponsorship. According to the law, national social security only covers those who are gainfully employed or who have been in the past. Based on this fact, many disabled people are dependent instead on public welfare through the Bundessozialhilfegesetz and Grundsicherungsgesetz. These forms of benefits serve, above all, to protect an individual at the minimum income level necessary for survival. They only cover essential rehabilitation and integration assistance and only accept recipients who are indigent, people who have no or only a meager source of income, or who possess only a few assets.

At the beginning of the twenty-first century, German disability policies were newly conceived. Today, the long-term goal is to encourage the social participation and self-determination of disabled people. They should no longer be passive objects of social welfare, but should make, as much as possible, self-determined decisions regarding the forms in which to receive support. In addition, consideration is to be made of the needs of disabled women. These basic goals, however, have as yet been only partially realized in the law and in practice.

—Julia Zinsmeister

See also Disability Law: Europe.

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DISABILITY LAW: INDIA

See Disability Policy: India

DISABILITY LAW: SWEDEN

The Swedish Disability Act (Lag om stöd och service till vissa funktionshindrade, SFS 1993:387) came into force in 1994. It is hereafter referred to as LSS, the standard Swedish abbreviation. LSS complements universal legislation such as the Social Services Act and the Health and Medical Services Act, giving priority to the social needs of persons with severe disability such as intellectual disability (mentally retarded from birth or young age; autism or conditions resembling autism; considerable and permanent intellectual disability after brain damage when an adult, caused by external force or illness), and other lasting physical or mental disabilities that are manifestly not due to normal aging, if these disabilities are major and cause considerable difficulties in daily life and, consequently, an extensive need for support and service. LSS succeeded an act of similar construction, the Special Services Act of 1985, offering social support only to persons with intellectual disabilities. In accordance with LSS, the target groups are entitled to 10 different support measures, one of the most important being the right to personal assistance. Local authorities are responsible for nine and county councils for one support measures. The same kind of social support can be given in accordance with the Social Services Act and LSS. However, because LSS is a human rights statute there are decisive differences: LSS has a higher level of ambition (”good living conditions” as opposed to the “acceptable standard of living” as decreed by the Social Services Act), there is an unconditional right to support when needs are not met, applications for support may not be turned down on the grounds of insufficient funding, and LSS measures are free of charge.

The political intention with LSS is to strengthen citizenship in the encounter with the public sector. Freedom from coercion and influence over assessment of needs are ways to guarantee the civil element of citizenship. Equalization of opportunities to live a life like others and be able to participate in society and the common welfare expresses the social element of citizenship. However, the reform has not been implemented to the extent that the politicians intended. Appraisals indicate that a smaller number, half of the expected 100, 000 or 1 percent of the population, have shared in the benefits of this reform. This result particularly applies to persons with mental disabilities. Thus, first, persons with severe disabilities have not, for different reasons, been able to exert their legal rights. Second, officials and experts, such as social welfare officers and physicians, seem not always to understand the intent of LSS and its precedence over the Social Services Act. Third, local politicians, who very well may understand the intent of LSS, giving persons with severe disabilities priority, still defend municipal self-government and follow their own priorities. The result has been several cases of judicial disobedience when favorable decisions in courts have not been enforced. The state tries to overcome this problem, earlier by fining disobedient municipalities, and since 2002 by using sanctions.

—Barbro Lewin

See also Social Model: Sweden.

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DISABILITY LAW: UNITED STATES

Disability law in the United States is at a pivotal point in its development. The past half-century has seen a move from the medical and vocational models, which addressed disability as either a medical issue to be cured or a justification for welfare and benefits, to a civil rights model, which seeks to remove the barriers that impede the full integration of people with disabilities into society.

The Americans with Disabilities Act (ADA) is the current prominent national policy and legal statement affecting the lives of persons with disabilities. Though the ADA is the largest and most sweeping legislation, it does not stand alone. Among others, the Rehabilitation Act, Individuals with Disabilities Education Act (IDEA), Fair Housing Act Amendments, and various state laws all combine to complete the American disability law landscape or framework. These laws, and the legal issues involved in narrowing or enlarging their focus, are explored below.

AMERICANS WITH DISABILITIES ACT

The ADA was signed into law on July 26, 1990. It is sweeping legislation, intended to create broad social change. At the signing ceremony, President George H. W. Bush described the ADA as

> the world's first comprehensive declaration of the equality of people with disabilities, and evidence of America's leadership internationally in the cause of human rights. With today's signing of the landmark Americans with Disabilities Act, every man, woman, and child with a disability can now pass through the closed doors, into a bright new era of equality, independence, and freedom.

The ADA has a preface section and three main parts. The preface section states Congress's goals and reasons for passing the ADA. This section of the law identifies people with disabilities as "a discrete and insular minority who have been faced with restriction and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society," and sets the nation's proper goals regarding individuals with disabilities as ensuring "equality of opportunity, full participation, independent living, and economic self sufficiency."

The preface section also sets out the operative definition of disability for the entire statute. An individual with a disability is defined as someone with a physical or mental impairment that substantially limits one or more major life activities of the individual, a record of such an impairment, or being regarded as having such an impairment. In a series of cases, the U.S. Supreme Court has recently interpreted this definition to mean that individuals and their impairments must be considered in their mitigated states. Thus, for example, an individual with 20/200 vision who is rejected for a position as a pilot based on an employer's uncorrected vision requirement is not considered disabled for the purposes of the ADA, where eyeglasses can correct that individual's eyesight to 20/20.

The next three main parts of the ADA (commonly referred to as Titles I to III) cover nondiscrimination in employment, public services, and places of public accommodation, respectively. These will be discussed in turn.

Title I: Employment

Perhaps the most heavily litigated provisions of the ADA have been the employment sections. They impose comprehensive—from application to termination—obligations on covered employers.

The ADA's general rule of nondiscrimination in employment is that "no covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment."

Covered Entity

An employer is a "covered entity" if that employer has 15 or more employees. Most recently, in *Clackamas Gastroenterology Associates, P.C., v. Wells,* the Supreme Court developed a six-part test to determine whether shareholder-directors are employees for the purposes of ADA Title I. The crucial element in this test is control.

In *Board of Trustees of the University of Alabama v. Garrett,* the Supreme Court held that Congress's abrogation or limitation of the states' Eleventh Amendment sovereign immunity was invalid insofar as Title I provided for suits against the states for monetary damages. Therefore, states are treated differently for ADA Title I purposes than are private employers. After *Garrett,* a state employee does not have a viable claim against his employer for monetary damages under ADA Title I.

Prohibited Inquiries

There is a substantial body of case law relating to the range of permissible inquiries (both before and during employment) under Title I. The general preemployment rule is that a potential employer may not try to learn if the applicant has a disability, unless it is legitimately necessary for the conduct of the job. Preemployment medical examinations are not permissible. This provision allows individuals with disabilities to be judged on their qualifications and not on their disabilities. After an employer has made a conditional offer, but before the start of employment, the employer may require a medical examination or ask disability-related questions if all employees—or a least all employees performing similar tasks—must take it and it can be shown to be related to the job qualifications. The examination is subject to rigid confidentiality restrictions. During the course of employment, an employer may not make inquiries or require a medical examination "unless such examination or inquiry is shown to be job-related and consistent with business necessity."

Reasonable Accommodation

The concept of reasonable accommodation is central to Title I's antidiscrimination provision. An employee is not a "qualified" person with a disability for purposes of Title I if he or she cannot perform the essential job functions with or without a reasonable accommodation. An employer's failure to make a reasonable modification, when asked, constitutes a separate claim of employment discrimination. A reasonable accommodation is a modification or adjustment to a workplace process or environment that makes it possible for a qualified person with a disability to perform essential job functions. Accommodations may include physical modifications to a workspace, flexible scheduling of duties, or provision of equipment, assistive technologies, and job training to aid in job performance.

To be eligible for an accommodation, an employee must make his or her disability known to the employer and request an accommodation. Once the accommodation request is made, the ADA requires a consultative "interactive process." In this process, the employer retains the right to choose the accommodation according to its reasonable effectiveness and the employee's good faith opportunity to participate in the process.

Undue Hardship and Direct Threat

A common critique of Title I is that accommodations for qualified individuals create economic hardships that are costly and burdensome for employers. The statutory mechanism for dealing with this criticism is the "undue hardship" defense. Employers only are required to make accommodations that do not impose undue hardships on them. An undue hardship is a significant difficulty or expense, in light of the firm's size and resources. Undue hardship is an affirmative defense that must be raised and proved by the employer.

Similarly, an employer does not need to make a requested modification if it creates a significant risk of a "direct threat" to the health or safety of the employee, applicant, or others in the workplace. In *Chevron v. Echazabal,* the Supreme Court interpreted this defense to include instances where the employee's disability creates a direct threat to his own health or safety.

Title II: Public Entities

ADA Title II requires that the services, programs, and activities of state and local government entities be accessible to people with disabilities. Before the ADA was enacted, the Rehabilitation Act of 1973 prohibited some public entities from discriminating on the basis of disability. This protection, however, was limited to public entities that received federal financial assistance. A primary purpose of Title II was to extend the existing prohibition on discrimination to state and local government entities, regardless of whether they received federal financial assistance. Title II is therefore the least revolutionary of the major titles of the ADA.

Title II's main antidiscrimination provision is that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."

To have a viable Title II claim, a plaintiff must demonstrate that he or she was either excluded from participation in or denied the benefits of a public entity's services, programs, or activities, or was otherwise discriminated against. The regulations promulgated by the U.S. Department of Justice pursuant to Title II offer extensive guidance on what this means. Conceptually, it is useful to think about the affirmative responsibilities of public entities in five areas: making reasonable modifications to policies, practices, and procedures; administering services, programs, or activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities; modifications to facilities; communications modifications; and accommodations in transportation.

Until recently, it has been an open issue as to whether individuals can sue states for damages for violations of Title II of the ADA. In *Tennessee v. Lane*, the Supreme Court held that an individual could sue a state for damages for not providing access to courthouses. It is still an open question whether individuals can sue states for damages for the panoply of other rights that fall within Title II's scope.

Reasonable Modifications to Policies, Practices, and Procedures

The Title II regulations provide that a public entity must reasonably modify policies, practices, or procedures when necessary to allow participation by a person with a disability. Analytically, this is similar to the reasonable accommodation requirement of Title I.

The regulations set the outer limits of reasonable accommodations. The regulations provide that modifications must be made *unless* the public entity can demonstrate that making them would fundamentally alter the nature of the program, service, or activity.

Although the reasonable modification requirement of Title II does not include an undue hardship defense, the courts have read undue hardship into the fundamental alteration defense. Thus, courts determining whether a modification will constitute a fundamental alteration consider whether the change will cause an undue financial or administrative burden on the entity.

Even if a given program, service, or activity has an essential eligibility requirement, the plaintiff still can be a "qualified individual with a disability" if he or she can meet that requirement with or without "reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provisions of auxiliary aids and services."

Integration

The regulations provide that public entities must administer services, programs, or activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. In *Olmstead v. Zimring,* the Supreme Court considered the interplay between this integration mandate and the "fundamental alteration" limit on reasonable modification of policies.

In *Olmstead,* two women with mental retardation and psychiatric conditions brought suit under Title II, claiming that the state of Georgia had discriminated against them by keeping them in institutionalized settings instead of community placements that were appropriate for their needs. The Court held that this unjustified institutional isolation constituted discrimination within the meaning of Title II. However, the Court recognized that the duty to accommodate was not absolute. In deciding whether this accommodation would fundamentally alter the state's mental health treatment program, the proper inquiry was *not* the cost of accommodating these two plaintiffs weighted against the states' overall mental health budget.

In July of 2001, President George W. Bush entered an executive order reinforcing the *Olmstead* decision and providing guidance to the U.S. attorney general, the secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the commissioner of the Social Security Administration in its implementation. As part of the administration's "New Freedom" initiative, the Centers for Medicare and Medicaid Services distributed more than $120 million in grants in 2001 and 2002 to help states increase community-based integration for people with disabilities. However, years after the *Olmstead* decision, states face a lack of coordinated community-based services and a shortfall of funds in carrying out the integration mandate.

Facilities Modification

Title II applies to a public entity's physical structures. Courts have interpreted this reach to include, among other things, city buildings, botanical gardens on the premises of a state university, publicly owned sporting arenas and theaters, and recently, city sidewalks. The regulations provide that each service, program, or activity conducted by a public entity, when viewed in its entirety, must be readily accessible to and usable by individuals with disabilities. This does not mean, however, that each existing facility must be physically accessible to and usable by individuals with disabilities.

The regulations set forth the "program access" standards for facilities. What a public entity must do to ensure program access to its facilities varies according to whether the facility is an "existing" facility, a new facility, or a facility that has been altered.

In ensuring program access in existing facilities, a public entity does not have to take action that will result in fundamental alteration in the nature of a service, program, or activity or cause an undue financial or administrative burden. The public entity has the burden of showing that compliance with the program access standard would result in such alteration or burden. The decision that compliance would result in such an alteration or burden must be made by the head of the public entity, in writing.

Notably, a program must be accessible "when viewed in its entirety." Therefore, if a government program offers identical services at more than one facility, not every facility must be accessible. To allow some facilities to remain unchanged, the alternative facilities must offer equivalent services in terms of type of service, hours of operation, convenience, and quality.

The regulations create a different set of responsibilities for public entities for construction of new facilities and alterations of existing facilities. For new construction, the regulations provide that each facility or part of a facility constructed by, on behalf of, or for the use of a public entity be designed and constructed in such manner that the facility or part of the facility is readily accessible to and usable by individuals with disabilities. Alterations to existing facilities are subject to a similar standard.

In contrast to the regulations governing existing facilities (where entities are exempted from making fundamental alterations and bearing undue financial burdens), the regulations for new construction and alteration are more stringent. There is no "undue burden" provision, with the regulations stating facilities "shall" be accessible.

Effective Communication

Like the program access standard, Title II's communications provisions have a statutory and regulatory component. Title II's definition of qualified person with a disability links the "provision of auxiliary aids and services" to the concept of reasonable accommodations. The Title II regulations have a separate section devoted to "Communication," which makes clear that communication is an integral part of a public entity's responsibilities under Title II.

The regulations provide that auxiliary aids and services be furnished when necessary to afford an individual with a disability an equal opportunity to participate in and enjoy the programs, services, or activities of the public entity. The effective communication obligation is owed to people with hearing, speech, and vision disabilities, as well as those with mental and physical impairments.

In terms of types of auxiliary aids and services, a public entity is to give primary consideration to the requests of individuals with disabilities. Auxiliary aids and services for people with hearing impairments include qualified interpreters, notetakers, written materials, amplifiers, captioning, teletypewriters (TTYs), telecommunications devices for the deaf (TDDs), and others. For people with vision impairments they include qualified readers, taped text, Braille, large print, assistance locating items, and others. For people with speech disabilities they include TTYs, computer terminals, speech synthesizers, and communication boards. The regulations provide that a public entity does not need to take any action that it can demonstrate would result in a fundamental alteration or an undue financial or administrative burden.

Transportation

Title II has a separate part dedicated to nondiscrimination in transportation provided by public entities. Transportation was an area where the ADA's framers recognized an existing pattern of discrimination and inequity.

The ADA explicitly states that "discrimination against individuals with disabilities persists in such critical areas as . . . transportation" and "individuals with disabilities continually encounter various forms of discrimination, including . . . transportation . . . barriers." The debates on ADA passage suggest that the framers viewed transportation as crucial to unlocking other opportunities that the ADA would help create.

Public transportation is especially important to people with disabilities because the evidence suggests that they are more reliant on public transportation than the general population. The legal and policy tensions specific to transportation issues are a microcosm of the entire act. These issues include mainstreaming of existing transportation to accommodate people with disabilities versus paratransit (i.e., transportation services usually performed by vans that are provided separate from mass transit's normal operations), and whether there should be a "threshold" or "necessary" level of spending on mass transportation options for people with disabilities.

ADA Title II's transportation provisions require accessibility standards for fixed-route systems (e.g., buses and rails that run on fixed schedules), paratransit, demand response systems (e.g., any system, such as taxicab service, that is not a fixed route), and rail service that is dedicated to commuters and that runs between cities.

Title III: Public Accommodations

Title III extends the ADA's antidiscrimination mandate to places of public accommodation and commercial facilities. Title III therefore is broader in scope than Title II. The goal of Title III is to integrate people with disabilities into the mainstream of American life.

The overarching requirement of Title III is set out in its antidiscrimination provision:

> No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to) or operates a place of public accommodation.

The premise of Title III is straightforward: Places of public accommodation are barred from discriminating against people with disabilities in their use of facilities and the provision of goods and services. To this extent, Title III parallels Title II of the Civil Rights Act of 1964.

However, discrimination under Title III is defined broadly to include failure to make reasonable modifications of policies, practices, and procedures; failure to ensure effective communication; and failure to take steps to make facilities physically accessible. The defenses to a charge of discrimination rely on concepts of undue burden, fundamental alteration, and lack of "readily achievable" modifications.

Title III provides general and specific prohibitions on discriminatory conduct. General discrimination prohibited under Title III includes denial of participation, participation in unequal benefit, providing a separate benefit when separation is not necessary, failure to ensure that people with disabilities receive goods or services in the most integrated setting appropriate to their needs, denying an individual with a disability the opportunity to participate in an integrated benefit because of the availability of a separate benefit, using contractual or administrative methods that have the effect of discriminating or that perpetuate the discrimination of others who are subject to common control, and discrimination on the basis of association with a person with a known disability. Specific types of discrimination under Title III include discriminatory eligibility criteria; failure to make reasonable modifications of policy, practice, or procedure when necessary to permit a person with a disability to benefit from a place of public accommodation; failure to ensure effective communication through the provision of auxiliary aids; and failure to remove architectural barriers to access when it is readily achievable to do so.

A place of public accommodation may not assess a charge to a person with a disability for any action, aid, or service required by the ADA, even to cover the actual costs of the action, aid, or service. Rather, the cost of compliance must be considered an overhead expense.

The defense to the reasonable modification requirement is that the requested modification would fundamentally alter the nature of the goods or services being provided. The U.S. Supreme Court addressed the application of the fundamental alteration defense in *PGA Tour, Inc. v. Martin.* Casey Martin, a professional golfer, has a degenerative circulatory disorder that obstructs the flow of blood from his right leg to his heart. Martin requested that the Professional Golfers' Association (PGA) allow him to ride a golf cart in its tournaments, instead of complying with the normal rule that participants walk the course.

The PGA Tour conceded that a golf cart was necessary for Martin to participate in the tour, but argued that the requested modification would fundamentally alter the nature of the event in three ways: by altering "such an essential aspect of the game of golf that it would be unacceptable even if it affected all competitors equally," by giving the individual with a disability an unfair advantage over the other players, and by imposing administrative burdens on the operator of a place of public accommodation. The Court found that none of those possible alterations rose to the level of a permissible defense in this case, and held that Casey Martin was entitled to use a golf cart as a reasonable modification.

Title III provides an affirmative defense in situations where providing a modification would pose a direct threat to the health or safety of others. The statute defines "direct threat" as "a significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services."

The ADA regulations provide that the direct threat determination should be based on individualized assessment and on reasonable judgment that relies on current medical knowledge or the best available objective evidence. It must consider the nature, duration, and severity of the risk, the probability that the potential injury actually will occur, and whether modifications will mitigate the risk.

Title II also requires physical accessibility of public accommodations. For existing facilities, Title III requires architectural barriers to access to be removed "where such removal is readily achievable, i.e., easily accomplishable and able to be carried out without much difficulty or expense." If removal of a barrier or barriers is not readily achievable, a place of public accommodation must attempt to make its goods and services accessible to people with disabilities through alternative methods that are readily achievable. Examples of alternatives to barrier removal include providing curb service or home delivery, retrieving merchandise from inaccessible shelves or racks, and relocating activities to accessible locations.

Title III entities making alterations or renovations to existing facilities for other than barrier removal purposes must "make such alterations . . . in such a manner that, to the maximum extent feasible, the altered portions of the facility are readily accessible to and usable by individuals with disabilities, including individuals who use wheelchairs." New buildings, constructed for first occupancy after January 26, 1993, must be fully accessible to and usable by people with disabilities. The only exception to compliance occurs when the entity demonstrates that full compliance is structurally impracticable. Structural impracticability will be found "only in those rare circumstances when the unique characteristics of terrain prevent the incorporation of accessibility features."

SECTION 504 OF THE REHABILITATION ACT

The Rehabilitation Act of 1973, and Section 504 in particular, is in many ways the direct predecessor to the ADA. As originally passed, the primary focus of the Rehabilitation Act of 1973 was vocational training and rehabilitation. The stated purpose of the act was to "provide a statutory basis for the Rehabilitation Services Administration," an agency charged with carrying out the provisions of the act, and to authorize various rehabilitation programs.

The final part of the original 1973 act contains the portions of the Rehabilitation Act that over time have had the greatest impact. Section 501 requires affirmative action and nondiscrimination in employment by federal agencies of the executive branch. Section 502 established the Architectural and Transportation Barriers Compliance Board (Access Board), which also is responsible for developing accessibility standards for the ADA. Section 503 requires that to receive certain government contracts, entities must demonstrate that they are taking affirmative steps to employ people with disabilities.

The enduring hallmark of the Rehabilitation Act of 1973, however, is Section 504. This section provides that no otherwise qualified individual with a disability shall, solely by reason of his or her disability, be excluded from the participation in, denied the benefits of, or subjected to discrimination under any program or activity receiving federal financial assistance. This sweeping language was the first explicit Congressional statement recognizing "discrimination" against people with disabilities.

The regulations promulgated pursuant to Section 504 of the Rehabilitation Act introduced the concept of "reasonable accommodation" to disability discrimination law. The "employment" section of the Section 504 regulations states:

> A recipient [of federal funds] shall make reasonable accommodation to the known physical or mental limitations of an otherwise qualified handicapped applicant or employee unless the recipient can demonstrate that the accommodation would impose an undue hardship on the operation of its program or activity.

The regulations provide examples of reasonable accommodations, including altering facilities and modifying work schedules.

The Section 504 regulations' approach to facility access issues is similar to ADA Title II. The regulations provide that no qualified person with a disability be denied the benefits of, excluded from participation in, or otherwise subjected to discrimination because a recipient's facilities are inaccessible to people with disabilities. This is commonly known as the "program access" requirement. A recipient of federal funds does not have to make its facilities accessible; rather, accessibility is achieved when each program or activity within the facilities, viewed as a whole, is accessible. Examples of steps to ensure program accessibility include redesigning equipment, reassigning classes to accessible buildings, and home visits.

Another issue the regulations make clear is that education is covered by Section 504. The regulations provide that recipients of federal funds that operate public or secondary schools must provide a free appropriate public education to each qualified handicapped person, regardless of the nature of severity of that person's handicap. Similarly, the regulations provide that qualified persons with disabilities may not be denied admission or subjected to discrimination by postsecondary schools on the basis of disability.

The Rehabilitation Act and its accompanying regulations frame the issues of employment, and facility and educational access for persons with disabilities as a balancing test. Accommodation is desirable, when the methods of ensuring accessibility are reasonable. Although "reasonable" is not defined, a guiding principle is that a reasonable accommodation or modification does not require a change to the fundamental nature of the job, program, or facility.

Conceptually and doctrinally, the ADA and Section 504 of the Rehabilitation Act of 1973 have a close relationship. Both are premised on the belief that people with disabilities have a right to be included in society and that a denial of that right, including failure to make reasonable accommodations, constitutes discrimination. The ADA concepts that the courts have struggled with—reasonable accommodation, the definition of disability, and fundamental alteration—have their bases in the Rehabilitation Act. The ADA is explicit that Rehabilitation Act regulations and cases are instructive in interpreting the ADA.

SECTION 508 OF THE REHABILITATION ACT

The implementation of Section 508 of the Rehabilitation Act was designed to spur innovation throughout the e-commerce industry. Enacted as part of the Workforce Investment Act of 1998, Section 508 requires that electronic and information technology (EIT), such as federal websites, telecommunications, software, and information kiosks, must be usable by persons with disabilities.

Federal agencies may not purchase, maintain, or use EIT that is not accessible to persons with disabilities, unless accessibility poses an undue burden. The EIT Accessibility Standards, finalized on December 21, 2000, detail the requirements for federal entities. Section 508 does not require private companies that market technologies to the federal government to modify the EIT products used by company employees, or to make their Internet sites accessible to people with disabilities.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The IDEA originally was passed in 1975 (under the name Education for All Handicapped Children Act). As originally passed, this act was an express recognition of the number and needs of children with disabilities in the school system. Congress found that "there are more than eight million handicapped children in the United States today," whose educational needs were not being met. To meet these educational needs, IDEA focuses on higher expectations, mainstreaming students where possible, and an increased federal rule in ensuring equal educational opportunity for all students.

Under the IDEA, schools have to provide a free and appropriate public education (FAPE) to eligible children with disabilities. The FAPE should take place in the least restrictive environment appropriate to the child's needs. IDEA requires schools to develop an individualized education program (IEP) for each child. Each child's IEP must be developed by a team of knowledgeable persons and reviewed annually. This team includes the child's teacher, parents, and if appropriate the child, and an agency representative who is qualified to provide or supervise the provision of special education. If the parents disagree with the proposed IEP, they may request a due process appeal hearing and a review from the state educational agency, and may appeal this decision to state or federal court. In 2005, the IDEA was reauthorized with the Individuals with Disabilities Education Improvement Act of 2004.

FAIR HOUSING ACT AMENDMENTS

In 1988, Congress introduced a series of amendments to the Civil Rights Act of 1968, including a prohibition on housing discrimination against people with disabilities. These amendments are known as the "Fair Housing Act Amendments of 1988."

The Fair Housing Act Amendments make it unlawful to discriminate in the sale or rental of housing, and the terms and conditions of such sale or rental, on the basis of disability. The Fair Housing Act Amendments have a broad scope, protecting not only a buyer or renter with a disability but also a person with a disability who lives with a buyer or renter, or any other person associated with the buyer or renter.

Discrimination under the Fair Housing Act Amendments includes a refusal to permit an occupant with a disability, at his or her own expense, to make reasonable physical changes to the existing premises; a refusal to make reasonable accommodations in rules, policies, practices, or services; and a failure to construct multifamily dwellings (which contain four or more units) so that specified portions of those facilities are accessible to individuals with disabilities.

STATE DISABILITY LAWS

Before the passage of the ADA, the primary responsibility for regulating discrimination on the basis of disability belonged to the individual states. Different states had laws covering nondiscrimination in employment, public accommodations, and state services. Many states covered one, but not all, of these areas. These pre-ADA state statutes generally regulated far less conduct than the ADA.

Congress's passage of the ADA was grounded on a recognition that stronger protection was needed than that offered by the states alone. The ADA was a shift toward a comprehensive federal model of protection for a wide range of people with disabilities. The ebb and flow between and among the U.S. federal and state laws is, of course, reflective of changing views about the role of the federal and state government in the lives of citizens. With the recent narrowing by the Supreme Court of federal civil rights laws, and the ADA in particular, states' civil rights laws take on a renewed importance for the protection of people with disabilities from discrimination.

Today, every individual state has some law relating to discrimination on the basis of disability. The scope and coverage of these laws run the gamut. Some state statues offer protection that is greater than, or equal to, the ADA, while others offer less protection.

One example of a state that offers more protection for people with disabilities is California. California had a history, even pre-ADA, of offering strong legal protections for people with disabilities. The California disability antidiscrimination statute, the

Fair Employment and Housing Act (FEHA), is comprehensive in scope. FEHA prohibits discrimination in public and private employment, and it contains a reasonable accommodation requirement. Another California statute, the Unruh Civil Rights Act, guarantees people with disabilities full and equal accommodations in business establishments.

In 2000, California amended the FEHA. The amendments expand on the ADA's protections in several significant ways. For example, as discussed, to be considered "disabled" for the purposes of the ADA, an individual needs to be considered in his or her mitigated state. The FEHA amendments reject that view, providing that "under the law of this state, whether a condition limits a major life activity shall be determined without respect to any mitigating measures." Similarly, while the ADA limits coverage to individuals whose impairments result in a *substantial limitation* of a major life activity, an individual is covered by California's FEHA if his or her impairment *limits* a major life activity.

CONCLUSION

The laws discussed above make up the American legislative landscape as it relates to the rights of people with disabilities. The political and judicial climate of the United States is split between those who believe the ADA represents the federal government reaching too far into the lives of states and private businesses and those who feel this is the most important civil rights law of the past several decades. Time will tell the direction and scope that judges and politicians allow the ADA to take.

—Michael Waterstone, Charles D. Siegal,
Eve Hill, and Peter Blanck

See also Americans with Disabilities Act of 1990 (United States); Fair Housing Act Amendments of 1988 (United States); Rehabilitation Act of 1973 (United States).

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DISABILITY LEAVE

In the United Kingdom in the early 1990s, a pioneering job retention program for disabled people was introduced under the title "disability leave." Designed to assist newly disabled people or people whose impairment deteriorates to retain their employment, the program provides for a period of leave with expert assessment, advice, rehabilitation, retraining, workplace adaptation, and, perhaps most important of all, job protection.

Disability leave was developed by the Royal National Institute of the Blind (RNIB) and has subsequently been adopted by a number of major employers across the United Kingdom. RNIB has pressed successive governments to put the scheme on a statutory basis, but to date this has not been accepted. Yet with recent changes to disability employment and benefit policies, some elements are now in place. What is missing is a clear policy for job protection.

BACKGROUND

RNIB developed disability leave as a response to the large number of people in their 40s and 50s losing their sight at work who through redundancy, resignation, or early retirement also lost their jobs. It was recognized that sight loss (or any other impairment) need not be an obstacle to staying in work but that all too often both employer and employee believed it was.

Disability leave offers major benefits to both employer and employee. To the newly impaired employee, the program provides support, retraining, rehabilitation, and crucially, the chance to avoid what is likely to be a long period of unemployment with the inevitable associated drop in income. To the employer, disability leave has many benefits including the retention of experienced staff, avoidance of unnecessary recruitment costs, lower staff turnover, and a reduced early call on occupational pension funds.

WHAT IS DISABILITY LEAVE?

Disability leave does not simply refer to a "leave" entitlement, but rather to a whole process of assessment, advice, retraining, and workplace adaptation including the provision of assistive technology and job protection. Typically, a company's disability leave plan will involve early intervention to identify and engage with employees who are experiencing sickness or disability. A home visit may be arranged as early as four weeks although eight weeks is a more typical period. If appropriate, a case manager is appointed who provides support and advice to the employee and the manager. Following an expert assessment, a range of options are considered to enable the employee to continue in his or her current job including retraining, workplace adaptation, and the provision of assistive technology. However, in certain circumstances the job itself may need to be modified with possible reallocation of duties among colleagues. As a last resort, it may be necessary for the employee to be redeployed elsewhere in the organization.

RNIB developed the policy of disability leave in the early 1990s in consultation with statutory, voluntary, and trade union organizations concerned with employment and disability. Subsequently, it has been adopted by a range of mainly larger companies including Barclays Bank, HSBC, Royal Mail, and the TUC. However the great majority of employers continue to respond to the onset of an impairment in an ad hoc and typically negative manner. This reflects widely held prejudicial views about the difficulties of employing disabled people and also worries about the additional costs that may be incurred.

In the absence of widespread adoption of disability leave on a voluntary basis, RNIB has pressed successive governments to put the scheme on a compulsory basis. RNIB wants disability leave to be as well-known as the statutory maternity leave program that provides job protection and income for women during pregnancy and the first year following birth. However, to date, this has not been accepted with the government arguing that disability leave should be provided by employers as a "reasonable adjustment" under the Disability Discrimination Act (DDA).

FOUR ELEMENTS OF A SUCCESSFUL POLICY

Disability leave is one way to assist newly disabled people to retain paid employment. But, as with any voluntary program, it can have only a limited impact. Disability leave needs to be put on a statutory basis and supported by a broader set of policies that promote job retention. Overall, four elements are critical to success: job protection, cost sharing, early and timely intervention, and a flexible and supportive benefits system.

Job retention through disability leave, or indeed any other program, is not possible if there is no job to return to. In the United Kingdom, this protection should be provided by the DDA with employers being required to retain newly disabled employees and to make "reasonable adjustments" to the work environment. However, typically the DDA comes into effect only when an individual makes a complaint of unfair dismissal on grounds of disability; that is, *after* the individual has lost his or her job. Even if an Employment Tribunal finds in favor of the disabled employee, it cannot under current legislation require the employer to reinstate. At best, the disabled person will receive substantial compensation from his or her ex-employer but will, nevertheless, still be out of work.

The second key element of any job retention strategy is cost sharing. Most employers are not convinced by the business case for retaining newly impaired employees. They believe that there will be substantial costs associated with retraining and workplace adaptation and that these will outweigh the benefits of keeping an experienced employee. Without a compulsory job retention program that allows for some element of cost sharing, employers will not keep on newly disabled employees.

In the United Kingdom, this issue has been partially addressed through the Access to Work program. This provides government funding for adaptation of premises and equipment, special aids, support workers, and travel to and from work. In many cases, Access to Work can cover all of the additional costs associated with retaining a newly disabled person, which should be enough to alleviate employer concerns. However, as many as three-quarters of employers have not heard of the program and the financial support it can provide.

While Access to Work is concerned primarily with funding changes to the work environment and equipment, the Employee Retention Grant Scheme introduced in the Republic of Ireland in the late 1990s provides financial support for the development and implementation of a job retention strategy for newly disabled workers. Under a two-stage process, employers receive funding to buy in expert skills to develop a written individual retention strategy and then further aid toward implementing the strategy including retraining and job coaching. In general, cost sharing is needed to ensure the provision of return to work services through individual casework and to fund workplace adaptations and equipment.

The third necessary element of a successful job retention strategy is early and timely intervention. Within disability leave programs, there is typically a home visit at eight weeks. This is in sharp contrast to the usual practice in the United Kingdom, which has been to allow newly sick or disabled employees to drift out of work and onto long-term benefit dependency. This is changing with a stronger focus on job retention in the Department for Work and Pensions (DWP) latest Five Year Plan (DWP 2005). But the United Kingdom is still some way from the early interventions required in countries such as Denmark, Sweden, and the Netherlands.

The fourth key element of a successful job retention strategy is a benefits system that is flexible and supports a gradual return to work after a period of disability leave. In the United Kingdom, benefit rules have tended to discourage the combination of sickness/incapacity benefit with a wage, allowing for part-time working. However, this also is starting to change as the findings of DWP Pathways to Work and job retention pilots show the advantages of flexible benefit/pay packages.

DE FACTO DISABILITY LEAVE

Despite the UK government's stated opposition to disability leave, key elements are now in place. There is cost sharing through Access to Work. Timely intervention and benefit flexibility is starting to be delivered through Pathways to Work and the proposed Rehabilitation Support Allowance. What is missing is effective job protection. This is not and will not be delivered by the type of disability discrimination legislation that exists in the United Kingdom and the United States. Yet, as both Bloch and Prins and Thornton have argued, this is *the* most important element in a job retention strategy.

—Steve Winyard

See also Disability Discrimination Act of 1995 (United Kingdom); Job Retention.

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DISABILITY MANAGEMENT

Disability management is used to refer to a wide range of concepts and approaches. Most commonly, the term is used in three areas: work and work discrimination, symptom/condition management, and resource management.

Within the area of work, disability management commonly refers to a field of practice that has focused on how employers manage disability overall within the workplace, including issues such as preventing disability, returning to work after a disability event, providing reasonable accommodations within the worksite, and cost-benefit and -effectiveness analyses of the management services. Within the United States, there is a national certification system for disability management specialists, referring primarily to human resource specialists with experience in managing work-related disability issues. Given the passage of the 1990 Americans with Disabilities Act in the United States, the Disability Discrimination Act in England, and other related civil rights legislation in many countries, the focus has shifted toward evaluating discrimination in the workplace experienced by disabled people, and the effect of this discrimination on the disabled person, the disability community as a minority group, employers, and society in general. The field of disability management has also focused on organizational health, that is, how disability influences cost, cost-benefit, and productivity within worksites as organizational units. The field of disability studies has instead focused on analyzing the oppression of disabled people as a minority group, particularly evident in the area of access to work opportunities, tracing the oppression to a capitalist political economy and ideology.

Disability management has also been used to refer to the management of symptoms, conditions, and impairments affiliated with disability. In this case, *disability* is used to refer to disease, medical or chronic conditions (e.g., diabetes, heart disease, arthritis, multiple sclerosis), or broader impairment categories (e.g., physical, cognitive, mental, sensory). *Management* refers to how people who are living with these conditions manage or control the symptomology, and the use of treatments affiliated with each. Research has focused on how people respond to symptoms and control them in emergency and acute situations as well as over their lifetime, treatment strategies for managing symptoms, and the relative outcomes, effectiveness, and long-term impact of treatments, primarily related to quality of life and cost/cost-benefit issues as framed within a medical approach.

The focus on condition or impairment management has expanded beyond symptom management to self or self-care management, that is, managing everyday self-care in the home given specific conditions or a long-term disability. Self-care is often linked with overall health promotion strategies, including nutrition and exercise to maintain or prevent declines in function. Intervention programming in this area has included a range of strategies, including self-care rehabilitation within traditional rehabilitation settings, community-based health promotion groups or intervention programs, telerehabilitation in which rehabilitation or medical professionals consult remotely with clients on specific self-care issues in the home, and use of Internet and/or self-paced learning modules for specific client populations. Most programming has focused on specific groups, such as people living with diabetes, asthma, chronic heart conditions, and back pain. The focus in this application is on finding effective strategies to help people manage themselves within the home setting and preventing or decreasing use of costly emergency medical care, long-term care, or institutionalization services. The approach centers on self-efficacy and the development of active problem-solving skills. Increasingly, the use of a peer mentor approach, that is, the use of people who have been through a disability experience to mentor other people new to it, is being emphasized. Peer mentoring is being shown to be as effective as or more effective than traditional patient education delivered by medical professionals in realizing outcomes related to symptom management, overall activity, and role participation, and reduced cost related to use of medical and health-related services. The effects of remote peer mentoring, using strategies such as peer Listservs and electronic mail support groups, are also being examined, showing similar positive outcomes.

A social learning and peer mentoring approach is also a guiding tenet for another application of disability management that focuses on the right to live in the community, and the right to have access to equitable supportive resources to live and participate long term. Coming from the independent living and disability rights movements taking place in many countries, the term *disability* is reconceptualized away from the individual, and the focus on the deficit or dysfunction in the individual assumed in prior approaches, to disability as the oppression of a minority group as a result of societal and environmental barriers, including access to community living resources. Resource management involves finding, accessing, controlling or coordinating, and troubleshooting supportive resources such as affordable and accessible housing, personal attendant services, transportation, assistive technology, and any other supports for community living. This involves accessing and coordinating these resources across many systems with different policies and eligibility criteria. The emphasis is both on learning self-advocacy skills, on an individual basis, and on collective activism to change systems, assert civil rights, and improve societal conditions and opportunities for the disability community as a minority group. Resource management has been emphasized within centers for independent living and other disability activism organizations, and it is being increasingly used as a model approach within the delivery of home and community-based waiver programs to support transition out of institutions and long-term community living choices. The movement has also expanded beyond resource management to focusing on disability experiences as lived by disabled people themselves, and the sharing and critical analysis of those experiences from multiple perspectives.

—Joy Hammel

See also Community Living and Group Homes; Health Promotion; Occupational Therapy; Peer Support.

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DISABILITY POLICY: INDIA

The history of a comprehensive disability legislation in India is fairly recent. It can be said to have begun with the ratification of the 1995 Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (henceforth called PWD Act) by the Indian Parliament. Prior to that, disabled people in India were receiving services—both by the government and nongovernment agencies—but they did not have any legal protection. They could not claim these services as a matter of right. According to Ali Baquer, for the first time, through the PWD Act, it was impressed on society that it has a responsibility to accommodate its disabled citizens and treat them at par, as full and equal citizens—with respect and dignity.

The passage of the PWD Act marked a new dawn in the life of disabled in India. However, one cannot talk about this landmark act without briefly tracing the background in which this legislation became the law of the land and also at the responses of society and state toward the challenges faced by disabled in India—especially during the colonial and postcolonial period. In her pioneering work, which documents the history of disability policy and programs in India, D. Rama Mani has briefly touched on the perception of disability as an issue of charity in ancient and medieval India. She further suggests that with the inroads of Western civilization and the missionaries in the eighteenth century, the old order—of families supporting and providing for their disabled kith and kin—crumbled. If charity and welfare models were in place before the onset of India's colonization by the British, the medical/pathological/rehabilitation model was initiated during the colonial period, which again remained predominantly charity based. The efforts to rehabilitate the disabled were sporadic in the sense that certain categories were totally left out of the purview of services. The responses came from the voluntary sector and the missionaries, which started with the setting up of the hospitals and charitable homes for destitute and handicapped children in the 1880s. Special schools for hearing impaired at Mumbai in 1884 and for the blind in 1887 at Amritsar, Punjab, were opened by the Roman Catholic missionaries. By the time of independence, nearly 100 special residential schools and training centers for disabled people were running.

While echoing similar views, Maya Kalyanpur and Anuradha Mohit have stated that the institutions set up during the colonial period were patterned to perpetuate custody rather than care for disabled people. Their "asylum-like character . . . unleashed in its wake the process of dehumanization of the PWDs [people with disabilities]." In light of this statement if one looks at the responses of the state, they are manifested in the inclusion of disability in the census, which started in 1872 and continued until 1931, and the passage of the Indian Lunacy Act of 1912, which was established for the mentally retarded and mentally ill people. This act did not allow any medical or therapeutic intervention but entitled the judiciary to relegate mentally ill, then called people deemed of unsound mind, into prisonlike psychiatric institutions.

After independence, however, with India adopting a system of welfare state, policy makers started looking at disability as a rehabilitation issue. The focus was on prevention of disability and its causes, on one hand, and provision of services in the field of education and employment of disabled people, on the other. The disability groups, which were more organized and raising their voices, were able to get concessions and subsidies from the government. Special mention can be made of organizations of the blind, such as the National Federation of the Blind, which were able to obtain concessions in air travel. Like in other countries, disabled veterans were also given differential treatment compared to civilian disabled people. From the 1950s to 1981, the International Year of Disabled Persons, the government responded to the needs of the disabled by making meager budgetary allocations, to be given in the form of grants-in-aid, to nonprofit organizations, for delivering services to the disabled in the area of education, rehabilitation, training, and employment. These nongovernmental organizations (NGOs), however, remained dominated by able-bodied, philanthropic individuals and professionals. There was hardly any place for disabled people to plan the services and programs meant for them. At the same time, need was also felt to prepare a large pool of professionals who could train the disabled in different vocations and work in the national training institutes set up by the government of India. The four national institutes were the National Institute of Visually Handicapped at Dehradun, National Institute of Orthopedically Handicapped at Calcutta, National Institute of Mentally Handicapped at Secundrabad, and Ali Yavar Jung National Institute of Hearing Handicapped at Mumbai.

The year 1981 marked the beginning of change in the condition of disabled people in India. It was the International Year of Disabled Persons, and being a signatory to the UN resolution of 1976, the government of India had committed itself to mandates that provided for equal participation of disabled people in all walks of life and emphasized recognition of the rights of disabled and evolving strategies for their development. Statutory provisions were made and strengthened. For the first time in independent India, the disabled were counted in the decennial population census. The way the data were collected and questions framed, however, left out several categories of disabilities. Because of this, authentic figures could not be gathered, and, instead of improving on it, the practice was done away with in the next census, in 1991. It was in the decade of the 1980s that positive action started in favor of delivering services to the disabled—reservations in educational institutions and employment were given on extended, the Lunacy Act of 1912 was repealed, and the National Mental Health Act was passed in 1987. In the same year, the Justice Baharul Islam Committee was appointed to draft the legislation emphasizing the rights, equal opportunities, and full participation of disabled people. The new national education policy was implemented with focus on inclusive education for disabled children in integrated settings. The state governments also responded by running central government-sponsored programs for the disabled and starting their own programs as well. The public sector responded overwhelmingly by opening doors to disabled people.

Despite these developments, disability remained a marginalized issue until the early 1990s, when some young like-minded disabled advocates, prominent among them being Javed Abidi, Anuradha Mohit, Sarabjeet Singh, Ali Baquer (nondisabled advocate), A. K. Chowdhury (nondisabled advocate), and Lal Advani, formed the Disability Rights Group (DRG) in 1994 to lobby with India's policy makers to accept the recommendations of the Justice Baharul Islam Committee and accordingly pass the legislation. The NGO sector was still dominated by able-bodied people who were largely dependent on government funding for their existence; education of disabled children was still under the purview of Ministry of Social Justice and Empowerment rather than education; disabled people were still relegated to C- and D-category jobs in the government sector; and, with globalization, opportunities for disabled people in the job market were shrinking day by day.

The formation of this DRG was inspired by none other than the stalwarts of the American disability movement Judy Heumann and Justin Dart, who informed these young disability activists via a satellite conference that the Americans with Disabilities Act was a result of a sustained campaign and self-help advocacy movement of disabled people. After a prolonged campaign, several rounds of talks, lobbying, sit-ins, protest marches, press conferences, media mobilization, and agitations, the Persons with Disabilities Act was finally passed by the Indian Parliament on December 31, 1995, and became a law on February, 7, 1996, with the president giving his assent.

According to a conservative estimate, there are 70 million disabled people in India. The act places them on par with other citizens of the country in respect to education, vocational training, and employment. For the first time, the private sector was called on to respond to the disabled. It also streamlines the services existing for the disabled and extends them further; for example, the reservation of posts has been extended to groups A and B and it forces the state to ensure that every child with disability has access to free education up to the age of 18 years. The state has been entrusted with the responsibility to prevent disabilities and provide medical care, education, training, employment, and rehabilitation for persons with disabilities. Furthermore, the state must create barrier-free environments for them, protect their rights, and counteract any abuse or exploitation. It must also provide sufficient mechanisms to implement the intentions and provisions of the act through the constitution of coordination and executive committees at central and state levels with adequate representation of disabled people in them and the office of commissioner at the federal as well as state level. The act gives definition of disability and recognizes seven disabilities that are entitled to the benefits of the act. The categories that have been left out of this act have been included in the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999. The PWD Act is designed to encourage fuller participation of disabled people in the community and eliminate discrimination. The act may not yet have significantly affected the large number of Indian disabled people but definitely has highlighted disability as a development and human rights issue.

—Meenu Bhambhani

See also Disability in Contemporary India; Experience of Disability: India.

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DISABILITY POLICY: UNITED STATES

In the United States, as in other countries, individuals with disabilities have historically lagged behind the remainder of the population in terms of key socioeconomic indicators and have been excluded from full—and often even partial—participation in society. And, like other countries, the United States has struggled to find the correct mix of policies to bring people with disabilities into the larger society and to equip them to participate meaningfully.

The United States first addressed disability as a health issue and attempted to ameliorate the circumstances of people with disabilities through treatment and care. In the past 30 years, however, policy has shifted. Instead of viewing disability as a medical condition that inherently prevents full engagement in society, today’s policies view society as an institution that has discriminated against those with particular medical conditions. Thus, disability law in the United States today focuses on preventing discrimination based on disability and breaking down the structural barriers to full participation.

A cautionary note: Disability policy in the United States is a dynamic mixture of federal and state laws, regulations, and cases. Often states are on the cutting edge, forcing the national government to catch up. Sometimes the opposite is true. This entry, however, focuses on federal laws, which must be dealt with in all jurisdictions. Moreover, the scope of this entry is limited in that it ignores much substantive disability law and the compelling policy issues that arise in connection with those laws. This article, for example, focuses on the Americans with Disabilities Act’s efforts to erase those impediments to full participation in society that exist today. Much thought, however, has gone into the ADA’s role in ensuring that new obstacles to full participation do not develop as society changes. One of the most fascinating current issues involves how the ADA’s mandates should function with respect to the accessibility of new technologies such as the Internet. Thus, though this entry explores the basics of disability policy, it leaves much uncovered.

The farthest-reaching statement on disability law and policy is found in the Americans with Disabilities Act of 1990 (ADA). In broad terms, the ADA extended to the private sector employment requirements placed on the federal government and federal contractors by the Rehabilitation Act of 1973. It also mandated access to public services—with special emphasis on transportation—and to “public accommodations and services provided by private entities.” This includes everything from hotels and amusement parks to laundromats.

Although the ADA has a broad focus, the component that is perhaps central and that has stirred debate is the accommodation mandate with respect to private employment embodied in Title I of the act. This title places much (but not all) of the initial cost of integrating people with disabilities into the workplace on the private employer. Academics have criticized the approach as inefficient and ineffectual, though whether either is true remains to be seen. Given the centrality of employment as a tool of economic independence and as a route to social integration, the success or failure of Title I may announce the success or failure of the ADA.

EXTENT OF DISABILITY IN THE UNITED STATES

Tens of millions of individuals in America have disabilities. And those going through life with a disability face myriad obstacles. Much of society has traditionally been, and remains, physically inaccessible to people with disabilities. While the lack of physical access to society is troublesome, it is only the most visible of an array of concerns. As shown by the statistics below, people with disabilities lag behind the nondisabled population in a variety of social and economic indicators.

- 27 percent of individuals with disabilities are employed, compared to 78 percent of their nondisabled peers.
- Employees with disabilities with full-time jobs had average annual earnings of $29,513 in 1998, which was more than $8,000 less than the $37,961 average earnings of their nondisabled counterparts.
- Fewer than 11 percent of individuals with disabilities have more than 16 years of education, while almost 24 percent of individuals without disabilities attain that level of education.
- Fewer than 10 percent of individuals with disabilities own a home, while homeownership for the population as a whole exceeds 70 percent.
- 34 percent of persons with disabilities live in households with a total income of $15,000 or less, compared to only 12 percent of those without disabilities.
- People with disabilities are roughly 20 percent less likely to vote than those without disabilities, even after controlling for demographic and other factors relating to voting.

All agree that society has a role in ameliorating the condition of the population of people with disabilities. But how best to respond has not been obvious. Over about the past quarter century, the thinking in the United States has undergone a transformation. Whereas traditionally the government saw itself as a caretaker for people with disabilities, it has recently embraced a disability policy that seeks to integrate those with disabilities into society. The former approach is often referred to as the medical model or charity model and the latter as the civil rights model.

MEDICAL MODEL

From the viewpoint of the medical model, disability is conceived of as an infirmity that inherently precludes full participation in the economy and society. It is the job of doctors, rehabilitation professionals, government bureaucrats, and social workers to take care of individuals with disabilities and to help them adjust to a society structured around the abilities and interests of the nondisabled.

Thus, society's role with respect to people with disabilities is paternalistic; its treatment of them is viewed as a form of welfare or charity. People with disabilities are seen as one component of a larger population that, for whatever reason, cannot fend for itself in society as currently structured. Importantly, this perspective never questions whether society is structured correctly; it merely seeks to help those who cannot function normally within it.

This perception of disability evolved following the Civil War, when the United States created a pension system, in part to manage a population of disabled former soldiers adjusting to postwar society. The legislation linked the definition of disability to an inability to work and established physicians as the gatekeepers of disability benefits.

To this day, many contemporary employment, health care, and rehabilitation programs for persons with disabilities are modeled on this theory. These are policy relics, however, for with the passage of the Rehabilitation Act in 1973 and the ADA in 1990, the United States signaled a significant shift toward the civil rights model.

CIVIL RIGHTS MODEL

The civil rights model conceptualizes persons with disabilities as a minority group entitled to the legal protections of equality that emerged from the struggles of racial minorities and women. Proposing "disability" as a social and cultural construct, the civil rights model focuses on the laws and practices that subordinate persons with disabilities. It insists that society secure the equality of persons with disabilities by eliminating the legal, physical, economic, and social barriers that preclude their equal involvement. The emphasis is not on giving any group special benefits; rather, the issue involves balancing the scales. As one commentator suggests:

> The configurations of the existing environment confer enormous advantages on nondisabled persons. Machines have been designed to fit hands that can easily grip these objects, steps have been built for legs that bend at the knee. . . . Everything has been standardized for a model human being whose life is untouched by disability. All aspects of the built environment, including work sites, have been adapted for *someone*; the problem is that they have been adapted exclusively for the nondisabled majority. (Hahn 1993:103)

Thus, while the medical model focuses on caring for a population of individuals whom society has left behind, the civil rights model focuses on changing society so it leaves behind fewer people.

The shift toward the latter conceptualization of society's role in the lives of people with disabilities started in the 1970s, when individuals with disabilities began to assert their right to be independent in pursuing education and housing. As a result of these efforts, national disability policy began to recognize the right and ability of individuals with disabilities to live independently. For example, Title VII of the Rehabilitation Act of 1973 initiated funding for centers for independent living (CILs). Those centers, which provide services *for* individuals with disabilities and are operated *by* individuals with disabilities, have been enormously successful over the past two decades: Only 10 centers existed in 1979, while in 2002 there were more than 350.

The focus on independent living led to a patchwork of federal and state laws addressing the accessibility of voting and air travel, as well as the right of people with disabilities to enjoy education and independent housing. Then, in 1990 the ADA was enacted. It embraced a range of disability rights issues and made specific findings that relied on the civil rights model.

In language reminiscent of law that addresses the civil rights of other minority groups, the ADA reported that

> historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem; . . . [and] individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society.

To begin to rectify the history of discrimination, the ADA set out to ensure that, at least going forward, the disability population will enjoy "equality of opportunity, full participation, independent living, and economic self sufficiency."

THE ADA AND THE CIVIL RIGHTS MODEL

The ADA signals a shift in the underlying philosophy of disability rights law in the United States. Moreover, the legal mechanisms created by Congress and realized in the ADA to achieve these policy goals appear to be well designed to reflect the civil rights model on which the statute is based.

The ADA sets out nondiscrimination mandates and requires that society adjust to accommodate individuals with disabilities in virtually every corner of society. Those principles touch on many aspects of public life, but where they function most prominently and controversially is in the area of employment.

The ADA's treatment of employment is indicative of the structure of the ADA as a whole and can be seen as an example of how the ADA implements the civil rights model. This title sets out a general prohibition of discrimination in employment: "No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment." And the statute goes on to realize that goal by requiring “reasonable accommodation” by employers. The concept of reasonable accommodation mandates that an employer make changes to its work environment to accommodate a qualified candidate with a disability so long as the alterations would not be unduly burdensome to the business as a whole.

This legal structure flows logically from the civil rights model. According to the model, individuals with disabilities, like certain other groups, have been suppressed by long-standing, built-in societal discrimination. For them to become equal members of society, this discrimination must be extirpated. The ADA tackles this policy imperative by prohibiting discrimination based on disability. In seeking to cure the condition that the civil rights model posits as the root cause of the marginalization of people with disabilities, the act demonstrates its commitment to this perspective.

Arguably, the civil rights model only forbids discrimination between equally qualified people on the basis of irrelevant factors. To that extent, a “passive” ADA might be acceptable and avoid problems of distributive justice among people applying for the same job. It would also be wholly ineffectual. People with disabilities may have the same capabilities as nondisabled individuals, but they face a two-pronged challenge. Not only are there biased attitudes toward individuals with disabilities, but society has been constructed in a way that physical impediments also stand in the way of full participation. Thus, to achieve a level playing field, as called for by the civil rights model, disability policy must not only outlaw discrimination, but it must also address the physical obstacles. The reasonable accommodation principle is a response to these physical impediments.

The act thus goes further than typical civil rights legislation in that it requires employers to accommodate applicants with disabilities. While most legislation designed to protect a group from discrimination mandates that the regulated individuals or entities simply *not* discriminate, the ADA requires an affirmative duty on the part of society, and in the context of employment, private employers. This accommodation mandate, however, is not a departure from the civil rights model, but rather a logical extension of it.

By requiring that the workplace be physically reconfigured or a job assignment be altered (so as to make a barrier irrelevant) to create a work environment hospitable to a qualified individual with a disability, the accommodation mandate removes barriers to equality. Thus, the reasonable accommodation mandate, when coupled with the nondiscrimination principle, seeks to create the equality envisioned by the civil rights model.

In sum, the themes of nondiscrimination and accommodation that run through the employment provisions of the ADA, as well as the text of the document as a whole, implement the civil rights model of disability policy. Having solved the theoretical problem, however, people have begun to face the practical one: Does the structure of the ADA, particularly in the employment context, represent a fair and cost-effective outcome?

LAW AND ECONOMICS PERSPECTIVE

The ADA’s treatment of employment has been the subject of examination. The prohibition against disability discrimination, as well as the requirement of reasonable accommodation, put much of the responsibility of integrating people with disabilities into the workplace on private employers. Commentators have questioned whether this is an equitable and efficient means of allocating the cost of a societal good.

Concerns about distributive justice arise with respect to the ADA because it burdens certain segments of society while benefiting others. Compelled to bear some of the burden of the employment sections of the ADA are nondisabled job applicants and employers. Nondisabled job seekers are now forced to share the employment market with qualified individuals with disabilities. Although it is true that this does impose a cost on this portion of society, it seems minimal (and inherently fair).

Whether employers are suffering net costs at the hands of the ADA, however, is a closer question. Businesses seek to make a profit. To do so, they presumably strive to operate in the most efficient manner possible. Legislation affecting private companies can either help or hinder this effort. Much analysis has gone into what effect the ADA’s antidiscrimination and reasonable accommodation mandates have had in this regard.

One can make a compelling argument that the antidiscrimination principle of the ADA improves the efficiency of private employers. Historically, antidiscrimination law in the United States has aimed at ensuring that a person who fits a particular job is able to obtain that job, despite irrelevant personal features: A person's skin color, gender, sexual orientation, or religion generally have little bearing on the match between the person's skills and a particular job. By forcing employers to ignore these irrelevant criteria, civil rights policies should enable the employer to build a workforce better able to perform the required tasks, thereby increasing the employer's efficiency.

The antidiscrimination principle of the ADA is in line with these laws; it performs the same filtering function that traditional antidiscrimination law performs by removing misleading signals from the employers' information mix. An employer will no longer be able to ignore a qualified individual simply because of his or her disability. Thus, there is a plausible argument that the ADA's embodiment of the antidiscrimination principle should increase efficiency.

It is much harder—though not impossible—to show that the reasonable accommodation mandate inures to the economic benefit of the private employers required to implement it. The explicit command that employers accept the burden of paying for accommodations—up to the undue hardship ceiling—sets the ADA apart from other civil rights legislation and, in turn, has created significant theoretical disputes.

The Rehabilitation Act of 1973 imposed reasonable accommodation duties on the government and government contractors; the ADA extends those duties to private employers. The theory supporting the former does not necessarily justify the latter. Although the government may have aims beyond strictly maximizing its output, such as providing employment to those who might not otherwise find it, a private entity's overriding goal is to maximize its profits. And to reach that goal, it seeks to operate in the most efficient manner possible.

It is not yet definitively established what positive impact reasonable accommodation has had on this effort. One must first look at the practical costs to an employer of accommodation. Research has suggested that many people with disabilities require no accommodation, and of those who require accommodation, the cost is usually *de minimis*. For example, a study of workers with disabilities for the U.S. Department of Labor found that only 22 percent of employees with disabilities received some form of accommodation. Of those accommodations, roughly one-half cost nothing, and of the other one-half, more than two-thirds cost less than $100. Thus, at least according to this study, the reasonable accommodation requirement often imposes little or no actual costs on an employer.

Moreover, accommodation is required only when it is not unduly burdensome. Practically, therefore, it is only in the circumstance where a substantial, but not overly burdensome, accommodation is mandated that concerns about efficiency arise. And even in this circumstance, the costs to the employer are mitigated by a variety of tax incentives. There are several tax provisions set out in the Internal Revenue Code available to businesses to foster ADA implementation and compliance: a "disabled access credit" available for small business, a tax deduction available to any business when improving accessibility for customers and employees with disabilities, and a tax credit available to any employer for a percentage of the first- and second-year wages of a newly hired employee with a disability. Beyond this, there are state tax code provisions applicable to small businesses to foster the hiring and retention of employees with disabilities.

Even with these tax incentives, some (usually large) employers may at times be forced to endure significant direct costs under the reasonable accommodation requirement. Those costs must be compared against the benefits that inure to an employer from accommodation and hiring of an employee with a disability to determine whether accommodation increases a business's efficiency.

At first blush, reasonable accommodation may appear inefficient for an individual employer. Theorists posit two applicants with identical skills, one with a disability and one without. It would be inefficient for the employer to hire the applicant with a disability and pay for accommodation, when the employer could hire the applicant without the disability and not be forced to bear those costs.

Though this is a persuasive theory, it has been countered by scholars who contend that reasonable accommodations are efficient in many contexts because they carry hidden benefits. For example, studies support the proposition that employees with disabilities as a group tend to be more efficient workers in that they tend to have lower turnover, less absenteeism, and lower accident risks. Thus, the cost of accommodation may be offset by workplace attributes that individuals with disabilities tend to possess.

Moreover, certain accommodations may be efficient in that they improve the productivity of other employees without disabilities. For example, ramps and elevators assist workers with rolling carts, and accommodations involving technology improve productivity and workplace safety for all workers.

Finally, making reasonable accommodations may be efficient in that it reinforces what would otherwise be an economically rational decision. A certain individual may possess such unique abilities that the cost of altering the workplace may be more than offset by the increased profits realized by having the person contribute to the business venture. In this scenario, the cost of accommodation would be less than the increased efficiency realized by hiring this specific employee.

Whatever the reason, research indicates that accommodations often are a profitable undertaking. One study found that for every dollar invested in an effective accommodation, companies realized an average of $50 in benefits.

Even ignoring these micro findings, reasonable accommodation may work at the macro level by increasing the efficiency of society as a whole. This is because the costs of providing accommodations may be offset by the gains realized by greater employment of individuals with disabilities. According to this theory, government benefits paid to people with disabilities will decrease because fewer individuals with disabilities will be in need of government support. In addition, the more individuals employed, the more the government collects in the form of income taxes. In other words, it may be efficient to have individual employers "run" this social welfare program, so that even if there are net costs, they are smaller than if the government ran the program.

All of this is not to say that the federal government plays no role in the employment context. In fact, aside from the tax incentives mentioned above, legislation has been recently enacted that is designed to help individuals with disabilities transition into the newly opened work environment. In the Ticket to Work and Work Incentives Improvement Act (TWWIIA), Congress sought to remove two of the barriers that stand in the path of individuals with disabilities seeking employment: potential lack of health care coverage once employed, and lack of training for and access to certain jobs.

Individuals with disabilities have traditionally faced a severe disincentive to entering the workforce in that employment income would disqualify them from Medicaid and other benefits under the Social Security Disability Insurance program (SSDI) and the Supplemental Security Income program (SSI), which have been available to individuals who could not engage in "substantial gainful activity." Thus, once individuals with disabilities gained employment, they could lose government-provided health benefits. Yet their new jobs often did not provide insurance and did not pay enough for individual coverage. And, even when insurance was available or affordable, many individuals were denied coverage because of their disabilities. This led to a situation where, among working Americans with disabilities, almost one in five had no health insurance.

TWWIIA addresses these issues by allowing states to permit qualified individuals with disabilities to purchase Medicaid health insurance after entry into the workplace even though their income may be above the poverty level. In addition, TWWIIA has provisions that address the potential loss of health benefits by those returning to work after a disabling injury.

Moreover, the lack of skills training and access to job sites often makes finding employment especially difficult for individuals with disabilities. To address this issue, TWWIIA's Ticket to Work and Work Self-Sufficiency Program provides recipients of disability insurance with a "ticket" to purchase employment training services from qualified Employment Networks (ENs). ENs are public or private entities that provide services such as workplace accommodations, peer mentoring, job training, and transportation assistance to ticket participants seeking employment.

TWWIIA and the ENs work in conjunction with broader welfare-to-work transition programs such as the Workforce Investment Act (WIA) and the

Temporary Assistance for Needy Families Programs (TANF), which provide incentives and training to help low-income individuals (including those with disabilities) find employment. The ADA requires that services provided by ENs or through the WIA or TANF be accessible to those with disabilities. Thus, TWWIIA, working alongside the ADA, has created a situation whereby individuals with disabilities are now able to access a range of job-related services to help them find and retain employment.

Such policies demonstrate America's commitment to integrating people with disabilities into the workforce. However, the costs of these programs need to be considered when determining whether the ADA's employment construct is efficient for society as a whole. This is especially relevant since some economists have questioned whether the ADA creates a net increase in employment. It has been argued that the accommodation requirement, because it hypothetically increases an employer's hiring costs, may lead to less overall employment, and thus *less* employment of people with disabilities. If indeed fewer individuals with disabilities are employed, this would defeat the argument that accommodation helps to relieve the social welfare system.

Whichever way one evaluates the efficiency argument, it is important to note that the efficiency of the program was not an overriding consideration at the time of the ADA's adoption. The ADA as a whole, and the accommodation requirement in particular, represented a national policy that costs and economic efficiency are dispensable (within limits) if more people with disabilities are employed. As explored below, it is a subject of debate whether the ADA has accomplished this goal, and conclusions are influenced by how one defines disability for purposes of the law.

IMPACT OF U.S. DISABILITY LAW

People with disabilities have been employed at substantially lower rates than people without disabilities, although the rates tended to fluctuate with overall economic conditions. The ADA was aimed at this employment gap. It came into effect for most private businesses in 1992, but as early as 1996 some commentators suggested a deterioration in the employment situation of individuals with disabilities in relation to other groups.

The period following the enactment of the ADA has been one of rapid changes in the economic structure of the United States. Manufacturing sector jobs have declined in favor of service industry jobs; job mobility has increased; and the economy has seen an upsurge and, at the end of the decade, a substantial retrenchment. In the face of those large-scale changes in the economy, researchers have attempted to determine the impact of the ADA on the employment of people with disabilities. The studies, several of which are discussed below, have yielded contrary interpretations of employment trends among people with disabilities.

One recent study attempted to trace the employment of individuals with disabilities over time using national survey data. People were identified as having a disability if they answered the following question in the affirmative: "Do you have a health problem or disability which prevents you from working or which limits the kind and amount of work you can do?" The study attempted to evaluate the ADA's impact by looking at the change in the number of weeks worked and the average weekly earnings of this group over the course of the 1990s. Based on this analysis, the authors argue that the ADA had a negative causal impact on the number of weeks worked by individuals with disabilities and had no impact on the wages of those individuals.

Other studies with similar survey data have suggested similar results, even while employing a different methodology. In one study, the authors examined the impact of the ADA on three groups of U.S. states: (1) states that, prior to the ADA, had no disability discrimination law; (2) states that, prior to the ADA, had only a "traditional" disability discrimination law—one that prevented discrimination on the basis of disability (nonaccommodation states); and (3) states that had an ADA-like statute—one that prohibited discrimination and also required reasonable accommodations (accommodation states). The authors theorized that by comparing results among the states grouped in this manner, one could better isolate the effects of the ADA, and the accommodation requirement in particular.

The authors found that for this sample the employment of people with disabilities declined. Moreover, when comparing the decrease in employment between the non-accommodation states and the accommodation states, the study found that the decrease in employment was more severe in the former group. The finding that states that had no accommodation requirement saw a decline that surpassed the states that already had an accommodation statute suggests that this mandate was the component of the ADA that was largely responsible for the employment decline.

Thus, some studies suggest that the ADA, and the accommodation provisions in particular, have a *negative* impact on the employment of people with disabilities. But other authors question the methodologies used by previous scholars, and in particular their failure to focus on people the act was designed to help—*qualified* people with disabilities—rather than all people who answered yes to the broad question: "Do you have a health problem or disability which prevents you from working or which limits the kind and amount of work you can do?"

Studies that have sampled individuals the ADA more likely covers have reached more encouraging results. When focusing on the ADA target group (i.e., those individuals who are not work limited but are functionally limited), one study found an increase in employment rates. Another study, examining a population of "disabled" individuals drawn from a Social Security Administration survey, found that the ADA had a positive impact on certain people with disabilities, although it may have had a negative impact on those people with disabilities who were not already, at the time the ADA became effective, participating in the labor market.

Authors of those later studies identify aspects of prior studies that may have skewed their results. For example, reports finding that the ADA had a negative impact may have underreported the positive influence of the ADA because, if more people with disabilities have jobs, fewer may view themselves—and report themselves—as having disabilities that limit their ability to work. Thus, the number of employed people with disabilities would not accurately be reflected.

While the studies may have underreported the number of employees with disabilities, at the same time, they may have inflated the number of individuals with disabilities who are unemployed. Increasingly stringent welfare requirements coupled with more generous federal disability laws create incentives for unemployed individuals to classify themselves as having disabilities. This effect may have caused certain individuals to exaggerate their disabilities, which would in turn inflate the number of unemployed labeled as having disabilities, possibly rendering research findings inaccurate.

It is evident that, even a decade after the ADA's enactment, the results of its employment provisions remain unclear. Some studies find that the statute has led to diminished employment. But those findings may result from limited methodologies and data sets that fail fully to account for the inherent problems with the definition of disability and the measurement of that population.

Nevertheless, even if one discounts research that suggests a negative impact on employment, the studies, when looked at as a whole, indicate that the ADA is serving its antidiscrimination and integration mandates, albeit perhaps as not in regard to large numbers of people with disabilities. Given that the ADA came into being during a time of economic prosperity, it will be important to track its results in the slow growth period that has defined the recent economy.

Broadly, the ADA raises the policy issue of the proper scope of such antidiscrimination laws as applied to private entities—necessarily enforced by private litigation—to bring people with disabilities into the mainstream. Would employment rates improve significantly if the initial costs of accommodation were shared among employers, persons with disabilities, and the government? And, at what point would a system including greater government support create an unwieldy bureaucracy?

These broad questions, concerning the proper mix of public and private endeavors, color the debate with respect to the public accommodation provisions of the act as well. And though the answers are not clear yet, it is the passage of the ADA that has allowed us to begin to ask those important questions.

—Jeffrey A. Schwartz,
Charles D. Siegal, Michael Waterstone,
Eve Hill, and Peter Blanck

See also Americans with Disabilities Act of 1990 (United States); Citizenship and Civil Rights; Disability Law: United States; Rehabilitation Act of 1973 (United States).

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DISABILITY PRIDE

Disability pride represents a rejection of the notion that our physical, sensory, mental, and cognitive differences from the nondisabled standard are wrong or bad in any way and is a statement of our self-acceptance, dignity, and pride. It is a public expression of our belief that our disabilities are a natural part of human diversity, a celebration of our heritage and culture, and a validation of our experience. Disability pride is an integral part of movement building and a direct challenge to systemic ableism and stigmatizing definitions of disability. It is a militant act of self-definition, a purposive valuing of that which is socially devalued, and an attempt to untangle ourselves from the complex matrix of negative beliefs, attitudes, and feelings that grow from the dominant group's assumption that there is something inherently wrong with our disabilities and identity.

Dr. Martin Luther King Jr. (1967) once wrote,

> One must not overlook the positive value in calling the Negro to a new sense of manhood, to a deep feeling of racial pride and to an audacious appreciation of his heritage. The Negro must be grasped by a new realization of his dignity and worth. He must stand up amid a system that still oppresses him and develop an unassailable and majestic sense of his own value. He must no longer be ashamed of being black.

Although there are many barriers facing people with disabilities today, one of the single greatest obstacles we face as a community is our own sense of inferiority, internalized oppression, and shame. The sense of shame associated with having a disability has, indeed, reached epidemic proportions. Disability rights movements in different countries have made many gains in the area of civil rights over the past decade, but what good is an Americans with Disabilities Act or a Disability Discrimination Act if people will not exercise their rights under these laws because they are too ashamed to identify as being disabled? "As long as the mind is enslaved," King wrote, "the body can never be free." As long as people with disabilities remain ashamed of who we are, we will never realize the true equality and freedom we so desire. We must first take pride in ourselves as a community. We must no longer be ashamed of being disabled.

Dismantling centuries of internalized oppression, however, and promoting a widespread sense of disability pride are easier said than done. Unlike other civil rights movements, people with disabilities do not always have the benefit of a generational transfer of disability history and pride through the family structure. There are no "disability churches" per se, neighborhood enclaves, or other communal institutions where people with disabilities can come together by choice and consistently receive positive messages that counteract the depredation wrought by the onslaught of cultural terrorism. There is a tremendous need to create a counterculture that teaches new values and beliefs and acknowledges the dignity and worth of *all* human beings. Disability pride is a direct response to this need.

—Sarah Triano

See also Disability Culture; Disability Studies.

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DISABILITY RIGHTS EDUCATION AND DEFENSE FUND

The Disability Rights Education and Defense Fund (DREDF), with offices in Berkeley, California, and Washington, D.C., has been a leading cross-disability civil rights law and policy center since it was established in 1979. DREDF carries out its mission through training, legal assistance, advocacy, policy and legislative development, litigation, and research. DREDF is unique in the disability rights movement in the United States because it was founded and continues to be led by people with disabilities and parents of children with disabilities, and it achieves social change by organizing and training at the grassroots level, crafting and promoting legislation and policy, and defending those policies in the courts.

DREDF identifies economic and social disenfranchisement of people with disabilities as the result of prejudice and discrimination rather than as an inevitable consequence of the physical and mental limitations imposed by disability. This worldview closely aligned DREDF with other civil rights struggles, thus leading to an invitation in 1981 to join the executive committee of the nation's largest coalition of civil rights groups, the Leadership Conference on Civil Rights (LCCR).

DREDF plays a central role in articulating the principles of disability rights law and developing and disseminating strategies for groundbreaking disability civil rights legislation and litigation. DREDF is best known for advocating successfully for federal civil rights laws, representing members of Congress and leading disability organizations in amicus curiae briefs in cases argued before the U.S. Supreme Court, and national grassroots training and empowerment for thousands of parents of children with disabilities and adults with disabilities.

DREDF laid the groundwork for enactment of the landmark 1990 Americans with Disabilities Act (ADA) by preserving and advancing its predecessor law, Section 504 of the 1973 Rehabilitation Act when it came under attack by the Reagan administration and in the courts in the early 1980s. Similarly, DREDF organized to preserve regulations implementing the Education for All Handicapped Children Act. DREDF is also credited with playing leading roles in the passage of the ADA and other groundbreaking laws such as the Handicapped Children's Protection Act of 1986, the Civil Rights Restoration Act of 1987, and the IDEA Amendments Act of 1997.

In 1987, DREDF established the Disability Rights Clinical Legal Education Program and began teaching disability rights law at the University of California, Berkeley, Boalt Hall School of Law and supervising law students in the practice of law. DREDF litigation seeks not only to enforce existing laws but also to clarify and advance disability rights through the pursuit of law reform cases, such as by filing the first full-inclusion special education case that went to the U.S. Supreme Court, *Holland v. Sacramento City Unified School District* (1994).

Since 1990, DREDF has worked internationally in 17 countries with advocates who seek assistance in the development of law and policy reform strategies. Ongoing future challenges include restoring, sustaining, and preserving the ADA from further erosion in the courts, and meaningful enforcement of IDEA. As DREDF works in coalition with racial, economic, and environmental justice groups, future challenges will broaden the reach of DREDF's expertise to key areas such as equitable and accessible health care services.

—Julia Epstein

See also Activism; Advocacy; Advocacy, International; Disability Law: United States; Disability Policy: United States; Justice.

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DISABILITY RIGHTS OF CHILDREN

See Children with Disabilities, Rights of

DISABILITY STUDIES

DISABILITY STUDIES AND DISABILITY RIGHTS

Disability studies functions as the theoretical arm of disability rights movements. As an interdisciplinary field of study and scholarship, disability studies analyzes the meanings attributed to human corporeal, sensory, and cognitive differences. Participants examine the role that disability serves in expressive traditions, scientific research, and social science applications. They study the status of disabled persons, often by attending to exclusionary scholarly models and professional structures. Interestingly, a key aspect of disability studies has involved focusing on the privilege that accrues to nondisabled persons within built environments. Implicitly, then, researchers question the ethics of inbuilt social exclusions by tracing out their origins. As a result, they track down many historical "genealogies" of practices and attitudes concerning disabled persons.

In seeking to understand the variety of interpretations that make disability an evident facet of human diversity, the field includes many methodologies such as quantitative assessment, qualitative interpretation, critical analysis, and historical genealogies. Nonetheless, because disability studies marks a departure from fields of knowledge and professional training that may have sustained exclusionary practices and mandated social shame, participants in disability studies primarily engage in efforts to reevaluate the implications of traditional approaches to disability. New scholarship proposes research topics that allow disability perspectives to emerge. As a result, the experiences that infuse life with a disability are valued for insights that can be culled for innovative strategies to assist new generations of disabled persons. Such disability perspectives bring to the forefront of cultural commentary a body of insight previously marginalized within many universities during an era of scholarship in which eugenics ideas prevailed.

It should be emphasized that disability studies initiatives, research projects, and curricula have been developed worldwide, with formations primarily in global urban centers and wealthy nation-states. This entry, however, will be limited to the United States, and to an extent, Canada, the United Kingdom, and Australia. Disability studies takes place when groups of committed advocates, activists, and scholars pursue work locally to make the persistence of disability exclusions across a variety of regional and global contexts better understood, documented, and interpreted. Only very recently, during the last decade of the twentieth century, did disability studies begin to be more generally recognized as an area of academic inquiry, while the moniker "disability studies" came into usage during the1980s. The new term sought to differentiate its concern with the well-being of disabled persons from what one scholar has termed the "disability business." The disability business was perceived as a megalithic operation of management interests and government surveys that were frequently answerable to the goals of nondisabled persons at the expense of their disabled clients, family members, or neighbors.

At present, disability studies consists of a nascent, yet rapidly expanding scholarship that draws researchers from across a diversity of academic fields. Most universities have been inaccessible to disabled persons; as a consequence, scholars in disability studies observe the ways in which curricular ideas also suffer from this central exclusion, taking as a given that disability experiences offer a substantial vantage upon human existence. Because aspects of fields of study may reiterate the perpetuation of "able-ist" bias, disability studies can sometimes involve a rejection of habits, methods, and undertakings of universities in the past in their assumptions about bodies and capacities. Thus, disability studies also entails studying the myriad ways that traditional fields have been willing to study their topic from a distance without embracing the insights and critical perspectives of disabled persons concerning their own predicament. The distinction entails making claims for critical insights to be gained by partaking of disability-based experiences, knowledge, and lifestyles.

Disability studies scholars distinguish their undertaking as "new" in order to mark a distance from the viewpoint of modern eugenics that sought to "improve human stock." At the beginning of the twentieth century, such an enterprise targeted the eradication of disabilities from human populations. Not only are many events and public spaces of modern life organized by policies that effectively segregate persons with disabilities from a civic mainstream, but traditional responses to disabled persons, termed the "study of disability" as opposed to "disability studies," also see disabled persons as clients, informants, or research objects to be treated, managed, regulated, controlled, and investigated. So not only must social barriers to the inclusion of disabled persons be broken down, as disability rights proclaims, but the sources for misperceptions about disability experiences need to be redressed. These objectives require studies of discourse, and of the etiologies and histories of the definitions of pathology and aberration, in addition to study of the histories of the development of environments and communication modes that privilege some players and exclude others.

Universities, such as renowned Stanford University, whose first president David Starr Jordan promoted eugenics ideas about the obvious inferiority of disabled persons' lives and bodies, may not be perceived as immediately welcoming of disability perspectives. Recently, for example, Princeton University garnered international press coverage for hiring eugenics theorist Peter Singer. Singer argues not only that parents should decide whether disabled infants should be killed at birth but also that adult disabled persons have no evaluative criteria to contribute to a discussion over the value of a life lived by a disabled infant. Able-ist biases in top-flight universities, from their physical plant specifications to their presumptions about body qualifications, make them chilly places for disabled persons. Many note how ideas for gas chambers, first developed as a means to ease the difficulty for health practitioners in administering lethal injections, were developed within academic settings and with demonstration project methodologies. When Harriet McBryde Johnson, a disability rights lawyer and noted disability rights commentator, visited Princeton for a series of forums with Peter Singer, she reflected on the ethical conundrum such a visit provokes. On the way out, she thought about her "brothers and sisters," the 14 arrested protestors for Not Dead Yet, who "were here before me and behaved far more appropriately than I am doing." Johnson's statement recalls that of Virginia Woolf, who, when invited to speak at an Oxford college, still could not access the Bodleian Library to review a manuscript on the basis of her gender. "And I thought how it was better to be locked out than to be locked in," Woolf commented with a similar ambivalence.

Just as they were previously closed to the participation of women or as they discriminated against members of racial or ethnic groups, universities have not immediately embraced the influx of "out" disabled persons into their hallowed halls. As a result, many well-worn ideas and representational practices await critical reexamination with the supposition that patterns of interpretation likely uphold unrecognized investments concerning the inferiority of disabled persons. Research conducted to endorse ideas about eugenic segregation, the sterilization of those assessed as "feebleminded" or hereditarily deficient, or prevention of disabled persons on the premise of the social burden they present simply support oppressive disability ideologies of a previous, yet not quite antiquated, era. Old-school disability research may verify reasons that disabled persons should be excluded from public forums and civic roles. Furthermore, many technologies have been developed as means for containing unruly bodies and punishing the disruptions associated with bodies that "deviate" from the normal.

A key issue for disability studies, then, has been to determine the extent to which newer professionals who work within these frameworks can update disciplinary practices to make their research feasible for progressive disability goals. Similar questions had been asked about psychiatry, for example, after Holocaust genocide and medical experimentation implicated practitioners who had been schooled in the field and proceeded to generate from it violent medical interventions on disabled children and adults. Were premises in the field corrupting or did these perverse practices simply represent a complete aberration from mandated formats of investigation and hence only reflect violent impulses in the practitioners themselves? A similar revolutionary questioning guides disability studies as it surveys the current state of the university and interrogates fields such as behavioral and abnormal psychology for their routine support of evaluation practices designed to condemn disabled persons for their differences.

Scholarship in disability studies affords a unique and divergent vantage point from the paradigms that sustain traditional study, management, and interventions. For example, disability studies research would interview clients not to determine who would make the best fit for counseling or special education services, but to find the unique worldview that disabled persons have imbibed as a result of their marginalized social predicament. Those who endure demeaning cultural practices can often best assess the sources and mechanisms of their operation.

Following the advent of disability studies in the 1980s, many academic approaches toward disability were routinely put to the side as simply too "medical" in nature. What the first generation of scholars meant by this criticism of a "medical model" was that the research upheld an exclusively interventionist and individualized approach to disabled bodies. All insufficiency appeared localized within the dysfunctional body itself. A medical model approach proceeds on the assumption that the only valuable knowledge concerning disabilities would need to be directed toward curing, concealing, or fixing bodies so that individuals could be made to "pass" as normal. For a first generation of disability studies scholars, cure approaches reinforced social ideas that impaired bodies should be rejected. At the very least, these scholars focus on social barriers that disabled persons face and leave aside fields that pay attention to the repair of impaired bodies.

Importantly, the limitations of a medical model that early disability studies references may itself have little relation to actual practitioners of medicine. Instead, concepts of a "medical model" refer to the social premise, frequently held outside of medicine, that disability requires referral to the purview of medical practitioners. Several disability studies scholars have shown how factions of physicians in the American Medical Association initially resisted the idea that insurance decisions should be assigned to clinical assessments. Nonetheless, legislatures in Germany and the United States, for instance, decided that physicians would function as the gatekeepers for disability verification. They thus inaugurated a class of medical authorizers to diagnose and certify the validity of all disability claims. This professional gate-keeping, the practice of which often divides disabled people from the services they need, has become one of the foremost obstacles addressed by disability studies today—particularly in countries that lack universal health care systems such as the United States.

This system of evaluation requires disabled persons to endlessly submit to professional gazing to qualify for social supports. But the enforcers of this policy, that is now a habit of thought in many Western countries, may trickle down to the shoe store clerk who will not sell a shoe to a person with lower-limb muscle spasticity prior to obtaining a doctor's note. In an increasingly bureaucratized social state, the medical model has left disabled persons frequently vulnerable to the whims of general practitioners in spite of the fact that such professionals may have little knowledge about the condition in question. Consequently, one often finds practitioners invested with the power to assess patients for the purpose of qualifying for benefits, supports, and general consumer services such as airline travel or equipment.

In contrast, a rights era of disability studies endorses a cross-disability and nonspecialized approach to meaningful inclusion for disabled persons. Subsequently, as this entry observes, disability studies will ask for the modification of practices that are premised on privileging some bodies and excluding others.

Prior to the rights-based disability platform of the 1960s, a focus on disability in society entailed advocating for charitable contribution and safekeeping for persons with particular kinds—even "brand names"—of disabilities. For instance, mid-nineteenth-century institutions governed their populations so that they housed only the least severe. This ensured patient success and further supported ideas behind the rejuvenating mission of cures in benevolent nature. A return to the community for each institutionalized individual formed a key objective. More difficult disabilities were left to the family where they sometimes received local support in the form of outdoor relief or made up a large percentage of those housed in indoor relief efforts such as almshouses. A widely accepted international theory of disability at this time, established by the French educator Eduoard Séguin, argued that those diagnosed as idiots suffered from a weak will. Training schools sought to correct this insufficiency—or at least ameliorate it—by subjecting disabled individuals within their charge to extensive rituals of personal hygiene tasks of rote repetition. Patients found themselves locked into an inflexible regimen of care and engaging in tasks that demanded concentration for extended periods of time. In cultivating such habits, training institutions aimed to improve a "defective" internal landscape by targeting the external body as a site of personal management.

From the 1920s onward, rehabilitation era disability professionals emphasized the acquisition of personal adjustments and skills that could enable a disabled person to survive in a society that was not built to accommodate them. In the United States, France, and Germany, for example, special schools that aimed to "salvage" human beings by educating the physically weak emerged in urban centers. These schools for "crippled children" pre-date legislation for disabled children that provides rights for a free and appropriate formal education (prior to 1974, 80 percent of disabled children did not have access to a formal education). Federal mandates in the United States continue to update this effort at social inclusion and the necessity of public education for schoolchildren with differing bodies, minds, and emotional habits alongside all others in a "least restrictive" environment.

In the 1920s, evolving from hospital schools, and offering an alternative to segregated warehousing, special schools for children with physical disabilities offered a curriculum that included rehabilitation services; in-house dentistry; occupational, physical, and speech therapies; Franklin Delano Roosevelt (FDR) era swimming pools; and a variety of wheeled transport and home-styled modification devices—all within the confines of a one-stop educational facility. Special schools explained their mission as a matter of "salvaging" the educable from the disability mix that had simply been consigned to training schools and workshop labor under the expansive eugenics era category of "feebleminded."

In this mold, special schools accompany the expansion and professional credentialing enterprise of other helping industries, in addition to nursing. Participants at schools for handicapped children also underwent continual assessments in specialized quadrants of the schools, for example, physical, emotional, dental, personal hygiene, and small and large motor control. But like rehabilitation medicine itself, special schools also sought distance from medical environments and fix-it approaches to disability. They too critiqued a "medical" approach in favor of education and rehabilitation. It is important to differentiate the agonistic distancing of professional service industries from medical approaches and the medical model critiques of disability studies. Unlike professionals who advocate for rehabilitation as a solution to a problem presented by disabled persons, disability studies represents the social and material predicament of disabled persons as a matter of inclusion, recognition, and social change. Furthermore, disability attends to the environmental resistance to inclusion—attitudes and the enforcement of normative expectations upon bodies—as opposed to individual adjustments.

Disability studies, uniquely, must put the status and experience of disabled persons prior to its own success as a professional operation. Thus, whereas rehabilitation and a rehabilitation movement could oppose disability rights in favor of principles of intervention, service, and care, disability studies aims to place the perspectives of the objects of scrutiny and remediation front and center to its concerns. One is reminded that even in the closing of the most inhumane institutions, a variety of interests will come forth to oppose such efforts: Care worker unions will protest out of a desire to keep their jobs in a specialized field; family members will often ally themselves with care workers and claim that the work of keeping a disabled person at home lacks sufficient social supports to be feasible; local businesses catering to institutional living complain that their economic livelihood will be undermined; nearby neighborhoods will resist under the argument that "freeing the inmates" poses threats to everyone's well-being. Yet disabled persons themselves, on the verge of emancipation, offer up ambivalent and less certain opinions. Few yearn to keep institutions open in that they represent sites of state-sponsored incarceration, but neither does it seem appropriate to look forward to life where one may be viewed as a persistent burden, economic drain, and social misfit. Scholars in disability studies seek to expand on the limited choices offered to disabled persons to live meaningful lives by redressing the social constraints that continue to underwrite such hostile public beliefs. Rather than individual insufficiency, disability studies aims its critique at the material social conditions—such as poverty, unemployment, and disability insurance restrictions on wage earning—that produce abject dependency.

Historically, populations of dependents have found themselves concentrated in poor houses, workshops, and almshouses with others who cannot effectively sell their labor in a competitive market rife with prejudice toward functional and aesthetic differences. One function of this lumping of the unemployable was the development of large bin categories of disabilities; such classification strategies emerged in the mid-twentieth century—an era dominated by rehabilitation and charity model approaches. Bin categories include “muscular dystrophy,” a label that represents more than 37 manifestly different etiologies of neuromuscular disorders, or “cerebral palsy,” a general term for hugely divergent muscular rigidities. Etiological clusters, such as paralyzed veterans or people with epilepsy, receive attention and management from agencies designed to attend to their lesser social opportunities. Thus, children with vision impairments might be sent to a blind school to acquire different skills such as Braille along with white cane techniques or canine companion assistance. Deaf children might be channeled to a deaf school where they acquire sign language or vocalization skills in the press to access regular educational curriculum. Multiply disabled children, those who have been projected to be low achieving by means of newly minted evaluation tools such as intelligence tests, and ranging from those termed “retarded” to those negotiating cultural barriers or nonstandard literacy, undergo institutional referral and placement throughout the twentieth century. A substantial number of infants and children with all kinds of disabilities continue to be abandoned and placed as “wards of the state.” Individuals located within such sweeping categorizations represent not only disabled people, but rather the fallout from modern standardization practices that prove inflexible and unduly narrow when it comes to the rote expectations of all bodies within capitalism.

While pointing out the permeability of these categories of human differences, disability studies reassesses the historical solutions that have been arrived at in terms of placement, tracking, and a deterministic foreclosure on social possibilities. Yet the advent of the field has also been theorized as developing from experiences that issue from clustering together kinds of bodies that share designations of deviance. Collectivities can better foment collective action for improved social situations. Strongholds for initiatives in disability rights have come from collectivities of individuals who may have endured segregation at one time and now resist oppressive protocols. In other words, disability studies is also linked in history to the predominance of kinds of disabled living and the social opportunities afforded to highly particular groups. These include veterans groups, who sometimes claimed exclusive rights to remediation services but also precipitated the development of technologies such as power wheelchairs and curb cuts that benefited others. Not only did a post-polio president, FDR, seek to include disabled citizens as beneficiaries of services for disabled veterans, but in the late 1940s, disabled Canadian veteran John Counsell formed the Canadian Paraplegic Association, an advocacy group that demanded the supply of accessible cars outfitted with hand controls to all who could use them. Furthermore, in the 1960s “person first” advocates sought to upgrade social awareness by interrogating the linguistic implications of referring to persons with disabilities as handicapped, crippled, or disabled. In Britain during the early 1970s, the Union of the Physically Impaired Against Segregation (UPIAS) was formed as a coalition among those who had fought to escape confinement in nursing homes. The members of this organization may have been the first to formulate what would come to be recognized as the “social model of disability”: one that viewed impediments as the product of social rather individual liabilities. UPIAS (1974/1975) put forth mandates about the social nature of disability experience that merit repeating:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, and housing.

Likewise, the 1990s saw the rise of disability groups comprised of former poster children who critiqued the proliferation of telethons for those with muscular dystrophy and other disabilities and tendering the exhibition of disabled bodies as pity-ridden social capital for raising research and cure funding.

These efforts all paralleled various other civil rights agendas seeking to redress the invisibility experienced by devalued lives. Such movements shared a key strategy: to place distance between their own bodies and the belief that lack of success could be attributed to biologically located deficiencies.

INSTITUTIONALIZING DISABILITY STUDIES

As further evidence of political piggy-backing by various civil rights agendas, one witnesses a surge of interest in disability studies research and scholarship immediately following the passage of legislative initiatives such as the Americans with Disabilities Act in 1990 in the United States. As a result of this legislation and that which came before it (Section 504 of the Rehabilitation Act in the 1970s), a new generation of disabled students made their way to universities. Yet, despite the implementation of policies, codes, and mandates for inclusion, college students with disabilities often found themselves involved in highly individual struggles with able-ist barriers in the pursuit of their own education. After all, laws may exist but that does not mean that institutions and professions comprehend the barriers that their own fields of operation have put into play. This generation, the inheritors of legislation and ideas about the social nature of disability, committed itself to bringing the insights gleaned from struggles for disability rights into every avenue of social organization and thought. As many in disability studies have put it: “If disability studies didn’t come along I would have had to invent it.”

Put quite simply, many younger disabled persons became attuned to the fact that disability studies offered them further grounds for social theorizing and policy action toward their own predicaments. Disability studies affords students with disabilities a basis for asserting the right to accessible classrooms, libraries, and laboratories that had previously seemed off-limits due to prohibitive scheduling, inaccessible locations, and discriminatory attitudes. This post-ADA generation of students with disabilities forced opportunities for advocacy regarding obstacles that many took for granted as inevitable barriers. Suddenly, excessive work hours, timed tests, small print, fluorescent lights, inadequate table heights, flights of stairs to stages for ceremonies, and expectations about presentable appearance appeared as unnecessary barriers that by design excluded many disabled persons.

In addition, disability studies allows students and researchers to examine the buried able-ist exclusions that inform research premises. The research that has ensued tackles issues such as objectivity in nondisabled research perspectives and pathologizing ideas about human variation that sometimes inform premises. For example, disability perspectives require us to rethink assumptions that a bus with high stairs represents a democratic and publicly available mass transit objective accomplished. Deaf studies, likewise, asks us to rethink assumptions about oral eloquence and the aesthetics of sound that condition so many of our daily encounters. And in a basic way, disability studies demands reconsideration of dubious general public educational requirements such as the expectation that children will be able to hop on one foot as a mandated qualification to graduate from kindergarten. Just as universal design asked that we think about the ways architectural exclusions get inserted into a built environment, so disability studies asks us to analyze the assumptions about normalcy that go into validating educational, business, and civic practices. The field of disability studies seeks to expose the ways that naturalized exclusions have seeped into every cranny of modern social life.

Nearly 100 disability studies courses are currently offered at colleges and universities, while many curricular and research plans continue apace. Universities offer degrees, concentrations, minors, or simply courses of study in disability studies. Examples include Canadian programs in disability studies at Ryerson University; a master of arts degree in Critical Disability Studies at York University; a concentration in disability studies for a master’s or PhD in the Cultural Foundations of Education program at Syracuse University; undergraduate and interdisciplinary minors in disability studies at universities that include Ohio State University in Columbus, Ohio, and the University of California, Berkeley; and an interdisciplinary PhD in disability studies at the University of Illinois at Chicago.

In addition, a web search currently yielded more than 50 affiliated programs, centers, clusters, and research institutes at universities. University-affiliated centers crisscross the globe from the Centre for Developmental Disability Studies at the University of Sydney in New South Wales to the Program in Disability Studies at Rutgers University where coursework has been revised so as to include the topic of disability geography. As mentioned earlier, the Centre for Disability Studies at the University of Leeds has been principal in setting the agenda and commitments of disability studies globally by publishing a journal in disability studies and establishing a research track to accompany degrees at all levels. Faculty at Leeds assist in publishing the international journal *Disability & Society* and pilot the list serve on disability research known simply as "the UK Listserv" by international participants. In addition, the Center on Disability Studies at the University of Hawaii emphasizes cultural approaches to disability and maintains commitments to working with disability coalitions in the Pacific Rim. Organizers recently launched an online periodical titled the *Review of Disability Studies: An International Journal.* And the Centre for Research into Disability and Society in New South Wales offers PhD scholarships to enroll at Curtin University while Temple University has launched courses and a graduate certificate program in disability studies proper.

In the United States, disability studies originates with the formation of the Society for the Study of Chronic Illness and Disability in the early 1980s. Chair of the Sociology Department at Brandeis University, Irving K. Zola, began distributing a newsletter from his office that collected together and advertised new initiatives on behalf of disability as a social experience. The photocopied newsletter publication contained a letters column, featured book reviews, and opinion columns. Significantly, early issues feature Zola's review of Erving Goffman's *Stigma: Notes on the Management of Spoiled Identity* and thus inaugurated a discussion of the disability coordinates of self-perception and social interaction that continues to fuel one aspect of the field. Zola, and his family and colleague's newsletter, which gained library subscriptions and an international mailing list, eventually grew into the current online academic journal *Disability Studies Quarterly.*

In 1986, at the urging of its membership, and as the push for an Americans with Disabilities Act gained momentum, the Society for the Study of Chronic Illness, Impairment, and Disability (SCIID) changed its name to the Society for Disability Studies (SDS). Other methodological models also developed alongside the strict social model advanced by UPIAS. For instance, at this time and prior to the ADA, Harlan Hahn pioneered a minority group model of disability contending that disabled people represented a distinct minority. The effort to study and analyze disability as culture, one that gives impetus to unique institutions, art, and perspectives, arose from the minority model. In the United States, the claims of Deaf studies to emerge from a unique heritage and to constitute a linguistic minority influence the claims made on behalf of disability culture, crip culture, or simply subcultures. Pioneering studies of predominantly deaf communities in disparate locations such as Martha's Vineyard and Varna had shown the cultural variability of signed languages and regional differences in expectations about normalcy and self-expression. Deaf communal forms such as sign language, deaf poetry performance, and investments in the merits of segregated deaf communities all influence disability studies but conflict with many precepts. These surround questions of disability hierarchies, language facility, and discriminatory ideas about self-expression whether spoken or signed. Nonetheless, many counterdiscourses interrogate the premises of a dominant "normal" culture through the examination of developed subcultures, many geographically isolated or disenfranchised as pockets within urban spaces.

Increasingly, disability studies has found itself needing to emphasize diversity as a key factor in the social desirability of having disabled persons represented at universities and across educational forums. The emphasis on disability as a diversity category emerges from research efforts to find commonality in variation without losing the divergent vantage points that such conditions afford. Disability studies scholars have contended that just as race, gender, and sexual preference can be demonstrated as either neutral difference or as productive characteristics as opposed to tragic implications, disability itself comprises a form of embodiment artificially constructed as flawed. Yet alliances between multicultural agendas and disability studies efforts to include disability as part of human diversity education have been slow in coming. For instance, one initiative to allow disability to fulfill the multiculturalism requirement at Hunter College met with fierce opposition from race and gender scholars. Multiculturalism is beset by its own able-ist premises in having exceptionally high-achieving exemplars of one's ethnic or native traditions serve as singular justifications for cultural equality. Perhaps disability studies might inevitably discover that diversity as exemplified by multiculturalism can arrive with very narrow ideas about bodies in tow. Yet, at the same time, many scholars in these fields have embraced disability as a deepening of multicultural pedagogies.

As a new area of scholarship that has thus far resulted in a wealth of publications and collaborative projects, as opposed to university posts, disability studies bears much in common with other "identity" fields such as queer studies and gender studies. These fields of scholarly endeavor also feature an incredible output in scholarship and quality of thought while having received less in the way of material recognition such as degree-granting programs or funded faculty lines. The older industries of a "disability business" still largely hold the purse strings to disability undertakings. And these industries have been built up by means of a "charity model" that likely depicts disabled persons as incompetent and needy—a representation that is anathema to disability rights, which points out that the predicament of validating disabled persons as the "deserving poor" reinforces the idea of a natural state of unemployment and dependency for all disabled persons. Concepts of a charity model run deep. Ironically, practitioners of disability studies have been accused of "biting the hand that feeds them"—a criticism that upholds the idea of disabled persons as parasitic and ungrateful by comparison to the common lot of human beings.

In addition to curricular innovations, many access and accommodations offices have sprung up to manage new generations of disabled students who anticipate accommodation, as opposed to exclusion, from educational settings. These offices sometimes support a disability cultural mission and/or active disability support networks. Staff for disability offices may lack the authority that comes from having gained knowledge through a standard credentialing mechanism, such as that offered by special education or communication disorders under the auspices of a previous "disability business." A field offers credentials in an education that guarantees training in requisite areas and study in a centralized knowledge base. Access and disability awareness may be subsumed as components of occupational therapy or policy studies. Only disability studies forces a convergence of the historical study of social management, human rights categories, and access strategies as a matter of group survival—a mosaic approach that recognizes these aspects as mutually supportive and inevitably interwoven. At present, resident disability experts on campuses often represent homegrown and creative talent. Offices are staffed by individuals who share expertise in areas ranging from a judicial history of the ADA to experience in disability sports such as wheelchair basketball. One should also point to the cultural and academic sway exerted by two offices for disability services located at major state universities during the 1970s, University of California, Berkeley, and University of Illinois, Urbana–Champaign, as fulcrums for university accessibility plans based on the insights generated among disabled and nondisabled students who participate at those sites.

At present, many disability services offices at universities become sites where the interests of budget-conscious bureaucracies collide with the rights and goals of disabled persons. Services offices may need to enforce policies that test, retest, and validate impairments so that individuals may qualify, on a case-by-case basis, for "extra" services such as captioning, sign language interpreters, relocation of classes in accessible spaces, lighting modifications, and extra test-taking time. While the redesign of curriculum to meet accessibility differences is significant, even a new area opened up by technological possibilities to which faculty need to dedicate time and attention, disability services quickly become overburdened by the necessity of serving in all these capacities. In general, under state bureaucracies that operate many educational settings, it becomes easier for offices to test and evaluate students for disability status than to theorize the modifications necessary to promote an inclusive learning environment. Still, many have risen to the challenge of this multitasking necessity and offer content-based national conferences on the topic of disability studies among an array of disability issues necessarily bound up in working toward the maintenance of inclusive community forums.

It has been pointed out that disability studies first emerges alongside the insights obtained by participants in disability rights movements and activities during an era that fiercely advocates for deinstitutionalization. As a result, many scholars surface from a first generation of families who refused to institutionalize their disabled children and family members. Along with their traditional research plans, these scholars conduct research into the new experience of living at home with disabled persons and the reaction of a mainstream society to this new choice. In addition, in literary circles, authors such as the Japanese Nobel Prize winner Kenzaburo Oe are celebrated for their open and honest address of the efforts to live at home with disabled family members. Oe's autobiographical memoir, *A Personal Matter,* discusses the entirely altered coordination of household affairs that occurs as a result of living at home with his autistic, musically gifted son, Kikura. Oe's partner contributes to his books with watercolor portraits of family scenes.

The topic of living at home with disabled family members may have previously been the purview of talk show entertainment but not of academic study. One can clearly see from this approach that disability studies benefits from the insights of women's and gender studies that the personal is political. But also the personal is a matter for redress by professions. Professionalism itself, in its rebuke of any personal attributes from kinds of hairstyles to habits of facial expression, stands in the way of the integration of disabled persons' entrance into the workplace.

In addition to alternative family arrangements, many centers for independent living (CILs) have become cultural powerhouses for the talents and insights of disabled persons in the community. Several CILs have even formed their own research think tanks to rival the funding streams traditionally poured into legitimated university research locales. They sponsor events and training sessions to bring about disability awareness in the community and to enforce accessibility standards that remain little understood. CILs have sought to introduce universities to the rich field of disability studies proper. The Ohio-based Ability Center of Greater Toledo worked with representatives across an array of academic disciplines to endow a faculty position to chair a disability studies program at the University of Toledo. At the University of Illinois, Chicago, disabled students apply from across the globe in order to pursue work in disability studies at the master-of-science level. Many scholars in disability studies, facing a lack of pathways yet to be put into place in curricula and university recognition, may leave to ply their research and social insights in community education. Such an eventual exodus at the level of higher education, as has occurred at CILs, continues to perpetuate a separate location for the focus on social barriers to disability living. In short, such mini "brain drains" occur in newly minted academic programs because of a resistance to the ideas about disability emancipation held by those in traditional academic disciplines who consider disability to be their exclusive purview. At community centers, scholars who have now benefited from university coursework sponsor disability pride parades, promote projects on digital storytelling, and coordinate data banks on disability images, disability history archives, and autobiographical archives from movement participants and key leaders. This shift to CILs as alternative research and employment domains is also evidenced by their active cultivation of disability-based archives. For instance, instead of donating his papers to a university library, FDR historian and disability policy activist Hugh Gallagher left his papers with Toledo's Center for Independent Living.

RECENT RESEARCH TRENDS

Whereas clusters of professionals, previously charged with maintaining records and oversight of institutional warehousing, found themselves declared increasingly irrelevant, and since rapid-paced deinstitutionalization in the 1980s promoted community care initiatives, the traditional privilege accorded to expert oversight has been roundly rejected by disability studies. This rejection has occurred in the midst of active efforts to seek models self-governance and a reevaluation of the principles of guardianship.

Whether indigenously cultivated or generated from universities in the "first world" and translated to those societies deemed "less enlightened," disability studies scholars have increasingly found themselves participating in knowledge dissemination strategies as an effect of postcolonial contexts. Since many countries participated in cross-cultural comparisons of eugenic practices, disability studies has found it necessary to follow suit and use successes in one national milieu to pressure results in other cultures. Yet this situation of political cross-referencing often results in scholars from developed countries preaching to the "unconverted." Such power imbalances situate developing countries as less "modern" in comparison to industrial powers. In addition, they also find themselves promoting or imposing products and policies devised in contexts alien to specific disability needs of various global regions. Thus, one can find Western-manufactured wheelchairs running aground in geographies without paved roads, curb cuts, or nonurbanized environments. Finally, there are few opportunities offered by scholars in developed countries to participate in a reciprocal exchange of ideas about disability innovation. Thus, even disability studies has been caught up in reifying inequities on a global scale.

Consequently, the postmodern and international coordinates for disability studies analysis cannot be underestimated. While disabled persons have faced many barriers to higher education, access to discussions and materials on the Internet have shifted the terms by which individuals in diverse locations acquire interpretive skills about their home contexts. In other words, the Internet opened up participatory forums to a social group that had found schooling prohibitive and the negotiation of public environments frequently dangerous. In the public sharing that occurred on the Internet, disabled persons and disability advocates could share notes on disability predicaments globally while evaluating their own local sense of key obstacles to an equitable and inclusive society: public transportation; access to education; employment; stigma; and common prejudices about bodily, emotional, and mental differences. Likewise, these virtual communities encouraged individuals to swap bodily and social strategies for more successful navigations of hostile or indifferent environments. At present, online discussion groups pursue topics that range from social justice, bioethics, scholarship in the humanities, prosthetic supplementation, personal assistance concerns, and issues of sexuality as appropriate conversation topics for disability-based community. They have also generated a growing global sense of history that provides points for contrast and comparison between the cultural situations of disabled people.

New kinds of study modes and information transmission such as the development of digital media, availability of captioning techniques, keyboarding and voice recognition software have all played a part in getting formerly home-bound or segregated disabled persons into a more participatory cultural mix. Less expensive visual transmission modes such as digital video are making some of the more erased pockets of disability experiences available to the ways we imagine alternative human existences. Histories of institutionalization have shown us that disability oppression occurs not just in violent practices but also in their relegation behind walls, in confinement practices, and as a result of assumptions about bodies in clinics or institutions properly deemed "private." As a result, disability studies has helped to forward media as an powerful venue for accessing personal narratives and multiple voices. International film festivals in Australia, Russia, England, the Balkans, Toronto, and other sites have all sought to use digital formats as an opportunity to educate general populations and legislative agendas in their home countries.

Yet disability studies continues to face up to how inclusion occurs at the expense of the newly included subject. The classroom may be suddenly desegregated but nothing that disrupts the operation of business as usual can occur. Postcolonial studies, with its focus on the internalized oppression of the subaltern and the ultimate silencing of counterdiscourses, has proven integral to current trends in disability studies scholarship. Rather than repeat the error of turning disabled people into passive victims of inhumane social practices, for instance, disability studies has borrowed from theories of international resistance efforts to keep its own interpretive strategies relevant and less marginalizing in and of themselves. In doing so, disability studies—now christened "critical disability studies" by some to remind the field of its radical orientations—pursues analytical approaches based on insights gleaned from comparative disabilities, disability as a subcultural form of alliance, and even the internal fractures precipitated by the advent of disability hierarchies as manifest of more internal forms of social oppression.

Contemporary formations of disability studies analyses have also taken on cooperative research strategies to de-emphasize the singular nature of much scholarly work. As in women's studies and some social science-based research, one witnesses the rise of greater self-consciousness about issues of research interdependencies and the privileges that result in scholarly success based on individual genius models. One now regularly finds research attributed to coauthorship and collaborative research teams circulating in the published literature. Such efforts are not merely the fortuitous results of disciplinary practices, but rather an active effort to re-imagine the collaborative effort invested in research efforts.

For a time, participatory action research enjoyed popularity with disability studies. However, while it integrated disabled persons, they were left as informants but not essentially engaged in the more critical tasks of knowledge production. While disability studies generates new questions, projects, and politicized research agendas, the field must continue to be mindful of the fact that it also potentially replicates the exhaustion of research-based practices on disabled people's bodies. Even the most liberating research models run the risk of treating disabled persons' time and resources as readily and freely available to investigators.

One common future goal would be to offer real choices in collaboration and a legitimate role in the creation of research-based knowledge generation. Such efforts need to occur without the enforcement of exclusive, delimited contact on the part of research subjects who share conditions for example. Thus, disability studies is faced with the challenge of formulating new disability-based insights that engage dominant modes of thinking without simply reproducing traditionally oppressive modes of research conduct. Such an elusive objective continues to guide much current thinking in disability studies.

—Sharon L. Snyder

See also Anthropology; Bioethics; Body, Theories of; Education, College and University; Humanities; Models; Queer Disability Studies.

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DISABILITY STUDIES: AUSTRALIA

Disability studies has emerged as a growing area of academic research and professional education and training in Australia as it has in many other developed and developing countries (Green and Meekosha 2004; Meekosha 2004). This is a consequence of the rise of the disability movement and the more vocal demand for relevant curricula by disabled people and their allies. It also reflects the impact on universities of the Australian Disability Discrimination Act (1992), which covered issues of discrimination in education. The growing presence of people with disabilities in society—in particular their presence in the community following decades of deinstitutionalization—has further contributed to an awareness of the responsibilities of educational institutions to disabled citizens. In addition, the demonstrated failure of medical and individual pathology models of disability to explain and "liberate" people with disabilities from constraining and repressive modes of treatment has resulted in many alternative arguments for including disabled people in wider social relations.

However, disability studies remains fragmented with individual scholars scattered across universities and departments. These individuals may have little support from their colleagues, and the institutions demonstrate only a limited understanding of the growth of disability studies overseas. Disability studies as a discipline thus remains fragile in the Australian context, especially given a political climate of neoconservatism and a significant political backlash against minority agendas. The traditional interventionist disciplines such as special education, health sciences, occupational therapy, and rehabilitation have begun to use the language of disability studies, in effect rebadging their courses, without necessarily changing their individualized, medicalized approach or incorporating the ideas of the disability movement into their curricula. A similar phenomenon has been documented in the United States (Linton 1998). Other than the audits referred to below, there is currently no critical literature examining disability studies in Australia. Thus, in Australia we have not seen the growth of departments created around disability studies. Unlike in the United States (Thomson 2001), neither women's studies nor Australian studies has incorporated issues of disability. There is no scholarly journal catering specifically for disability studies, and we have yet to see any collections of readings in disability studies unlike the United Kingdom where there have been several (Shakespeare 1998; Barnes 1999; Barnes, Oliver, and Barton 2002), or the United States where collections in the humanities are widespread (Davis 1997; Snyder, Brueggemann, and Thomson 2002). Key Australian analyses of social movements continue to exclude any mention of the disability movement (see, e.g., Burgmann 2003).

An audit of 26 of 37 Australian universities undertaken in 1999 (Social Relations of Disability Research Network 1999) sought to document the extent and type of subjects addressing disability in a social context taught across various professional and disciplinary areas. No relevant subjects were found in seven of these universities. In those universities where there were subjects, the range of professional programs affected the likelihood of relevant subjects appearing—disability studies, rehabilitation studies, and special education courses were the most likely to have subjects that reflected social issues. It was rare to find any reference to disability studies or issues in general arts degrees or indeed to find a social analysis of disability in professions such as nursing or medicine (as discussed in Wilson 2000).

Most subjects about disability outside law and sociology reflected service delivery priorities and interventions relating to specific impairments, through an individualized perspective that focused on disabled persons and their experiences and relations with professionals. These subjects would clearly be seen as "not disability studies" as defined by Simi Linton (1998). However, there were a significant number of subjects that reviewed changes in social attitudesto disability, and the expansion of human rights approaches to disabled people.

In 2004, a follow-up audit (Green and Meekosha 2004) revealed that there has been an overall fall in subjects dealing with social dimensions on disability. In particular, Deakin University and University of New South Wales had lost a significant number of relevant subjects, perhaps a consequence of cutbacks in overall subject offerings in an increasingly financially constrained environment, or the moving on or retirement of specialist teachers with a commitment to this perspective.

On the other hand, there had been some promising improvements. Some professional programs that had not done so in the past, such as occupational therapy at Curtin University, had begun to identify the social dimensions of disability as an important component of study. Also, subjects exploring the social dimensions of disability were more evident—though still a rarity—in general arts degrees.

—Helen Meekosha

See also Disability Studies.

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DISABILITY SURVEYS

A survey is a method for collecting information about a population. The survey method has several components: a sample of persons that accurately represents the population; standard data collection procedures, including a standardized questionnaire; summary estimates of statistics for the population based on the information collected; and estimates of the sampling error of the statistics. A *disability* survey uses the survey method to collect information about disability. In some disability surveys, disability is the primary topic in the questionnaire; in others disability is a secondary topic.

THE VALUE OF DISABILITY SURVEYS

The main value of disability surveys is that they are relatively inexpensive, unobtrusive, and accurate. Disability statistics can be produced in other ways: in a census that enumerates *all* persons in a population, not just a sample, or in administrative records that include all members of a population, such as the medical care system for elderly people in the United States. However, producing statistics from censuses and administrative records systems is more expensive, more burdensome, or less accurate than producing them from surveys.

Surveys can produce a variety of useful disability statistics. One important use of disability statistics is to formulate and evaluate disability policy. Proponents and opponents of disability policies in employment and transportation use survey statistics in debate. Disability statistics are also used by manufacturers and distributors of disability-related products and services (e.g., assistive devices, disability insurance plans), as they plan for production, advertising, and sales. Scientific researchers use disability statistics to investigate the causes and consequences of disability.

DESIGN AND ANALYSIS OF DISABILITY SURVEYS

Samples for disability surveys are selected in several ways. In a *scientific* sample, the sample persons are selected at random with known probabilities of selection. A scientific sample can be selected from a preexisting list of persons; for instance, if most people have listed telephone numbers, a sample can be selected randomly from telephone directories. Also, a sample can be selected by randomly selecting residential areas, listing the addresses of dwellings in those areas, and then randomly selecting addresses from the list.

Samples for disability surveys may also be selected by establishing quotas for sample categories with selected characteristics. The quotas are set so that the resulting sample will have the same proportions of persons in each category as the population. For instance, if it is known from a census that 10 percent of a population is African American, then a sample of

1,000 persons would be designed to include 100 persons in that category. Data collectors contact people in the population until the quota for each of the categories has been achieved.

While all disability surveys use standardized data collection techniques, they may use different *modes* of data collection. Frequently used modes are face-to-face interview, telephone interview, and self-administered questionnaires distributed by postal mail. Many survey organizations have begun to use self-administered questionnaires distributed by electronic mail or postings on the World Wide Web. Modes differ in quality of data and cost of administration: Generally, face-to-face interviews yield better quality but cost more, while electronically distributed questionnaires yield poorer quality but cost less. To optimize data quality and costs, disability surveys may use combinations of modes.

Once disability data are collected from a sample, they are *weighted* to produce estimates of population statistics, and the sampling errors of the estimates are estimated. If the sample persons were selected with a known probability, the weight for producing estimates of population statistics is the inverse of the probability of selection. For instance, if the probability of selecting a particular case was one in a thousand (1/1000), then the weight for that case would be the inverse (1000/1), or one thousand. If the weights of all sample persons with a particular characteristic (e.g., mobility limitation) are added together, the sum is an estimate of the number of people in the population with that characteristic.

Sampling error is the variability in a population estimate that arises because it is based on a sample rather than a complete enumeration. It is often stated in this form: "It is estimated that 15.4 percent of the population has a disability, plus or minus 1.2 percent." If the sample was selected scientifically, statistical theory and computer software are available to estimate sampling error accurately. If the sample is not scientific, estimates of sampling error have a weaker theoretical basis and may be less accurate.

ILLUSTRATIONS OF APPROACHES TO SURVEYS

Two surveys will be described to illustrate approaches to disability surveys: Canada's Participation and Activity Limitation Survey (PALS) and the U.S. National Health Interview Survey on Disability (NHIS-D). PALS was conducted by Statistics Canada in 2001. It was a "post-censal" survey, meaning that the sample for PALS was selected from persons enumerated in the 2001 census; persons who were homeless or living in institutions were not included. The census included these questions: "(1) Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities? and (2) Does a physical condition or mental condition or health problem reduce the amount or the kind of activity this person can do?" The PALS sample was selected at random from persons who answered "yes" to either census question. At the beginning of the PALS interview, the census questions on disability were repeated, and then a series of disability screening questions were asked. If these questions elicited no report of disability, the case dropped from the sample. About 43,000 persons with disabilities were included in the sample, and they were interviewed by telephone.

The PALS questionnaire was consistent with the World Health Organization's International Classification of Functioning, Disability, and Health (ICF). The ICF definition of disability includes restrictions to participation in societal activities (e.g., school, work), limitations in personal activities (e.g., walking, talking), and impairments of body functions (e.g., hearing, seeing). The title of the survey—*Participation* and Activity Limitations—emphasizes this multiaxial definition. PALS' predecessor was the 1991 *Health* and Activity Limitations Survey (HALS). The title change reflects a trend toward a social rather than a medical definition of disability in surveys.

PALS estimated that 12.4 percent of the household population of Canada had a disability in 2001. The rate was 3.3 percent among children and youths (0–14 years) and 14.6 percent among adults (15 years and over).

In the United States, the NHIS-D was based on the annual National Health Interview Survey (NHIS). The NHIS uses a *clustered area probability sample*—small geographic areas are selected at random with probability proportionate to population size; survey staff then lists the addresses of dwellings in the sample areas, and small clusters of households are selected at random from the lists. Survey staff then visit sample households and conduct face-to-face interviews with members of sample families.

The first phase of the NHIS-D was a supplemental questionnaire to the NHIS in 1994 and 1995. In those years, more than 220,000 persons were included in the NHIS sample, and an extensive questionnaire module was administered to determine if they had any indication of disability. The definition of disability in the NHIS-D was not based on a single concept of disability; rather, it was based on a variety of disability definitions used in national programs and policies. In the second phase of the NHIS-D, persons identified in the first phase as having a disability were contacted, and a face-to-face interview on consequences of disability was conducted. About 36,000 persons (16 percent) were eligible for a second-phase interview, and about 33,000 interviews were completed. A variety of estimates of disability prevalence have been made using the NHIS-D, most falling in the range of 10 to 15 percent.

ISSUES, PROBLEMS, AND OPPORTUNITIES

A major issue in disability surveys is measuring disability. Disability is an inherently complex concept that is difficult to define and measure. When the paradigm for disability changed from medical to environmental, measurement became more difficult. Disability surveys have good measures of many impairments and simple activities, but they are only beginning to develop measures of complex activities and participation, and measures of environmental factors are still over the horizon.

Another problem is survey accessibility for respondents with disabilities. Conventional survey design assumes that sample persons are able-bodied, or that an able-bodied proxy respondent can accurately answer questions about a disabled sample person. These assumptions lead to standard survey practices that systematically exclude full participation in surveys by persons with disabilities, undermining the quality of disability survey data. Survey methodologists are now beginning to recognize and address this problem.

New information technology is creating opportunities for disability surveys by making it cost-effective to measure complex concepts (e.g., computerized adaptive testing) and to administer questionnaires in a variety of accessible formats (e.g., screen readers, voice recognition). On the other hand, some information technology is making it more difficult for surveys to yield complete interviews (e.g., telephone "caller ID," electronic mail filters).

—Gerry E. Hendershot

See also Consumer Satisfaction; Research; United Nations Disability Statistics.

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DISABLED PEOPLES' INTERNATIONAL

Established in 1981 in Canada, Disabled Peoples' International (DPI) is a leading international cross-disability organization of and directed by persons with disabilities working in human rights advocacy. Around the world, disabled people total approximately 600 million with 80 percent living in developing countries. They represent the diversity of all humanity. DPI recognizes this and works through building consensus on issues by gathering together to discuss them.

Each year, 135 National Assemblies meet to identify priorities for countries and regions of the world. The DPI World Council, made up of six representatives from each region, meets every two years to discuss disability in a global context at the World Summit. DPI's largest gatherings are World Assemblies, which are held every four years to develop a multiyear action plan. For example, at the most recent 2002 assembly, held in Sapporo, Japan, delegates from more than 100 countries came together and identified priority issues for immediate action. The result was the prioritization for a campaign for a UN Convention to protect the rights and dignity of persons with disabilities.

In addition to its main priority of human rights, DPI works in other important areas, among them sustainable livelihoods, independent living, and inclusive education. In recognition of DPI as an international authority on disability, the United Nations has conferred Special Consultative Status with the Economic and Social Council of the United Nations (ECOSOC). Through its work, DPI is committed to achieving full participation of all disabled people in society.

—Moira Horgan-Jones

See also Developing World; Disability Studies; Economic and Social Development.

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DISABLED PERSONS' FUNDAMENTAL LAW OF 1993 (JAPAN)

The Disabled Persons' Fundamental Law (DPFL) is one of 27 fundamental laws in Japan. Ranked between the Constitution of Japan and various substantive or procedural laws, a fundamental law stipulates basic principles in each policy area. The purpose of DPFL is to establish the fundamental principles regarding measures for persons with disabilities and designate the responsibilities of the national and local governments to comprehensively and systematically promote measures for persons with disabilities, and thereby to promote their independence and full participation in society.

DPFL was enacted in 1970 through an initiative of members of the Diet across party lines to establish better coordination between policy areas, such as education, employment, social welfare, and transportation. Major revision was made in 1993 reflecting a progress of guiding principles in disability policy that were deeply influenced by international movements, such as the International Year of Disabled Persons (1981) and the UN Decade of Disabled Persons (1983–1992). Lobbying from the disability community also played an important role in this amendment.

With the 1993 revision, DPFL now provides, among other things, that (1) "disabled persons" means persons whose daily or social life is substantially limited over the long term due to a physical, intellectual, or mental impairments (first official recognition of persons with mental illness as the target of disability services); (2) national and local governments are responsible for establishing a long-term development plan for disability services; and (3) persons with disabilities have a right to take part in the formulation of this plan. DPFL, however, is not well-known to general public. The disability community has asked to revise it to include the antidiscrimination principle.

—Hisao Sato

See also Experience of Disability: Japan.

DISABLED VETERANS

Killing and maiming are not only the unfortunate by-products of combat. They are crucial to war's very aims. Since the beginning of time, enemy armies have sought to develop ever more lethal weaponry to injure and eliminate the opposing force. Some soldiers recover from their wounds or recuperate from their diseases and are able to return to battle. They may eventually return home with little lasting physical damage. Others, who are not so fortunate, join the ranks of the permanently disabled. Of course, civilians as well as soldiers are injured in wars. However, the term *disabled veteran* is generally taken to encompass only those injured while in the military. Because most fighting forces have been disproportionately male, the term *disabled veteran* refers primarily to men.

Disabled veterans have always been war's most conspicuous legacy. From the earliest Stone Age conflicts to modern warfare, the human aftermath of war has been measured in decades, not months. At a fundamental level, disabled veterans of today's wars still share a great deal with their forbears two centuries ago. Both are forced to adapt to infirmities incurred as adults in the service of their country. The emotions they experience—pride, despair, fear, and anger among them—are common threads that link the American soldier disabled in the Iraq War to the disabled veterans of the Napoleonic campaigns. Both have needs that are, on the face of it, similar: medical care, a job, and, if they cannot work, some form of subsistence.

Yet, despite these important similarities, the way in which disabled veterans are treated and viewed has changed significantly over time. With the rise of the modern nation-state, the conscription of mass armies, and the development of welfare programs, disabled veterans became a subject of new concern to governments. They have been the targets of innovative social policies that have expanded the state's scope of responsibility, and the recipients of novel benefits that have taxed treasuries. Disabled veterans have proven an important constituency to be courted for states intent on establishing their patriotic concern for the fighting man and, in some cases, their legitimacy to govern. At various points in history, disabled veterans have become disruptive when their demands are not met. As a consequence, the lot of disabled veterans, though often difficult, has, in general, been superior to that of the civilian disabled. Especially since the twentieth century, disabled veterans in many countries have established a privileged place at the heart of the welfare state.

The treatment of disabled veterans has varied not only across history but also, in important ways, between countries. While the questions that the care of the disabled veteran raises are often similar—On what basis should pensions be awarded? What should be the role of voluntary organizations in their care? How should they be employed?—the answers that individual nations have offered differ dramatically. The solutions that countries have offered are a product, in the first instance, of national patterns of welfare provision. They reveal much about the relative weight accorded state versus charitable authorities, and the tendency to resort to compulsory versus voluntary means of enforcement. Care for the disabled also depends on public attitudes toward the armed forces, as well as feelings surrounding the particular war—and its resolution.

While soldiers have always been injured in wars, it was not until the wars of the nineteenth and twentieth centuries that disabled veterans existed in massive numbers and constituted a highly visible special category for attention. Research on the ancient world indicates how very differently disability was construed in a period in which many wounds were simply incurable. It does not appear, for instance, that the Greeks honored the wounded or disabled in speeches or special ceremonies. While Plutarch records that the Athenian state provided some support to men wounded in battle, these were likely payments to the indigent, rather than honoraria for service.

With the rise of the early modern state, from the sixteenth through the eighteenth centuries, came new attitudes toward the disabled. Some governments recognized the need to provide the disabled with statutory benefits so that they were not forced to rely on charity. To better raise a mass army, or so the logic went, the state had to prove its commitment to the injured man. Europe's first state system of benefits for rank-and-file disabled veterans was initiated by the English Parliament in 1593, which hoped by this measure to improve recruitment and reduce desertion. The first veterans' homes—France's Hôtel des Invalides (1633) and Britain's Chelsea Hospital (1685)—were founded in the following century to care for the aged and the disabled. Although the care that men received was superior, in most cases, to the treatment meted out in poor houses, these institutions, and those that followed such as Frederick the Great's Invalidenhaus in Berlin (1748), nonetheless distinguished sharply between officers and other ranks. In the Invalidenhaus, for example, officers were accorded sumptuous living quarters, complete with private gardens sheltered by high hedges, while ordinary soldiers had to settle for a room or two.

So long as armies remained professional fighting cadres, recruited or impressed for service, there was little incentive or need to equalize treatment across the ranks. Even those measures accorded by the state were not secure; within a few decades of the English Parliament's introduction of state-sponsored pensions, the benefit had been restricted to those disabled veterans incapable of work, and devolved on the individual counties. However, the idea of the nation in arms, pioneered by the French revolutionaries, made every citizen a potential soldier—and disabled veteran. Before the introduction of universal conscription, only a very small percentage of the population would have served in the military. In France, on the eve of the Revolution of 1789, the army numbered only 156,000 out of a total population of 29,100,000. In the U.S. Civil War, by contrast, the North mobilized 2,000,000 out of a total population of 32,000,000. From the nineteenth-century conflicts forward, the circle of those who would fight was dramatically expanded, even as the ability to inflict harm was magnified by technological advances in weaponry, such as the Gatling machine gun used in the Civil War and improved, recoilless artillery pieces.

The American Civil War, the bloodiest of the nineteenth-century conflicts, inaugurated a new age in warfare and in the history of disabled veterans. Scholars have called the Civil War the first "total war," by which they mean that the entire populace was mobilized: men in the field and noncombatants (women, children, and the aged) in supporting roles at home. By the war's end, 620,000 American lives had been lost—more than were killed on the U.S. side in the Korean and Vietnam Wars combined. Figures from the Union army indicate that the North alone had treated more than 7 million cases of disease and 250,000 wounds; 30,000 amputations were performed. As a consequence, after the Civil War, the U.S. federal government faced a veritable avalanche of claims. The government responded with a system of veterans' homes, preference in government hiring, land grants, free prosthetics, and above all else, pensions. Although southerners were not entitled to federal pensions (they were provided for, usually scantily, by state governments), the cost of pensions skyrocketed, as these entitlements were politicized by parties eager to court the veterans' vote. By the end of the nineteenth century, the federal pensions bill amounted to $150,000,000 a year, or 38 percent of the entire federal budget.

Although the European governments looked with horror on the rapidly escalating pensions bill in the United States, the Civil War would prove, in some senses, a trial run for the twentieth-century's two world wars. More men were mobilized to fight World War I than ever before in history. Both the total losses sustained and the rate of loss (calculated as a proportion of the mobilized populace) were unprecedented. More than 9.5 million soldiers died over a period of 52 months; on average, the war claimed the lives of 5,600 men every day that it continued. Twenty million men were severely wounded; 8 million veterans returned home permanently disabled. As a consequence of dramatically increased firepower, they had suffered some of the worst injuries ever seen. Shrapnel from the new exploding shells tore ragged paths through flesh and bone; poison gas (first used by the Germans in 1915 and quickly reciprocated by the British) seared eyes and lungs, creating the spectacle that the painter John Singer Sargent captured in his heartrending painting *Gassed*. Under the threat of constant shellfire and ubiquitous death, some men lost their minds. After months of exposure in rat-infested trenches, others contracted debilitating illnesses that eventually shortened their lives.

As firepower became more destructive, medicine's ability to mend bodies improved in tandem. As a consequence of sanitary innovations, World War I marked the first war in which injury, rather than disease, claimed the largest number of British casualties. Improvements in the delivery of medical services behind the lines, a host of surgical innovations (especially in orthopedics and in plastic surgery), and improvements in the treatment of infectious diseases ensured that more men returned home than ever before, swelling the ranks of the permanently disabled. Medical science's advances continued through the twentieth century. The widespread introduction of antibiotics during World War II (penicillin had been discovered in 1929) cut mortality rates in hospitals dramatically. It has been estimated that during World War II, 60,000 American, Canadian, and British soldiers survived a hospitalization that would have killed them two decades earlier.

More disabled veterans meant greater pressure on the states that had sent them to fight. World War I forced all of the belligerent nations to deal with disability on a scale never before experienced. The overwhelming numbers of casualties, combined with the widespread expectation that the war would be short, meant that none of the European states was prepared to deal with the problems that disabled men faced. All were forced to develop solutions amid wartime budgeting constraints and, in some instances (as in Russia and Germany), political turmoil. Some responses were common. Governments largely acknowledged the need to provide nationally funded pensions, even in those countries (such as Britain), where charitable organizations had, during the nineteenth century, played a leading role. In most countries, rehabilitation, training, and employment were also of central concern to the state, as officials sought to return men to the workforce. Integration into the labor market, rather than segregation in veterans' homes, was the call of the day.

Despite these commonalities, however, important differences remained in the treatment of disabled veterans after World War I. The cases of Britain and Germany indicate the range of government responses. While commentators in both countries agreed that it was the responsibility of the state, supplemented by the efforts of its citizenry, to provide for the disabled, British and German veterans fared very differently. In Britain, civil servants in the new Ministry of Pensions charged with their care sought to limit the state's obligations toward disabled veterans. Pensions assessments were based solely on the degree of physical disfigurement or illness and did not take account of a man's capacity to return to work. Successive British governments proved notably reluctant to institute programs that provided disabled men with a chance at gainful employment. As a consequence, the tasks of rehabilitation and employment were left largely to philanthropy and voluntary effort. In Germany, by contrast, state officials embraced the rehabilitation of the disabled as their foremost duty, and largely eliminated charities for the disabled. Pensions were intended to compensate men for the loss of earning capacity, as well as for the physical fact of disability. The Weimar Republic's National Pension Law (1920) accorded the disabled more than a right to pensions; they were also entitled to an occupational retraining course and free medical care for all service-related ailments. Under the Law of the Severely Disabled (1920), most employers were required to hire and to keep them. It was very difficult to fire a disabled man.

In general, most countries hewed closer to the German model than to the British and, in the aftermath of World War II (even in Britain), the tide had turned against predominantly voluntarist solutions to the needs of disabled veterans. The privileged position of veterans in relation to other categories of the disabled was well established. In Soviet Russia, for example, disabled veterans of World War II were entitled to privileges that distinguished them from the peacetime disabled: a free automobile (to be replaced every seven years), a gasoline subsidy, free public transportation, priority in housing, and the free installation of telephones. To a limited extent, the civilian disabled profited from wars' creation of an entirely new populace of disabled people. Medical advances made in connection with disabled veterans, such as new prosthetic devices, could be translated into improved care for the rest of the population. Some social legislation, such as Germany's Law of the Severely Disabled, was extended to peacetime disabled as well. However, in general, veterans jealously guarded their prerogatives, and protested vehemently against any attempt to integrate their care with other categories of the poor or disabled.

While disabled veterans throughout history had usually defined themselves as a group bound together by shared experiences, the massive numbers generated by the twentieth century's wars, and their favored place in the welfare state created new kinds of political organizations. The first mass veterans' associations dated to the late nineteenth century, with the Grand Army of the Republic (organized by Civil War veterans in the North) and the Kyffhauser Bund (founded by veterans of the Franco-Prussian War). These were mixed organizations of disabled and nondisabled veterans, of officers and enlisted men.

Although many of the veterans' associations founded in the twentieth century adhered to this model, with World War I also came the formation of organizations whose membership was restricted to war victims, defined as the disabled, their dependents, and the survivors of the dead. Some of these organizations, as in France, were nonpartisan, focused chiefly on securing improved benefits. Others, as in Germany, though ostensibly apolitical, were in fact deeply politicized along the spectrum of left to right; the country's largest war victims' organization, the National Association of Disabled Soldiers, Veterans, and War Dependents, enjoyed close ties to the Social Democratic Party, while one of its challengers, the Central Association of Disabled German Veterans and War Dependents, was thoroughly conservative. By 1919, there were seven national organizations of war victims in Germany, with a total membership, at the high point in 1921, of nearly 1.4 million. Through the 1920s, these organizations were involved in an increasingly bitter battle with their fellow citizens, whom they accused of neglecting them, and the state, which despite its innovative welfare programs, could not fully compensate veterans for their sacrifices. By the early 1930s, disabled veterans in Germany had become a constituency ripe for the picking by the Nazi Party. In Britain and France, by contrast, where veterans could take pride both in their victory, and in their fellow citizens' grateful response to soldiers' sacrifices, veterans remained bulwarks of the established order.

Throughout the twentieth century, disabled veterans came to occupy a position of great symbolic significance in the lands to which they returned. Not only were the disabled present in the greatest numbers ever seen, but they had become, in most countries, the state's favored wards, the subjects of costly and pathbreaking social legislation. Where disabled veterans had once been isolated in institutions such as the Invalidenhaus, they were now, quite literally, more visible on the street, in the workplace, and even on the movie screen, in films such as the Academy award-winning *Best Years of Our Lives* (1946). Changing attitudes toward disability, both furthered by disabled veterans and reflected in their situation, meant that an injury sustained in battle no longer necessarily stripped a man of his expectations for a well-paying job, marriage, or a family.

Yet, at the same time, the public image of the disabled veteran has often been an ambivalent one. Societies have tended to treat all veterans with caution, as men who have endured the fire of battle, have killed, and perhaps still contain within them the potential for violence. Because they carry the scars of war on their body, disabled veterans have been seen as an exaggerated instance of the general phenomenon. The civilian populace's guilt toward the disabled has undoubtedly played a role in stigmatizing these men as unstable. In novels and films in which disabled veterans appear, images of pathos have coexisted with threatening visions of danger. With rare exceptions, the quotidian struggles of disabled veterans are seldom depicted.

—Deborah Cohen

See also Advocacy Movements: France; Advocacy Movements: Germany; Citizenship and Civil Rights; Veterans.

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DISCREDITED THERAPIES

Alternative or discredited therapies are those that exist outside the framework of professionally accepted remedies as determined by mainstream medical systems. While one could speak of allopathic medicine as an alternative system in eighteenth-century China, this entry considers the context to be contemporary Western medicine. Among those therapies generally considered alternative, for example, are acupuncture, magnet therapy, and many herbal remedies.

Nevertheless, it is important to recognize that alternative or discredited therapies can also become mainstream or accredited, while previously approved interventions can be later discredited. Applying leeches to remove a plethora of one of the four humors, for example, was a mainstay of conventional medicine from antiquity into the nineteenth century. In 1833, some 40 million leeches were imported into France for medical purposes. By the end of the century, leeching therapy was overturned with successive changes in medical theory and practice. Over the past two decades, however, leeches have found new roles in postoperative management for plastic and reconstructive surgery; they have reentered accredited use, although for different theoretical purposes. Thus, the designation of alternative is a moving target.

The term *alternative*, or discredited, therapy fundamentally exists on the sociological level with allocation of resources—mainstream/licit therapies have the support of, for example, governmentally endowed institutes or departments at major universities; the alternative intervention often exists as a grassroots enterprise. Nevertheless, popular alternative therapies can command enormous market forces, which at times can overturn the traditional domination of mainstream medicine. Such changes are often full of social controversy.

Alternative or discredited medicine in Western Europe and North America may be said to have begun with the rise of mainstream medicine. Defining the latter means defining the former as “the other” kind of practice. Thus, in the early Western Middle Ages, magicians and sorcerers offered an alternative means of healing often sought by people with chronic conditions when doctors trained in humoral medicine or Catholic healing interventions were unsuccessful. At times, the Church and the more formal physicians joined forces to limit the appeal of such magical healers. By the thirteenth century, after the invention of the medical schools within the newfangled universities, physicians, lay governmental authorities, and the Church established regulations requiring that medical practice be certified by a license granted only after examination by the university faculty. In 1322, an illiterate woman, Jacqueline Félicie de Almania, and four of her colleagues were tried and excommunicated for unlicensed practice in Paris by the Medical Faculty, despite witnesses asserting her salutary effect in the face of mainstream impotence. Similar examples exist for medieval Spain, Italy, and England.

As university medicine grew in authority and prestige, its physicians entered medical service in the courts of the powerful. By the sixteenth century, figures such as Paracelsus (ca. 1493–1541) could be chased out of town after town for offering medical care that did not fit into the confines of the now codified theory and practice of the universities. In the late eighteenth century, some therapies, such as mesmerism, enjoyed a period of wild enthusiasm only to be officially and permanently discredited by a panel of experts. Others, such as electrotherapeutics for conditions such as stroke and insanity, were used with initial enthusiasm, followed by a period of discredit and but are now being investigated again and used by biomedical scientists.

In the United States, the slow absorption of proprietary, freestanding medical schools into the universities delayed the process of a more consistent division between accepted and discredited therapies until the late nineteenth century. This process was enhanced by the acceptance of the scientific method into medicine, though that acceptance was highly variable both chronologically and geographically. By the beginning of the twentieth century, requirements of verifiable proof of efficacy began to limit the social penetration of alternative medicine and increased the lists of discredited therapies. The ongoing "successes" of scientific medicine, from aseptic and antiseptic surgery to anesthesia to antibiotics to immunomodulators, generated a popular perception that scientific medicine would eventually be able to cure most, if not all, conditions.

Coincident with the shift from the acute- to the chronic-disease model in the second half of the twentieth century, the slow gains with respect to cures for cancer, HIV, and other objects of "wars on disease," as well as the social revolutions of the 1960s and early 1970s, popular acceptance of non-biomedical/university therapies grew. By the 1990s, the groundswell of use of such treatments had grown to the point that reportedly 42.1 percent of American patients acknowledged using such therapies. The National Institutes of Health (NIH) created the Office of Alternative Medicine (OAM) in 1993, which became the current National Center for Complementary and Alternative Medicine (NCCAM) in 1998. Such an official endorsement for the field has blurred the distinction between mainstream and alternative therapies in their classic definition.

As different cultures with a less professionalized medical history endorse the Western biomedical model to a greater or lesser extent, the relationship between "alternative" and "discredited" therapies varies. In China, for example, traditional Chinese medicine (TCM) shares a relatively coequal status with allopathic medicine. In Brazil, prayer competes with native remedies and allopathy. In addition, sociological relationships established by professionalized markets can reverse as one moves across cultural boundaries. Thus, in the United States, different alternative remedies have been embraced by both higher and lower socioeconomic groups, whereas in China, the likelihood of a person choosing TCM over allopathy decreases as one ascends to higher socioeconomic statuses.

Conditions, which include chronically disabling features, can fall into those with gradual functional "deterioration," no change, or slow gains, after the model of cerebral palsy, cancer, and HIV. Thus, people with strokes, traumatic brain injuries, amputations, chronic pain, and many others have sought out alternative therapies when biomedical science has not helped. In this way, modern people with such chronic conditions echo their medieval predecessors who, frustrated with the mainstream healer, sought out magicians, sorcerers, and the nonlicensed healers. While the salubrious claims of these complementary healers have not always been proven by science, more intense investigation may prove many of them and so embrace them as accepted therapy.

In the United States, over the past decade, such market forces have pressured both the government and insurance companies to accept in part previously marginalized therapies. In addition, certain medical disciplines, physical medicine and rehabilitation (PM&R) among them, have traditionally employed alternative therapies, from hippotherapy to acupuncture, in advance of more traditional allopathic specialties, further blurring the boundaries between accepted and discredited.

—Walton O. Schalick III

See also Acupuncture; Complementary and Alternative Medicine; Health; Humors, Theory of.

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DISEASE

Disease is a pathological state of a part of an organism. Disease may be brought about by multiple causes such as genetic, infectious, or environmental factors. Distinct symptoms usually indicate the presence of disease.

The concept of disease is at the heart of biomedicine. The purpose of biomedicine, also referred to as allopathic medicine, is to diagnose and cure physical pathology. Historically, disease has been understood in different ways. Before the use of the scientific method and the rise of biomedicine, disease and its symptoms were usually attributed to spirits, witchcraft, humoral processes, or other causes in the social world. In contrast, biomedicine tends solely to consider organic causes and aspects of disease. Discoveries such as the germ theory of disease and the existence of entities such as viruses and bacteria did much to bolster this latter understanding. Discovering the root physical cause of the disease is considered essential to treating, curing, and preventing it. For example, if a patient has a bacterial infection, an antibacterial medication is given. When a medication like penicillin was discovered to fight the disease process, it changed the health outcomes of entire populations. Similarly, when it was discovered that diseases could be transferred by germs, handwashing became a common practice. This simple behavior changed obstetrical practice and reduced infant mortality rates when babies started to be delivered into clean hands. In addition to curative medications and behavioral changes, biomedicine has discovered vaccines that can prevent diseases that were otherwise disabling or deadly such as measles and diphtheria. Because of the power of the biomedical approach to disease, medical research continues to flourish with the promise of curing an increasing number of diseases.

Biomedicine has made staggering improvements to the prevention and treatment of a myriad of diseases. However, the emphasis in this type of medical system is on disease rather than health or well-being. *Allopathic* means "against suffering or disease" and overwhelmingly focuses on removing pathology rather than sustaining health. In this disease-focused system, a person is often stripped of psychosocial or spiritual aspects and effectively becomes a set of body parts to fix. While this emphasis on pathology is changing to encompass health promotion to some extent, the Western medical system is still predominantly one of crisis management. Other systems, such as several Eastern medical models, focus on regular practices to sustain health in addition to disease treatment.

Current controversy exists over whether some conditions should be considered diseases or not in allopathic medicine. For example, a long-standing area of disagreement is addictions. Alcoholism, once considered a moral failing, is increasingly thought of as a disease with genetic factors related to the malfunctioning of neurotransmitters. Many psychiatric disorders have also been redefined as diseases rather than bad behavior such as Tourette's syndrome, eating disorders, and obsessive-compulsive disorder. For many in Western societies, having a troubling condition defined as a disease rather than a character flaw removes stigma and aids the solicitation of professional help.

Medical anthropologist Arthur Kleinman identified an important distinction between disease and illness. He argues that disease refers to the biological pathology as well as health care practitioners' understanding of the pathology according to biomedical models. On the other hand, illness refers to a broader set of experiences around the disease including the patient's and family's subjective recognition, naming, and experience of the problem. Whereas disease is presented as acultural in a medical model,[1] illness includes the sociocultural context of a problem. The social and cultural components of the experience of a condition have been identified as crucial to the course of the condition. Therefore, medical sociologists and anthropologists point to the importance of examining the illness in addition to the disease, even in biomedical contexts. In the study of disability, several anthropologists such as Robert Edgerton, Benedicte Ingstad, and Susan Reynolds Whyte proved that cultural context makes a significant difference in the identification, experience, and outcome of a condition. The disease/illness distinction is also especially relevant as allopathic medicine expands transculturally and as heavy transnational immigration creates multicultural communities. In such cases, experiences of illness and disability as well as symptom reporting may vary greatly, and it is crucial that important cultural differences are not dismissed in the professional health care setting.

—Eileen Anderson-Fye

See also Anthropology; Health; Health Promotion; Medicine.

Note

1. Many have convincingly argued that even biological pathology is shaped by culture. For example, heart disease and obesity-related health problems have been found to vary in their prevalence depending on a diet common to a particular culture or region.

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DISPARITY

The term *health disparity* is widely used to indicate inequalities in health status and health care services, as it relates to minorities. For example, a disproportionately high number of people in certain ethnic and socioeconomic groups have illnesses such as heart disease, obesity, and cancer. In addition, observed differences exist between Hispanic Americans and the general population in the proportion of having a usual source of care. Ethical judgments of such inequalities (fair or unfair) depend largely on a person's perception of the reasonableness of the underlying reasons for the inequalities, such as differences in income and access to insurance. Other inequalities are often considered unfair when race is the main reason for inequalities. For example, research has shown that the race/ethnicity of a patient is the main factor that affects primary care physicians' decisions on specialist referral or the use of expensive treatment.

Racial disparity in health surfaced in 1985, when the U.S. Department of Health and Human Services issued the first comprehensive national minority health study, known as the Secretary's Task Force Report on Black and Minority Health. The task force focused on differences in mortality for six key areas between minorities and the white population (cancer, cardiovascular disease and stroke, cirrhosis, diabetes, homicide and unintentional injuries, and infant mortality that collectively accounted for more than 80 percent of the mortality from 1979 to 1981) and concluded that the difference in mortality was not acceptable. Following the report, federal and state governments created agencies, such as the Office of Minority Health, to address these issues of health disparity. However, comparisons of the findings in the 1985 report to information released in *Health, United States 1990* showed very little change in the health status of minority populations.

By 1998, studies indicated that racial disparity had not improved as much as hoped. The long-standing considerable differences in death rates for infant mortality, heart disease, cancer, and HIV/AIDS between minorities and whites made a compelling case for a federal response. Consequently, President Bill Clinton launched a initiative that set a national goal of eliminating disparities in six key areas by the year 2010: infant mortality, diabetes, cancer, heart disease, HIV/AIDS, and immunizations.

In 1999, Congress authorized the Institute of Medicine's (IOM) study on the prevalence and impact of ethnic bias. Unlike previous governmental studies, the IOM report, titled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, focused on quality of treatment by examining provider-patient clinical encounter itself rather than mortality or prevalence of diseases. The report documented the prevalence of lower-quality treatment of minority patients, and concluded that minorities received unequal treatment because they are, in fact, minorities.

Policy makers started to express concerns related to the sole focus on racial and ethnic minorities as opposed to a more generally defined population, such as those whose health care needs are not well met. Concerns led to addition of the definition of *health disparity population* into a new federal law, the Minority Health and Health Disparities Research and Education Act of 2000: A population can be designated as "a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population."

Specification of certain segments of the population in the health disparity definition provides insight as to which segments are of greatest interest for policy makers. The National Healthcare Disparity Report, developed by the Agency for Healthcare Research and Quality (AHRQ) to meet the mandate by Public Law 106–129, the Healthcare Research and Quality Act of 1999, identified persons with disabilities and persons who use long-term care, among others, as priority populations worthy to track health care disparities. According to the U.S. Census (2000), nearly one in five persons, or 49.7 million people, had some type of long-lasting condition or disability. They represented 19.3 percent of the 257.2 million people who were age 5 and older in the civilian noninstitutionalized population.

Some disparities were documented based on national survey data, such as the Medicare Current Beneficiary Survey, the National Nursing Home Survey, and the National Home and Hospice Care Survey. However, other national survey data were not usable for reporting on racial/ethnic and socioeconomic disparities related to disability. Many data collections do not capture disability and, when collected, do not have adequate sample sizes of the disabled to examine racial/ethnic and socioeconomic disparities.

In general, the Medicare Current Beneficiary Survey (MCBS) findings indicated the presence of racial/ethnic and socioeconomic disparities in the quality of health care among disabled persons. According to the disabled elderly, the percent of persons who reported problems with the quality of care is higher among Asian and Pacific Islanders (11 percent) when compared with whites (4 percent), and higher among persons in poor households (6 percent) when compared with persons in high-income households (3 percent). Small sample sizes precluded assessment of disparities in the quality of health care among the disabled nonelderly. Similarly, access to care also indicates disparity among disabled persons. For example, among the disabled elderly, the percentage of persons with a problem getting to the doctor from their home was higher among Hispanics (16 percent) when compared with non-Hispanic whites (7 percent). In addition, there is an income gradient with this measure of physical access to a doctor: Persons in poor (11 percent), near-poor (9 percent), and middle-income (7 percent) households experienced more difficulty than persons in high-income households (4 percent).

The National Nursing Home Survey and the National Home and Hospice Care Survey data were used to examine racial, ethnic, and socioeconomic disparities in nursing home care. Within the survey data, differences in the management of pain and the receipt of rehabilitative services among nursing home residents were demonstrated. Significant disparities in influenza vaccination were not observed, but disparities in pneumococcal vaccination among some nursing home residents were present. Among persons ages 18 to 64, rates of nursing home discharges were higher among blacks (22 per 10,000 population) when compared with whites (16 per 10,000). In addition, when discharged from a nursing home, the percentage of persons who stabilized/recovered was lower among blacks (22 percent) than whites (34 percent).

Health disparities can be examined from the point of view of public health purposes. This approach follows the 1986 World Health Organization definition of health, which states, "Health is a state of complete physical, mental, and social well-being, and not merely the absence of disease or injury." *Healthy People 2010* and similar state initiatives have committed the nation to the goal of eliminating health disparities by 2010. *Healthy People 2010* defines health disparities as differences that occur not only by gender, race or ethnicity, education, or income but also by disability, geographic location, or sexual orientation. Of 28 focus areas that cover both health care and health status measures, the sixth focus area addresses disability and secondary conditions with one of three goals being the elimination of disparities between people with and without disabilities in the U.S. population.

The disparity findings suggest that people with disabilities tend to have lower rates of physical activity and higher rates of obesity. They tend to report more anxiety, pain, sleeplessness, and days of depression, and few days of vitality when compared to people without activity limitations. Health promotion activities are important for people experiencing a disability regardless of race or ethnic group, gender, or primary condition or diagnoses (e.g., major depression, arthritis, cerebral palsy, diabetes, spinal cord injury, or fetal alcohol syndrome).

A 2003 national survey that updates the Disability Supplement to the National Health Interview Survey (NHIS-D) conducted nearly 10 years ago examined health care use, costs, and access among people with disabilities. More than 33,000 households were contacted; 3,687 of which were identified as including a household member with a disability. According to the survey findings, people with disabilities are often confronted with socioeconomic and health-related disadvantages, compared to the rest of the general population. Commonly, disabled people, both mentally and physically, have lower incomes, are older in age, are more likely to be female, are more likely to be unemployed, and are often poorer in health. Thus, because of these disadvantages, people with disabilities are more likely to use the health care system exhaustively: (1) 90 percent of the sample reported employing physician services six months prior to the survey, (2) approximately 33 percent reported frequenting emergency room services six months prior to the survey, and (3) 90 percent reported taking at least one prescription drug on a daily basis. These numbers indicate higher health care use rates for people with disabilities when compared to the general U.S. adult population. Although those living with disabilities are often profound and intense users of health care services, they obtain these services much less regularly than is normally recommended.

The survey findings highlight barriers to care among the uninsured and those with gaps in coverage within persons with disabilities. For example, the uninsured were four times as likely to have postponed care because of cost when compared to those with insurance coverage. Also, the uninsured were three times as likely to go without needed supplies or medication. Those insured primarily by Medicaid were less likely to postpone care or go without necessary medication compared to those covered by Medicare or private insurance companies. In addition, the disabled, covered solely by Medicare, fared worse than people with private coverage (12 times as likely to postpone care, and 7 times as likely to forgo medication). The findings suggest that Medicaid provide the most important financial protections when compared to other sources of coverage such as Medicare and private insurance.

On the other hand, the Medicare Current Beneficiary Survey (MCBS) data allow comparison of health status between two groups of Medicare beneficiaries: the disabled under age 65 and the elderly population. In general, the survey concluded that disabled beneficiaries have poorer physical, mental, and functional levels than the elderly. The study also reported that the disabled were twice as likely to be in fair or poor health (59 vs. 23 percent), and twice as likely to have trouble performing one activity of daily living (44 vs. 26 percent) or instrumental activity of daily living (36 vs. 16 percent). The survey also noted that disabled persons bear heavier disease burdens and are more likely to report having three or more chronic conditions. Furthermore, the disabled are often poorer: They are more than twice as likely as seniors to live under the federal poverty level (45 vs. 20 percent); nearly 80 percent live on modest incomes under 200 percent of the poverty level. Mentally disabled beneficiaries are the most vulnerable: They are more likely to have incomes below poverty level.

Differences in health status and disposable income seem to lead to differences in health care utilization between the disabled under age 65 and the elderly Medicare beneficiaries. In 1998, the average number of prescriptions filled by disabled users (34) was much higher than for elderly prescription users (25). In addition, the disabled spend almost 50 percent more than the elderly on prescription spending ($1,284 vs. $841).

A recent Commonwealth Fund study singled out a vulnerable subgroup within persons with disabilities: Severely disabled persons enrolled in Social Security Disability Insurance (SSDI), waiting the mandated two-year waiting period before their Medicare coverage takes effect. Medicare provides coverage for individuals whose disabilities are severe and permanent enough, qualifying them for SSDI, even if they are not age 65 and older. However, unlike the elderly beneficiaries, federal law requires these individuals to wait two years after they receive SSDI before their Medicare coverage takes effect. Many of these individuals are no longer eligible for Medicaid when they receive SSDI payments that push them over the financial limits for Medicaid. Some may still be eligible for Medicaid benefits but are unaware of their potential eligibility. In 2002, a total of 1.2 million people with disabilities under age 65 were in the mandated two-year waiting period. About 400,000, or one-third, of all these individuals likely were estimated as uninsured. Thus, many, particularly those in the waiting period, report enormous problems: skipping medications, putting off needed care, feeling depressed and anxious about the future, and believing they were not in control of their own lives. The study findings call for eliminating the current Medicare two-year waiting period and beginning Medicare coverage concurrent with that of SSDI.

Mental disorders are disabling conditions. Former Surgeon General David Satcher's 2001 report on health disparities, titled *Mental Health: Culture, Race, and Ethnicity*, documents the existence of several disparities affecting mental health care of racial and ethnic minorities compared with whites: Minorities have less access to, and availability of, mental health services. Minorities are less likely to receive needed mental health services. Minorities in treatment often receive a poorer quality of mental health care. Minorities are underrepresented in mental health research.

Studies mentioned above tend to focus on disparity in access to care. We may need more research related to quality and outcomes in health care for the disabled. Another observation relating to the studies mentioned above involves little research on racial disparity relating to disability. With the exception of mental health, most disparity studies mentioned above do not report on racial/ethnic and socioeconomic disparities related to disability. Many survey data conducted or sponsored by federal agencies do not capture disability and, when collected, the definition of disability is often not consistent across data or over time. Even when disability status is captured, in many cases, the data do not provide adequate sample sizes of the disabled to examine racial/ethnic and socioeconomic disparities. The 2004 National Academy of Sciences' report, titled *Eliminating Health Disparities: Measurement and Data Needs*, recommended the use of state-based data such as vital records, administrative data from Medicaid and the State Children's Health Insurance Program, and data from registry systems for analyzing disparities in health and health care. Although those types of data provide information on race and ethnicity and socioeconomic status, disability information may not be available, limiting their use for studying racial and socioeconomic disparities relating to disability.

—Kyusuk Chung

See also Health Care and Disability; HIV/AIDS; Poverty; Race and Ethnicity; Socioeconomic Class.

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DISSOCIATIVE DISORDERS

Dissociative disorders are disturbances of normally integrated mental functions such as identity, memory, consciousness, or perceptions of environment. These can occur suddenly or gradually and may last a short time or become chronic. Dissociative phenomena, on the other hand, are seen in normal subjects and may result from hypnosis or a trance state. About 90 percent of the population is hypnotizable. Trance refers to altered state of mind during which a person performs uncommon physical feats, such as standing on one leg for hours or walking on a bed of nails. Dissociative phenomena have been recorded in the temples of Aesculapius in ancient Greece, in Native American culture, and among Indian monks. Dissociative phenomena can also be seen in various religious and cultural ceremonies internationally where the process of celebration induces a group dissociative phenomenon.

Dissociative disorders are usually psychopathological and include the following subtypes: dissociative amnesia, dissociative fugue, dissociative identity disorder, depersonalization disorder, and dissociative disorder not otherwise specified.

Dissociative amnesia is characterized by an inability to recall important personal information of stressful or traumatic nature. It may be *localized* (inability to recall events during a circumscribed time), *selective* (can recall only some aspects of an event), *continuous* (ongoing amnesia following a specific event), or *systematized* (inability to recall certain categories of events). Dissociative amnesia can occur at any age but is rare in children. Its incidence is higher in soldiers in combat. It is reversible, usually beginning and ending suddenly. Recurrences are not uncommon. Hypnosis and amobarbital interview may be helpful in retrieving lost memory.

Dissociative fugue presents as a sudden, unexpected travel away from home with inability to recall some or all of one's past. Onset is sudden, usually following severe psychosocial stressors. This state usually lasts for minutes to days, but may be prolonged for months. Although confusion may be present, most individuals appear quite intact and do not draw attention.

Dissociative identity disorder (formerly called multiple personality disorder) is characterized by the presence of two or more distinct personality states or identities that recurrently take control of the person's behavior. The patient may be unable to recall important personal information. This is a chronic and complex disorder, which may result from severe childhood abuse (physical, emotional, or sexual) or neglect. It is diagnosed three to nine times more frequently in adult females. It is more common among the first-degree biological relatives of patients with this disorder.

The person may have different personality states or identities, that is, the child, the angry person, the protector. Most patients are unaware of their disorder and may seek treatment for depression. Many patients receive other diagnoses prior to treatment and may not respond to medications. The transition ("switch") from one personality to another is usually quite sudden. The degree of impairment depends on the manner in which various personality states interact with each other. The switching is a vulnerable time. Patients may attempt suicide, mutilate themselves, or become violent toward others. Long-term psychodynamic psychotherapy using an integration approach is helpful.

Depersonalization disorder presents as recurrent episodes of depersonalization in which a person feels detached or estranged from one's self. He may feel as if he is an observer watching himself as if in a dream or movie. Reality testing remains intact. The prevalence of this disorder is unknown. It usually occurs in adolescence or adulthood. Most patients present with anxiety, panic, or depression. Clinical course may be chronic with recurrences following stressful events. Impairment is usually minimal and most patients function well, but some become incapacitated from fear of going insane.

Dissociative disorders not otherwise specified do not fit in any of the above categories. Ganser's syndrome (in which the person gives approximate answers) falls in this group.

—Surinder Nand

See also Psychiatric Disorders.

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DIVERSITY

Although *diversity* is a much overused term within multiculturalism, its potential for promoting social transformation—particularly with respect to disability—remains significant. At base the term suggests difference, or rather, the recognition and acceptance of difference; however, even this formulation does not adequately address the term's importance. Instead let us say that diversity represents not a point of acceptance but a stance toward the world that refuses to foreclose on the question of who counts among the ranks of humankind. Diversity, then, becomes a more active ethical position, available for adoption as opposed to a goal to be fulfilled.

This distinction is important at the outset because the overuse of *diversity* in contemporary politics and rhetoric has reduced the term's meaning to an objectively achievable goal. If we have human "differences" represented at any one point in time—African American, Jewish, women, gay—then we have achieved "diversity" and we can go on from there. Such a position cultivates certain forms of tokenism where the one stands in for the many and, as a consequence, the plurality of the many drops out. Pure efforts to operationalize diversity inevitably miss the point of the concept, and therefore, this entry sets out a philosophical overview of the term's important meanings.

Properly understood, then, *diversity* means a plurality of singularities working together toward collective understanding and action. The realization of diversity, which can never occur once and for all, must constantly be renewed and implies a recognition that beneath any collective banner those who comprise it must also retain their specificity. Consequently, diversity should not be viewed as a question of representation; particularly in the sense of one perspective effectively embodying a diverse whole. Instead, efforts to achieve diversity seek to avoid rhetorical efforts in the name of false unity. The goal is not a subsumption of differences beneath a singular identity—whether that identity be women, African Americans, disabled people, the working class—but rather a cultivation of shared participatory space where differences remain recognizable. Nor can diversity be adequately identified with more outdated political groupings of "the people," "the masses," "the proletariat." If this were so, and diversity functioned merely as another synonym for designations of group identity, the term's significance would prove much less consequential.

Diversity has come to stand in as an alternative form of identification—one that ultimately attempts to suspend the need for singular group identity overriding dynamic differences across populations. As Ernesto Laclau and Chantal Mouffe have pointed out, political formations coalescing beneath an identity (no matter how large the potential grouping) inevitably experience the fracturing of differences residing just below the surface of a unifying banner. One might say that efforts to unify a plurality of identities beneath a nodal point of belonging find themselves inevitably beset by the demands of diversity. The specificity of individual differences ultimately makes demands on the larger category charged with organizing shared modes of belonging. Conceived in this way diversity can be understood as a disruptive presence at work in all efforts at totalizing allegiance.

At the same time, diversity does not involve surrendering to relativism either. The existence of particularities among collective gatherings does not necessarily mean that organizing devolves into irredeemable difference. Philosophies of political organizing, as Michael Hardt and Antonio Negri point out, have often offered formulas that result in a false choice between unwieldy plurality or authoritarian singulars. Diversity's alternative philosophical gambit resides somewhere in between these extremes. Instead diversity focuses on forms of collective action taken in common among the individualities that comprise it. The effort of diversity is not to forge "unity" of identity based on a shared interest or essential quality, but rather to achieve an open process respectful of differences born of intellectual, social, geographic, and embodied experiences. While there is a defining nonallegiance to national boundaries, diversity actively recognizes the specificity of place and culture. Within this formula there is no need to negate local differences; rather the creativity of differences interacting with each other express the ideal of diversity. The conscious goal of diversity is to produce alternative routes of belonging that bypass more worn down points of group organization.

Yet this formulation is not without conflict. Nor is its achievement simple to pull off. One inevitably finds exclusions occurring even in the most "diverse" gatherings. Disability, for one, often finds a difficult time inserting itself into political efforts claiming to be diverse for a variety of reasons. First, modern liberation movements have traditionally sought to undermine social designations of inferiority by distancing themselves from criteria of "biologically based" insufficiencies. The contemporary history of women's weaker constitutions or biological racism, for instance, situates a population's inferiority as having a bodily basis. By way of refuting such ascriptions modern concepts of femininity and race have rightfully exposed the social underpinnings informing such beliefs. However, in the wake of these liberation formulas, disability functions as a remainder of true "inferiority" in that it continues to operate within the parameters of biology.

Furthermore, disabled participants in politicized identity movements have often found themselves left out of traditional activist practices. On the basis of inaccessibility that exists within political organizations—for example, lack of audio description and/or alternative print formats for people with visual impairments, lack of sign language interpreting and/or captioning for deaf participants, lack of physical accessibility for those with mobility impairments—disability itself has not been recognized as a legitimate constituency with issues in need of political redress. Thus, divisions often surface based on insensitivities in Leftist movements to the forms of marginalization that disabled people face. In addition, within disability groups one could also point out that lack of active recruitment of other marginal identities results in a failure of diversity among disability movements as well. Within this matrix of insensitivities, inadequate recognitions, and exclusionary practices little space is left for the exploration of the substantial overlaps that exist between disability, race, class, gender, queer, and other identities seeking political change. One basis for social claims of marginalization eclipse other equally pressing oppressions, and disability often finds itself holding the least status among competing discourses of social redress. Diversity and disability, it would seem, do not mix.

Thus, disability as diversity continues to function as oxymoronic. Disability and its intersections with other identities have not yet been adequately recognized as a cultural attribute with something to contribute to our understanding of social disenfranchisement, political organization, or collective well-being. In fact, disability often appears as the identity claim that will ultimately expose all identity claims as false. If people with disabilities who have obvious "things wrong with them" (or so goes this rationale) can also claim the political terrain of social constructivism, then all identity-based claims are in jeopardy. With the arrival of disability we have somehow reached the end point of identity politics because claims to social disenfranchisement based on prejudicial beliefs about inferior biologies must be disallowed from growing too sweeping (and, therefore, ludicrous). If disability gains recognition as a minority like any other, then it instantly metamorphoses into the largest minority group (some 20+ million in the United States alone). Difference becomes mere variation; disability threatens to re-biologize socially derived inequalities; minority status itself becomes a joke when one has to work in such large demographic quantities; and anyone could ultimately become a resident of minority landscapes. Claims to social justice become impossible, incoherent, and, ultimately, unwieldy.

Diversity undermines (or, depending on your point of view, exacerbates) such fears in that it endeavors to attribute differences differently. Differences are not so much based on one's possession of discrete characteristics (femininity, homosexuality, color, disability); rather, diversity seeks coalitions among those who use difference as a tool to analyze structural inequalities. Diversity is a shared methodological tool more than a static mode of being. Such an approach does not mean a rejection of biological and social identities. Instead, diversity cultivates a common-ness across previously segmented identities based on annunciations of common objectives. As a result, diversity cannot be achieved beforehand or a priori. It is a dynamic and ever-shifting product of politicized identity constituencies as they interact with each other to formulate and imagine another world where differences could be signified as wealth rather than lack.

In April 2005, for instance, the Perth Social Forum in Australia adopted the slogan "Another World Is Possible." A three-day symposium included environmentalists, feminists, aboriginal rights advocates, disability rights advocates, theorists of organizational behavior, anthropologists, Marxists, globalization philosophers, "slow food" proponents, and antiwar protestors. Diversity operated as the expressed goal in that participants were encouraged to pursue multiple activist interests without privileging any singular aspect of their identity interests. In other words, the inter- and intragroup efforts explicitly discouraged a single basis for belonging or legitimate activism. Instead, coteries of interests became the norm and participants found themselves teaching and being taught across a variety of perspectives. By the conclusion of the event, five key themes surfaced as interests identified "in common" among all attendees: the insufficiency of existing forms of political participation, the global ruination of environments (both natural and artificial), the continuing proliferation of poverty, increasingly narrowing criteria of meaningful human inclusion based on variation rather than homogeneity, and strong commitments to global peace agendas. These shared investments signaled not unity of identity but common political and social capacities among those gathered.

Critics of diversity might say that, inevitably, every identity group is formed on the basis of its exclusions—those who do not fit based on fetishized traits strategically reclaimed to counter mainstream devaluation. Diversity sets out to undo this limiting logic by inserting a more expansive formula for involvement. Even when a historical moment is dominated by a variety of unifying identity rubrics, diversity responds to the indefinite nature of dispersed networks—those intersected by myriad differences of race, class, gender, disability, age, sexuality, and cultural/geographic specificities. Because the multiple interests of the Perth Social Forum could still manage to define agendas in common based on the five themes identified above, one recognizes that diversity does not necessarily undermine the ability to exist in common. Diversity is not a devolution into incoherency; instead it seeks to transform the appearance of incoherency from the outside into an organizational strength. Consequently, diversity grapples openly with the need for alternative organizational strategies that do not cover over differences but rather cultivate them openly as desirable—a politics based on variation as a commonality of our embodied, political lives.

—Sharon L. Snyder and David T. Mitchell

See also Citizenship and Civil Rights; Democracy; Gender; Gender, International; Inclusion and Exclusion; Race and Ethnicity;

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DIX, DOROTHEA (1802–1887)

American social reformer

Dorothea Dix was a renowned social reformer and vocal advocate for the humane treatment of people with psychiatric disabilities. During her lifetime, Dix traveled extensively throughout the United States and abroad, visiting jails and almshouses to document the inhumane treatment of those with mental illness. She used these notes and observations to fight for the use of "moral treatment" in their care. Her reports regarding the treatment of those with severe mental illness were presented in numerous state legislatures, leading to the creation or enlargement of many hospitals designed specifically for the needs of this group. Dix believed that it was important to provide a place that focused specifically on assisting people with mental illness. She felt that the current system of care, one that focused on trying to address the needs of many disparate populations, including orphans, criminals, and paupers, was not specialized to adequately address of all these issues. Dix believed that a therapeutic setting, focusing on recovery, without restraint or confinement of patients, would be most helpful in restoring mental health.

Dix rose to prominence after submitting a petition to the Massachusetts General Court, titled the *Memorial to the Legislature of Massachusetts,* which documented the horrific conditions of people with mental illness living in confinement throughout the state. As a result, Massachusetts enlarged its state mental hospital to provide specialized treatment to low-income individuals with psychiatric disabilities. As an outcome of her successful efforts in Massachusetts, Dix became involved in conducting surveys and inspections of almshouses and prisons in other states, and she lobbied other legislatures to enact similar reform legislation. She played an instrumental role in the creation of 32 mental hospitals and became nationally known for her reform efforts.

Although Dorothea Dix was progressive in her views about psychiatric disability and specialized treatment for people with mental illness, she did not embrace reform in many other areas. As a woman, she did not feel that it was appropriate to engage in public speaking herself. So instead of addressing legislative bodies and other groups, she wrote speeches that were read on her behalf by prominent men who supported her efforts to create mental health care facilities. In addition, unlike many reformers and activists of the 1800s, she was not an abolitionist, and she maintained close ties with prominent slaveholder families. Some historians have argued that she was more effective in her advocacy of humane treatment for the mentally ill because she followed the strict social conventions of the time. She presented herself as a reluctant activist moved to action by the plight of people with mental illness. However, her conservative views in many areas have made her less appealing as a role model for subsequent generations that have rejected many of her beliefs.

Dix was born on April 4, 1802, in Hampden, Maine, a small village on the Massachusetts frontier. During her youth, there was significant tension within her family, particularly between her parents and grandparents. Dorothea's father lacked much of the ambition and drive that had characterized her grandfather's success. In addition, her father married a woman that his parents felt was beneath him. At age 12, Dix ran away from her parents and went to live with her grandmother in Boston. At 14, she moved in with the family of a prominent physician and became semi-independent from her family. While living with this family, Dix opened a private school. She continued to teach for the next 20 years, in various locations, at her grandmother's home and at the Female Monitorial School, and she also provided private tutoring. In addition, she published a number of books for children, including her most famous *Conversations on Common Things.*

Dix's focus on social reform was in part influenced by her strong commitment to the Unitarian faith. In the early 1820s, Dix began attending sermons every Sunday and Thursday, and focused her life increasingly around church lectures, sermons, and humanitarian projects. Dix seemed particularly influenced by the church's emphasis on the poor and unfortunate and its efforts to create a more socially just community. Dix regularly attended a Unitarian church led by William Ellery Channing, and over time developed a personal relationship with the pastor. Dix began tutoring his children and eventually began to accompany the family on summer trips and on a lengthy journey to the Caribbean.

During the late 1820s and the early 1830s, Dix developed significant health problems, including a chronic respiratory condition. In the winter of 1836, she experienced an episode of severe depression. Seeking rest and a change of scenery, she sailed for England in the spring. However, upon her arrival, her symptoms worsened and she became bedridden and despondent. Dix was taken in by a Unitarian philanthropist, William Rathbone II, and his wife, who were acquainted with William Ellery Channing. During her stay with the Rathbones, Dix continued to experience severe symptoms of depression, in addition to an episode of pneumonia. She consulted with William Rathbone and Oxford physicians regarding her symptoms. Dix was often confined to her room by chronic fatigue; however, she enjoyed frequent visits from the Rathbone family. Dix convalesced in England for a year and a half and, as she became stronger, she socialized increasingly with the numerous guests that visited the Rathbones. Through these interactions, Dix was probably exposed to the "reform movement of moral treatment" that was becoming increasingly popular in Europe. Upon receiving news of her grandmother's death, she returned to New England in the summer of 1837.

Dix's philosophy regarding treatment reform for individuals with mental illness was strongly influenced by the moral treatment movement. Originating at the York Retreat in England, this treatment focused on encouraging patients to use self-control instead of using physical and mechanical restraints. The York Retreat was a private hospital in which seven staff cared for 30 patients. Patients were expected to take part in daily activities, such as reading, writing, sewing, socializing, and gardening. Work also was considered an essential part of developing self-control. Exercise, warm baths, and a generous diet were believed to be important to calm and reassure patients. Privileges were granted to individuals who behaved in a desirable manner. This new philosophy emphasized that patients could be rehabilitated and cured, particularly if early treatment was provided.

During the nineteenth century, public hospitals provided treatment only for low-income individuals and those who had exhausted their financial resources. Hospitals were viewed as the option of last resort and were associated with moral degeneracy and poverty. In addition, hospitals exposed patients to contagious, infectious diseases such as sepsis. In general, families cared for members with physical and/or mental illnesses at home. The asylum movement sought to change the role of hospitals in American society. The movement focused on creating institutions that would provide specialized care in pleasant, homelike environments. The asylum movement subscribed to the belief that the increasing complexity, dislocation, and urbanization of American life had detrimental effects on people's physical and mental health. Asylums provided safe havens where people could recover from these effects.

Moral treatment in the asylums used a system of incentives and punishments to treat mental illness. Asylum staff developed an individualized regimen of various activities for each patient that included grooming, exercising, meeting with the physician, dining, recreation, educational activities, and some work activities. The regimen was changed as an individual's symptoms improved or declined. Individuals were discharged from the asylum when they no longer experienced symptoms of mental illness, exercised sufficient control over undesirable impulses, and demonstrated a determination to lead a productive life. Asylum superintendents would often send inquiries in the years following discharge to former patients to see how they were doing. Generally, hospital stays lasted a number of months while, for a smaller number of people, hospitalizations occurred for a period of years.

When Dorothea Dix returned to Boston, she met Samuel Gridley Howe, who encouraged her interest in humanitarian work at a local prison. Together, they worked on strategies to bring more public attention to the situation of people with severe mental illness. Dix began visiting jails and almshouses in Massachusetts, documenting what she found throughout the state. During her visits, she conducted a census of each institution's inmates with mental illness, documented their general condition, and intervened in particularly dire situations to alleviate suffering. She noted the availability of religious instruction and literature. Howe, who had recently been elected to the state legislature, encouraged Dix to summarize her findings in a petition to the legislature. Dix completed her petition, *Memorial to the Legislature of Massachusetts,* including the names and dates of the various places she had visited, for the opening session of the legislature, where it was presented on January 19, 1843.

In her *Memorial to the Legislature of Massachusetts,* Dix detailed graphic portraits of men and women living in filth; she described people living in "cages, closets, stalls, and pens!" who had been beaten and whipped. She gave case examples of individuals kept isolated in dark cellars, naked, and covered in human excrement. Many confined individuals had no clothing, heat, or furniture. Through the *Memorial,* Dix recommended legislative action to create asylums for those with severe mental illness. She advocated separating them from criminals, asserting that those with mental illness needed care, not punishment, and that by confining them in prisons, their conditions only worsened.

A pamphlet of the *Memorial* also was circulated throughout the state, causing considerable controversy, as some of the institutions included in her petition disputed her findings. However, a few prominent politicians and attorneys spoke out in her defense. As a result, Dix became increasingly influential and met with many legislators in an effort to lobby her cause. In the spring of 1843, the Massachusetts legislature allocated funds to greatly expand the State Mental Hospital at Worcester. Dix conducted similar investigations and engaged in lobbying efforts in other states, including New York, New Jersey, Pennsylvania, Kentucky, Illinois, Tennessee, Louisiana, Mississippi, North Carolina, Alabama, and Maryland. Her advice and assistance often was sought by state politicians because she was viewed as an objective outsider who could assess the plight of people with mental illness and provide guidance regarding legislation to address these concerns.

By the late 1840s, Dix focused on developing a national plan to address the treatment of people with mental illness. She created a federal memorial in which she described the plight of those with mental illness in various towns and villages throughout America. She argued that mental illness was increasing, and that other countries were experiencing similar problems. She focused on the potential for treatment to cure some individuals, and its ability to make those individuals whose conditions were thought to be "incurable" comfortable and socially useful. Her petition led to a bill proposing a federal land grant for 12,225,000 acres to be set aside as a public endowment. The income from this land was to be used to provide services for people with mental illness, as well as those who were blind, deaf, and mute. From 1848 to 1854, Dix continued to lobby for her plan, and the legislation was successfully passed by both the U.S. House and Senate. President Franklin Pierce, however, vetoed the bill and ended Dix's pursuit of securing funding for current and future state programs to address the needs of the people with mental illness. In a written defense of his action, Pierce stated that he did not want to establish a precedent in which the federal government was responsible for funding state programs.

Discouraged by the failure of her effort to provide a national endowment for treatment of mental illness, Dix returned to Europe. She traveled extensively to many countries, including England, Scotland, France, Austria, Italy, Greece, Turkey, Russia, Sweden, Denmark, Holland, Belgium, and Germany. During her two years there, Dix visited prisons and almshouses, again documenting her findings and advocating for reform.

When Dix returned to the United States, she continued to lobby and advocate on behalf of her cause. Within a few years of her return, the Civil War began. She was appointed superintendent of United States Army Nurses by President Abraham Lincoln. In this position, however, Dix was often in conflict with the Army Medical Bureau. She had difficulty adjusting to the bureaucracy and organizational structure of the military establishment. Since her previous work had been conducted more autonomously, she faced constant challenges to her authority. With Dix's reserved and distant manner, in addition to her unorthodox ways, many critics emerged, leading to a decline in her public image.

After the war, Dix again returned to advocacy work for people with psychiatric disabilities. However, she was disappointed to see that mental hospitals had become overcrowded, understaffed, and run down. Most of the facilities lacked adequate funding to provide the type of treatment originally envisioned by those advocating moral treatment. Many rural communities where asylums were located objected to funding treatment for predominately urban populations. In addition, the economic depression of 1857 and postwar depressions further depleted hospital funds. Asylum facilities were also strained by the huge influx of immigrants, who had few financial resources. These facilities became merely custodians of people with mental illness, not the therapeutic, tranquil environments for which she had fought.

Dorothea Dix died in 1887, at the age of 79. She is buried in Mount Auburn Cemetery in Cambridge, Massachusetts.

—Marie Hamilton, Judith A. Cook, and Jessica A. Jonikas

See also Activism; Depression; Institutionalization and Segregation; Mental Health; Psychiatry.

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DO NOT RESUSCITATE (DNR) ORDERS

Do not resuscitate (DNR) orders are advance medical directives that request that doctors do not attempt cardiopulmonary resuscitation (CPR) if a person's heart stops or the person stops breathing. A DNR order is then placed on the individual's medical chart, and sometimes a colored bracelet is also put on the person's wrist stating, "Do Not Resuscitate." In these cases, when the person's heart stops or the person stops breathing, doctors then abide by this directive, and the individual is likely to die in the hospital.

A DNR order may be applied before, during, or after a cardiac or respiratory arrest. Individuals may write their own advance directive, indicating a desire to have a DNR order placed on them, if they are considered rational and able to communicate their wishes in a clear manner.

A DNR order does not mean that no medical assistance will be given to the individual. For instance, emergency care and other health care providers may continue to administer oxygen, control bleeding, splint or immobilize, position for comfort, provide pain medication, and provide emotional support. However, they will not administer chest compressions, inset an artificial airway, defibrillate or cardiovert, or initiate cardiac monitoring.

DNR orders can be particularly controversial when the individual is incapable of expressing his or her own wishes, for instance, if the person is in a coma. In these circumstances, when the individual is unable to give informed consent, the authority to make such decisions passes to a surrogate decision maker, such as a legal guardian, spouse, or parent. Often there are conflicts between surrogate decision makers and other family members or friends who disagree about the treatment the individual would have wanted.

Doctors often discuss the need for DNR orders when a person has malignant cancer or a severe infection such as pneumonia, or if the person's kidneys do not work well. People who ask for a DNR order in these circumstances often express a desire to let nature take its course.

Although some doctors may raise the issue of DNR orders with people who are likely to become disabled, their use in these circumstances is far more controversial. It cannot automatically be assumed that because someone is disabled, or is likely to become disabled, that quality of life will automatically decrease, and it certainly cannot be assumed that disability is an automatic justification for a DNR order. Disability rights activists often campaign on this issue—they argue that it is wrong to suppose a person will have a lower quality of life simply because he or she is disabled—and condemn doctors who promote DNR orders as a reasonable medical response to disability.

Another issue that is of concern to disability activists is whether the person who is subject to the DNR order actually consents to this order. In some cases, it has been argued that an individual with a DNR order did not consent to such an order and did not even know that such treatment decisions had been made.

—Mark Sherry

See also Bioethics; Death; End-of-Life Care.

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DOCUMENTARY FILM

Since the beginnings of film, disabled people have been central subjects of the documentary genre. The evolution and subgenres of disability documentaries provide insight into shifting social attitudes toward people with impairments. In addition, different constituencies have used the documentary's association with empirical "objectivity" as a means to serve a variety of social and political ends. Disability documentary can be divided into the following subgenres: medical, eugenic, inspirational, and activist. Individual films tend to fall into one primary subgenre while exhibiting characteristics of others.

The medical subgenre can be traced to the earliest film technologies. Medical practitioners used film in the early twentieth century as a tool to document the symptoms of individuals with impairments for multiple purposes: archival, research, diagnostic, and educational. For instance, in addition to making multiframed images of normative walking, standing, and crouching movements, the pioneering photographer Eadweard Muybridge made chronophotographs of "abnormal" gait patterns in the United States during the 1870s. Audiences for these early films primarily consisted of the medical community and researchers, rather than the general public. Currently, this subgenre thrives in the form of films created as professional development material for medical and social service providers. These films provide information on matters ranging from the latest therapeutic techniques to understanding the daily obstacles faced by disabled people to updates on disability legislation. This subgenre also includes documentaries intended for general audiences. For example, popular, current-day versions of the medical subgenre have proliferated on television, showing the miracles of modern medicine to cure, or at least markedly improve, the lives of the ill and disabled. These documentaries contribute to the popular understanding of the medical model of disability, which casts disabled people as individual, pathological patients in need of medical care or cure.

The eugenic subgenre emerged in the late 1920s through the 1940s. Eugenicist documentary filmmakers created propaganda aimed at both the medical community and the general public to justify the treatment of people with a variety of impairments, including institutionalization and other forms of segregation, sterilization, and in the most extreme cases, euthanasia including medical murder. A notorious American example of such films is *Are You Fit to Marry?* (1928), which warned against allowing disabled children to grow, marry, and give birth to ever-more impaired progeny. The film functioned as a health propaganda film that drew direct equations between individual citizen's bodies and the health of the nation. In doing so, *Are You Fit to Marry?* popularized eugenics ideology and made it the responsibility of individuals and family to strictly police their reproductive fitness. Nazi propaganda films produced between 1935 and 1937 (with titles such as *Straying from the Path, Hereditarily Ill,* and *Sins of the Fathers*) promoted the sterilization of people with mental impairments or psychiatric labels. Furthermore, British films released after World War I such as *War Neuroses: Netley, 1917, Seale Military Hospital, 1918,* as well as U.S. propaganda films during World War II demonstrated modern applications of psychiatric therapeutic techniques deployed to integrate traumatized veterans back into society.

The eugenic subgenre in its most blatant form has mostly died out; however, elements can still be found on television documentaries exploring the ethical complexity of end-of-life issues, such as the Public Broadcasting Services' series titled *Before I Die: Medical Care and Personal Choices* (1997). In addition, a number of films recording decisions about medical surgery decisions surrounding conjoined twins have been released.

The inspirational subgenre documents the trials and tribulations of life as a disabled person, focusing on either the ability of the individual to overcome impairments or the tragic inability to do so. Such films are often created by nondisabled filmmakers and geared to a nondisabled general audience. These films focus on disabled people of notable or extraordinary accomplishments. These accomplishments are often attributed to individual courage and acts of great willpower. Such films include Jessica Yu's *Breathing Lessons: The Life and Work of Mark O'Brian* (1994). O'Brian, a poet and journalist, was an American polio survivor who lived 40 years in an iron lung. Susan Hannah Hadary and William A. Whiteford's *King Gimp* (1999), which documents 13 years in the life of Dan Keplinger, a young American painter with cerebral palsy, can also be included in this subgenre. While such films explore many facets of their subjects' lives—including their work, friendships, family lives, and romantic aspirations—they ultimately tend to cast such issues sentimentally, rather than politically. These works evoke easy emotions of sympathy, pity, tragedy, or triumph by unveiling how their protagonists strive to achieve beyond their presumed incapacities to produce art. In doing so, they portray disability as an individual phenomenon that is divorced from the wider struggles of disability civil rights agendas and often neglect the degree to which class status provides an enabling context for their accomplishments.

Often in direct contrast to the inspirational subgenre, the activist subgenre includes documentaries that explore the social and political dimensions of disabled people's lives and advocate, explicitly or implicitly, for systemic liberatory change. Early activist films, such as the controversial American film *Titicut Follies* (1967) by Frederick Wiseman, documented the abusive treatment of people with disabilities in criminal psychiatric institutions. More recent films continue this theme by exposing past and current atrocities against people with disabilities such as Mat Fraser's *Born Freak* (2002), Snyder and Mitchell's *A World without Bodies* (2002) and *Disability Takes on the Arts* (2004). Furthermore, activist films tend to situate their disabled subjects in community with one another rather than as products of independent genius. The Israeli film *Liebe Perla* (2000) exposes Nazi medical experiments on a short-statured Hungarian family. This history is unvieled as Perla, the only living survivor of this family, is assisted by Hannelore Witkofski (who was born in post-World War II Germany and is also short statured) in finding evidence about her family from Josef Mengele's gruesome "studies." Another example is the French film *Forbidden Maternity* (2002) by Diane Maroger. Maroger documents the transition to independent living of a couple with cerebral palsy, Nathalie and Bertrand. The film explores the couple's efforts to deal with the effects of childhood institutionalization, the lack of liberty available to those under disability guardianship laws, and Nathalie's forced sterilization approved by her mother. In all of these efforts, independent disability documentary filmmakers seek to expose a debilitating history as the source of their collective impediments.

The 1990s to the present day have witnessed an upsurge of activist films by and about people with disabilities. The focus on disability oppression as a human rights issue coincides with the passage of civil rights legislation such as the U.S. Americans with Disabilities Act (1990). These films also participate in the creation and dissemination of disability culture and disability arts. For example, David E. Simpson and Billy Golfus's film, *When Billy Broke His Head . . . And Other Tales of Wonder* (1994), documents Golfus's recovery from a traumatic brain injury. Endless medical and social service bureaucracies seemingly designed to keep people with disabilities a permanent underclass as well as debasing attitudes shared among nondisabled friends and family thwart Golfus's reentry into society. Golfus learns to navigate these obstacles through the discovery of the disability civil rights and culture movements in interviews and friendships with disabled leaders. Other examples include Mitchell and Snyder's documentary, *Vital Signs: Crip Culture Talks Back* (1995), which features leading scholars, artists, and activists with disabilities presenting myriad viewpoints on disability culture, civil rights, and the politics of representation. Whereas the inspirational subgenre often captures one exceptional individual's struggles for acceptance, new disability documentary cinema steers away from more singular tales of disability prowess in order to foreground the shared and sometimes contentious perspectives among those who comprise contemporary disability communities.

Increasingly, there has been a renaissance of disability documentary filmmaking from locations across the globe. Just in the past few years, an explosion of new works in this genre have been released. What characterizes these films as revolutionary is the degree to which they move from introductory lessons in the humanity of disabled people for predominantly nondisabled audiences to nuanced explorations into the intimacies of interdependent lives. Many of these works explore close relationships between disabled people and others, such as Martin Taylor's *Berocca* (UK, 2004), which details the experiences of a father with cerebral palsy with his son in northern England; South African filmmaker Shelley Barry's recent work such as *Whole–A Trinity of Being* (United States, 2004), which features an ode to a woman's tracheostomy site; the Korean documentary film *Turtle Sisters*, which details the efforts of a small group of disabled women trying to set up a viable living situation for themselves; and *The Silent Wedding* (Russia, 2004), which portrays deaf laborers in St. Petersburg making a bell that they will never hear ring. This brief catalog of works suggests the increasingly global scope of disabled people's rights movements seeking to use film as a medium for effecting social change.

—Carrie Sandahl and David T. Mitchell

See also Anthropology; Film; Humanities.

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DOPING IN PARALYMPIC SPORT

Doping is defined as the use of certain prohibited substances and methods intended to enhance and/or having the effect of enhancing athletic performance (as described in the World Anti-Doping Code Prohibited List). Use is considered to have occurred when there is evidence of the application, ingestion, injection, or consumption by any means whatsoever of any prohibited substance or method.

In Paralympic sport, the International Paralympic Committee (IPC) established the IPC Anti-Doping Code, in compliance with the general principles of the World Anti-Doping Code (WADC), to prevent—in the spirit of fair play—doping in sport for athletes with a disability. The code applies to the Paralympic Games and all competitions sanctioned by the IPC and to all sports practiced within the context of the Paralympic movement, including during preparation for competition. All participants (athletes and athlete support personnel) accept these rules as a condition of participation and are presumed to have agreed to comply with the code.

Doping control has been conducted at all Paralympic Games since 1988 and most World Championships organized by the IPC. Since 2004, and the introduction of the WADC, all IPC-sanctioned competitions are required to conduct doping control. In addition, the IPC conducts out-of-competition testing in cooperation with the World Anti-Doping Agency (WADA). In the event of an anti-doping rule violation, sanctions are applied, which include disqualification from competition, forfeiture of all medals, points, and prizes, and ineligibility from competition for a set period depending on the type of anti-doping rule violation and number of violations committed by an athlete.

The WADC Prohibited List is published and revised by the WADA. In recognition that there may be instances where athletes seek to use substances on the Prohibited List for therapeutic purposes, exemptions may be sought from the IPC Therapeutic Use Exemption Committee. Exemption is granted on the basis that an athlete would experience a significant impairment to health if the prohibited substance or method were withdrawn from the course of treatment and the athlete would gain no additional enhancement of performance other than that which might be anticipated by a return to a state of usual health following the treatment of a legitimate medical condition.

Doping control is conducted for two reasons, first, to protect athletes from the potentially harmful effects that some drugs may produce, and second, to ensure fair and ethical competition by preventing athletes from taking drugs in an attempt to increase performance.

—Andy Parkinson

See also Paralympics.

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DORRIS, MICHAEL AND REYNOLD ABEL ("ADAM")

(Michael, 1943–1997; Abel, 1968–1991)

American writer (Michael) and Native American fetal alcohol syndrome victim (Abel)

Michael Dorris was a young unmarried academic when he adopted three-year-old Abel, a Lakota Sioux child with apparent developmental delays. Abel Dorris was eventually diagnosed with the condition now called fetal alcohol syndrome (FAS). Michael Dorris's book about Abel's childhood and diagnosis, *The Broken Cord,* was an award-winning critical success, though its ethical and rhetorical dimensions remain troublesome to many. Abel Dorris died in New Hampshire in 1991, after being struck by a car. Michael Dorris also died in New Hampshire, nearly six years later, in the last of several suicide attempts. Michael Dorris's own struggles with depression, substance abuse, and abusive behavior were widely noted after his death. Michael Dorris's passionate activism toward prevention of FAS, especially among Native Americans, and posthumous revelations about his own mental illness, are perhaps as much a part of his legacy as his several novels and the Native American Studies Program he founded at Dartmouth College.

—Penny L. Richards

See also Fetal Alcohol Syndrome.

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DOWN SYNDROME

Down syndrome is the common name for a genetic anomaly, trisomy-21–nondisjunction of the 21st chromosome during meiosis, resulting in a zygote carrying an extra 21st chromosome. Down syndrome occurs in one out of every 600 to 800 live births, making it by far the most common form of chromosomal nondisjunction in the living human population.

Humans with Down syndrome have existed for at least as long as *Homo sapiens* and its immediate ancestors, but trisomy-21 was not identified until 1866, when British physician John Langdon Down associated it with phenotypical facial features such as epicanthal folds in the eyelids and flattened noses. Since these features can also be found in certain Asiatic populations, Down syndrome was for many decades referred to as "mongolism," and Langdon Down's discovery played a minor part in nineteenth-century debates over the question of evolutionary "polygenesis"—that is, the question of whether humans evolved from different ancestors corresponding to the different human "racial" subgroups (Down himself understood trisomy-21 to be evidence of human monogenesis). The genetic principles behind Down syndrome were not understood for nearly another century; until 1959, when French physician Jerome Lejeune identified the nondisjunction responsible for the syndrome, conventional wisdom held that Down syndrome was caused at some point in fetal development, and some researchers speculated that fetuses with "mongolism" were "throwbacks" to earlier stages of human evolutionary development.

Down syndrome is associated with mental retardation as well as a wide range of systemic health problems, ranging from congenital heart defects to childhood leukemia to a vastly increased risk of Alzheimer's disease in later life. In 1900, the life expectancy for people with Down syndrome was under 10 years, largely because of their increased susceptibility to infection; the discovery of antibiotics helped push the life expectancy beyond 20, and with the advent of open-heart surgery, saving innumerable children who would have died in infancy, the average life expectancy for people with Down syndrome increased to 55. The average quality of life for people with Down syndrome, at least in industrialized nations, has increased more dramatically still. Long considered ineducable "idiots" (when that term was considered to be a diagnosis rather than an insult) incapable of acquiring basic skills regarding speech and reading and therefore best consigned to mental institutions, people with Down syndrome have lately demonstrated significant capacities for learning and expression. It is no longer uncommon to find adolescents and young adults with Down syndrome graduating from high school, or older persons with Down syndrome working and living independently or in assisted-living environments involving other persons with developmental disabilities. At the same time, however, advances in prenatal fetal screening, combined with a widespread sense in the medical profession that "prevention" is superior to palliative care, have led many people to see Down syndrome as a human anomaly that is potentially eradicable, and whose eradication would be an unqualified benefit to the species as a whole. Accordingly, advocates for people with Down syndrome—and many people with Down syndrome themselves—have tended to applaud the social advances that have incorporated people with Down syndrome into the fabric of public life while remaining suspicious of new forms of eugenics that threaten to render those social advances moot.

—Michael Bérubé

See also Aging; Aging, International; Alzheimer's Disease; Community Living and Group Homes; Mental Retardation, History of.

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A comprehensive guide to publications relevant to professionals, researchers, parents, and all persons with an interest in Down syndrome and/or people with Down syndrome, http://www.altonweb.com/cs/downsyndrome/index.htm

▣ DRAMA AND PERFORMANCE

The discussion of disability in drama and performance can include widely varying, even diametrically opposed, types of representation: the literal representation of disability used toward metaphorical ends in canonical drama; plays, solo performances, and community-based theater projects created by disabled artists with disability themes at their core; and performance modalities created with a disability aesthetic in mind.

Drama and performance are vital and powerful parts of disability culture for several reasons. Disabled bodies have been on display in performance at several points throughout history. As sideshow freaks, mendicants, poster children, and medical subjects, disabled people's bodies have been deployed within highly specific kinds of spectacle and put on display in ways heavily circumscribed by the expectations of nondisabled audience members. The pervasive presence of disabled people in traditional dramatic literature is somewhat more complicated; while there are many examples of disabled characters that reinforce stereotypes, there are still other representations that simultaneously represent and resist traditional ways of understanding disability. The work of contemporary playwrights and performers from within disability culture, therefore, has been a powerful way in which the disability community has reclaimed and redefined disability identity in performance. At once influenced by and carrying forward the confrontational spirit of disability activism, these artists have placed the disability experience at the center of their work, claiming the public space of the stage as location to which they have a right of access, and within which they can confront the voyeuristic stare. The disabled performer can no longer be hidden or looked away from; because the stage allows this direct challenge to the traditional relationship between the disabled person and the nondisabled spectator, it is a particularly powerful place for disabled artists to give visibility and voice to the disability experience. Within the space of the theater, the disabled artist can perform the reality of disability, model new ways to imagine the place of disability within contemporary society, and posit disability as a catalyst for artistic creation. This last aspect, reflective of much recent thought, opens the way for disability to be the conduit toward a more general invigoration of theater and performance.

The disabled body has been as consistently on display in Western theater as it has in other literary and artistic genres. For example, Sophocles' play *Oedipus Rex,* William Shakespeare's *Richard III,* Tennessee Williams's *The Glass Menagerie,* and Margaret Edson's *Wit,* although spanning diverse eras and countries, all depend heavily on the presence of disabled bodies to motivate the action and to serve as metaphors. These examples likewise bookend a long dramatic tradition of using both moral and medical models of disability. According to the former model, the disabled body bears moral meaning: It can stand for extremes of evil or innocence, mark a tragic fate or punishment, underscore the mystical or all-knowing sensibilities of a character, embody the outcome of violence or neglect, inspire nondisabled characters to some personal transformation, or symbolize some internal foible or personal failing of a character. The latter model posits disability as a condition that is either cured or heroically overcome at best, and as tragic fate at worst.

The kinds of disability represented throughout theatrical history include a full range of cognitive and physical disabilities, and their depictions are historically contingent. It is important to remember this contingency in fully evaluating the representation of disability in canonical theater; some plays, while bound to the audience expectations of their times, have also been able to challenge simultaneously the moral and medical models of disability. For example, George Henry Boker's *Francesca da Rimini,* while in many ways a typical mid-nineteenth-century American melodrama, critiques the prejudice and pity directed at the humpbacked protagonist, even though he is finally the drama's villain. Plays have shown the intersection between disability and other identity categories; Tony Kushner's *Angels in America,* for example, shows how homophobia and the stigmatization of AIDS patients in 1980s America were intimately interwoven. Indeed, there have been periodic plays within traditional theater that have directly challenged stereotypical ideas about disability and identity, such as Mark Medoff's *Children of a Lesser God.* This does not mean that disability always intersects successfully with theater that purports to challenge social constructions. For example, although disability is a social construction like race and gender, some plays of political protest created by multicultural and feminist playwrights have distanced themselves from the stigma popularly associated with disability, instead using disability metaphorically to illustrate the destructive quality of social oppression. Yet in so doing, such plays reinscribe that oppression as it is enacted against disabled people.

Today, there is a vital and wide-ranging body of drama and performance coming from within disability culture, a tradition that traces its roots to the contemporary disability rights movement. As disability and theater scholar Victoria Ann Lewis (2000) points out, it is a wave of creativity that originated in "the rag-tag comedy troupes, the stand-up (or more accurately, sit-down) comics, the agit-prop collectives, and rowdy performance artists that were the inevitable camp-followers of the political activists and legislators who changed the social reality of disabled Americans" (p. 93). Disability in performance is no more a monolith than disability as an identity category; therefore, to consider disability in contemporary drama and performance is to consider the work of playwrights, community-based theater groups, monologists, performance artists, and dancers with a full range of visible and invisible disabilities. In using the disabled body as a subject of and catalyst for creative expression, these artists have aimed for goals such as creating solidarity through affirming the presence of disability culture, articulating emotions from sharp wit to righteous anger, relating specific experiences with disability, recounting disability history, promoting advocacy and activism, revealing the intersections of disability and other kinds of identity, and interrogating traditional ideas about normalcy and looking.

Among the earliest groups formally to place the disability experience at the heart of their creative endeavors were the National Theatre of the Deaf, established in 1967; the National Theatre Workshop for the Handicapped, begun in 1977 under the direction of Brother Rick Curry; and the Other Voices Project, founded at the Mark Taper Forum in 1982 under Lewis's direction. While representative of diverse performance goals and creative styles, these groups have been joined by others working along similar lines. For example, Wry Crips Disabled Women's Theater (Oakland, California), Actual Lives (Austin, Texas), and the DisAbility Project (St. Louis, Missouri) have created dialogues about disability within their own communities. Many individual playwrights from within disability culture have likewise written plays which address diverse subjects; among the best known of these is John Belluso, whose work includes *Gretty Good Time* and *The Body of Bourne.* Mike Ervin and Susan Nussbaum are likewise playwrights of note who have written about physical disability, while Willy Conley has created plays about Deaf culture. Perhaps the most prolific and multivaried work within disability culture has come from solo performers. Monologists such as David Roche and Mary Duffy have challenged the idea of the stare, and criticized the imposition of a disability identity on themselves that is pathologized or writ tragic. Still other performers have explored the intersection of disability with race; Lynn Manning's *Weights,* for example, recounts his life as a blind African American man. And artists such as Cheryl Marie Wade have lyrically portrayed disability pride in bodily difference. Building on that last element, dance artists such as Catherine Cole and dance companies including AXIS have used the movement of the disabled body as a means of expression that invites audiences to see disabilities, in the words of disability and theater scholar Carrie Sandahl, as "states of being that are in themselves *generative* and, once de-stigmatized, allow us to envision an enormous range of human variety—in terms of bodily, spatial, and social configurations" (p. 22).

That final point marks cutting-edge thinking in disability drama and performance, as artists and scholars currently explore the idea of a disability aesthetic that would lead to a more broad re-envisioning of theater; after all, as Sandahl observes, "just as the disabled body challenges widely held beliefs about what constitutes the human form, disability theatre poses similar challenges to the form that theatre itself takes." Deaf/West Theater, for example, mounted its production of the musical *Big River* on Broadway in 2003, in which it integrated American Sign Language completely into the visual landscape of the performance itself. In playing with different configurations of signers and speakers, and of Deaf and hearing actors, the production not only disrupted the hierarchical relationship between speaking and signing extant in society, but it created a kind of choreography for the musical in which actors' bodies—whether Deaf or not—expressed in new ways. This and other uses of a "disability aesthetic" in contemporary direction, playwriting, and performance of all kinds posit the possibility that through a disability perspective, a more general broadening of our culture's understanding of representation and performance might be accomplished. In this way, performance—and ideally, the society that it reflects—would be thus reinvigorated by disabled people claiming their rightful place on the stage.

—Ann M. Fox

See also Aesthetics; Dance; Disability Culture; Representations of Disability, History of.

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DRUG ABUSE

See Substance Abuse

DU PRÉ, JACQUELINE (1945–1987)

English musician

Jacqueline du Pré was born in Oxford, United Kingdom, on January 26, 1945, and died October 19, 1987, at age 42 She was diagnosed with multiple sclerosis (MS) in 1973.

Du Pré has been called the world's greatest cello player. At the height of her popularity, she worked with Sir John Barbirolli and the London Symphony Orchestra, Itzhak Perlman, Zubin Mehta, Pinchas Zuckerman, and Daniel Barenboim. Many music critics consider her interpretation of Elgar's *Cello Concerto in E Minor* to be the finest ever recorded. In 1967, she married Daniel Barenboim and in the glamour world of the 1960s, the couple achieved rock star iconic status. But her MS caused her much anxiety and grief. Her marriage with Barenboim collapsed as her condition deteriorated. In the public image, she was the ultimate beautiful disabled heroine touched by tragedy.

The film *Hilary & Jackie* is based on the book *A Genius in the Family* by du Pré's sister Hilary and her brother Piers. In the book, her decline into "madness" is chronicled, but people familiar with MS will instantly recognize the exhaustion, ambivalence toward work and career, depression, strange and numbing bodily sensations, lack of coordination, and incontinence. Thus, her life did have many tragic elements—the degeneration of her body confronted her continually with the loss of the powerful person she saw herself as being. Her life became a series of struggles in trying to retain her power, and as each element was eroded, she sought some other way to affirm herself. She was not a victim of MS but a passionate musician battling her impairments. These personal battles are as important for our understanding of disability as those more publicly known because they reveal her individual encounters with the realities of disabling societies—issues that received much less attention during her lifetime.

—Helen Meekosha

See also Multiple Sclerosis.

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DÜRER, ALBRECHT (1471–1528)

German artist

Albrecht Dürer, born on May 21, 1471, was the third of 18 children born to Albrecht Dürer, a goldsmith who had moved to Nuremberg, Germany, from the

Kingdom of Hungary, and Barbara Holfer, the daughter of Albrecht Dürer the Elder's master. Albrecht Dürer the Younger became a highly celebrated artist in Germany and many of the contemporary German humanists were his friends. To demonstrate their respect, the Germans chose Dürer as the first artist to have a public monument erected in his name and the first artist to have his home and tomb restored. Over the centuries he also became internationally known, especially throughout Europe, in the United States, and in Russia.

During his education and training, Albrecht Dürer learned a number of skills that later became highly valuable to him. After attending a Nuremberg school for a few years, at the age of 13 he went into an apprenticeship with his goldsmith father. Later he completed an apprenticeship with Michael Wolgemut where he learned to design landscape backgrounds, panel painting, and the craft of woodcut illustrations.

Throughout his life, Dürer had significant contact to individuals with health problems and with disabilities. First, it is noteworthy that most of his siblings did not survive beyond the first few years of life. Second, his brother Albert suffered from severe arthritis after having worked in a mine for four years to support Albrecht's training and education. In honor of his brother Albert, who had forfeited his own dreams of becoming an artist to support Albrecht, Dürer painted *The Hands,* which later was renamed as *The Praying Hands.* Third, after his father's death, Dürer became the caregiver for his disabled and blind mother.

—Ingrid C. Hofmann

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DWARFISM

Dwarfism is a rare phenomenon that nevertheless seems to have occurred in every recorded human society, as evidenced by images and records from ancient Egypt, Greece, and Rome; Renaissance and Baroque Europe; the nineteenth-century freak show; and contemporary cinema. The role, status, and cultural representation of dwarfs have varied: While many have traditionally been employed as jesters, pages, or entertainers, others have been successful soldiers, diplomats, or even rulers. In the modern world, self-help groups or representative organizations tend to favor terms such as *restricted growth* (United Kingdom) or *little people* (United States) or *short stature* (Australia), rather than the word *dwarf.*

From a medical perspective, there are at least 200 separate forms of skeletal dysplasia, and short stature can also be a consequence of other syndromes. The most common cause of disproportionate short stature is achondroplasia, a dominant genetic condition involving a mutation in the FGFR3 gene that leads to the characteristic short arms and legs and different skull shape. Restricted growth affects approximately 1 in every 20,000 births, with around 60 percent occurring in average-height families. While rare forms of skeletal dysplasia are fatal, and in most others there can be medical complications such as sleep apnea and spinal stenosis, people with skeletal dysplasia do not usually experience intellectual impairment, shortened lifespans, or major health problems.

The growth of support groups and improving social acceptance has meant that most people with restricted growth now lead normal lives and achieve the same social goals as average-height people. For example, members of this community have worked as doctors, lawyers, politicians, businesspeople, academics, and teachers and in many other occupations. While the world is not configured well for people who average just over 4 feet, most environments can be negotiated independently.

Public fascination is perhaps the most debilitating problem for people with restricted growth. While making fun of other minorities is proscribed, laughter at the expense of dwarfs seems to remain socially acceptable. Traditional images of dwarfs—including the paintings of Velasquez and the Brother Grimm stories—are more dignified than the infantilized characters portrayed in Walt Disney's *Snow White and the Seven Dwarfs* and subsequent pantomimes.

Perhaps because of cultural devaluation, extensive limb lengthening (ELL) has been attractive to some families affected by skeletal dysplasia. Orthopedic surgeons can achieve increases of around 6 inches in height, using metal fixators on the legs, and sometimes the arms. The procedure is painful and expensive and immobilizes the patient for months or years during early adolescence. Controversy surrounds the practice, which is denounced by many adults with restricted growth. Human growth hormone (HGH) has also been prescribed to some affected children. While it brings on the growth spurt and changes the growth curve, there is doubt as to whether it contributes to any increase in adult height. Genetic screening is not viable for such a rare condition, and antenatal ultrasound rarely detects skeletal dysplasia in utero until the third trimester of pregnancy, which is too late for selective abortion in many jurisdictions. For these reasons, dwarfism will remain part of the human experience, and the emphasis should be on acceptance and inclusion.

—Tom Shakespeare

See also Folk Belief; History of Disability: Medieval West; Visibility and Invisibility.

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▣ DYBWAD, GUNNAR (1909–2001)

American (German-born) author and civil rights advocate

Gunnar Dybwad was born in Leipzig, Germany, on July 12, 1909, and received his doctor of laws degree in 1934 from the University of Halle in Germany. He also earned a degree from the New York School of Social Work in 1940. His career in special education and human services spanned eight decades. During that time, he was made a fellow in several prestigious professional organizations including the American Association on Mental Retardation, the American Sociological Association, the American Orthopsychiatric Association, and the American Public Health Association. He was also an honorary fellow in the American Academy of Pediatrics.

Dybwad published several books and monographs in the field of mental retardation. In addition, his work has been published in more than 20 journals including the *Journal of Rehabilitation*, *CHILDREN*, *International Rehabilitation Review*, *Policy Studies Review*, *Journal of Rehabilitation in Asia*, and *International Journal of Religious Education*.

He was executive director of the National Association for Retarded Children from 1957 to 1964, served as a consultant to President John F. Kennedy's Presidential Panel on Mental Retardation, and was an expert witness in several landmark court cases in educational rights and institutional abuse, including *Mills v. Board of Education* and *Wyatt v. Stickney*.

He and his wife Rosemary were instrumental in the formation of the International League of Societies for Persons with Mental Handicap, which later became Inclusion International. He was president of Inclusion International from 1978 to 1982.

Dybwad was twice recognized with honorary doctorates: first a doctor of humane letters from Temple University in 1977 and then doctor of public services from the University of Maryland.

Dybwad's academic career included professor of human development at Brandeis University from 1967 to 1974, visiting professor at Syracuse University, and visiting scholar at the Canadian Institute on Mental Retardation.

Dybwad was at the center of the development of thoughts that are now taken for granted: normalization, deinstitutionalization, inclusive schooling, self-advocacy, and self-determination. Considered by many to be the grandfather of the self-advocacy movement, Dybwad worked in support of self-advocacy literally until his death September 13, 2001, at age 92.

—Hank Bersani Jr.

See also Advocacy; Rosemary F. Dybwad.

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DYBWAD, ROSEMARY F.

(1910–1992)

American author and civil rights advocate

Rosemary F. Dybwad was born on May 12, 1910, in the town of Howe, Indiana. The daughter of a missionary, she spent her teen years in Manila, Philippines. She spent her college years in Oxford, Ohio, at Western College for Women where friendships with international students led her to apply for a fellowship with the Institute of International Education.

She was a graduate student in sociology at the University of Leipzig from 1931 to 1933. During those years, she met Gunnar Dybwad and in 1934 they were wed and returned to the United States briefly. In 1935, she entered the University of Hamburg, receiving her doctorate in 1936. In 1939, she gave birth to their son, Peter, and 1941 their daughter, Susan. She was as proud of her accomplishments as a mother as she was of her work as a scholar and an advocate.

When her husband became director of the National Association for Retarded Children in 1957, Rosemary volunteered to assist with the voluminous international correspondence as similar parent groups were forming all across the globe. She began an international newsletter and became a driving force in the establishment of the International League of Societies for Persons with Mental Handicap.

In 1964, Rosemary and Gunnar became codirectors on an international mental retardation project in Geneva, which took them as consultants to some 30 countries. Upon returning to the United States, she began publishing an international directory of mental retardation resources. The third and final edition was published in 1989.

In her later years, she was a tireless advocate, supporter of self-advocates, and social change agent, spending time on picket lines, in demonstrations, and writing and speaking in support of self-advocates and in opposition to segregation.

Rosemary F. Dybwad died of cancer in 1992. Her memory lives on in the Rosemary F. Dybwad International Fellowship Trust Inc., which supports international travel for scholars and self-advocates.

—Hank Bersani Jr.

See also Gunnar Dybwad.

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DYSARTHRIA

Dysarthria is primarily a medical term. It is used to describe speech that is difficult to produce and/or difficult to understand as the result of lesions or damage to the nerves that send messages to the muscles involved in speech production. This includes the muscles for articulation or pronunciation (such as lips, tongue, jaw) as well as the muscles controlling nasality, phonation, and respiration. The muscles may be weak, be uncoordinated, move slowly, or not move at all. People with dysarthria may also have difficulty swallowing.

People may be born with dysarthria (such as individuals with cerebral palsy or muscular dystrophy). It may also result from a stroke, brain injury, tumor, infection, or a progressive neuromotor disease, such as Lou Gehrig's disease (amyotrophic lateral sclerosis; ALS), multiple sclerosis, or Parkinson's disease.

Dysarthria can be characterized in many different ways depending on the extent and location of the lesion. It may be localized, affecting only one muscle or muscle group (such as only respiration) or it may be generalized affecting many components, respiration, nasality, and phonation as well as articulation. People with dysarthria may experience limited lip, tongue, and jaw movement, slurred speech, slow speech or rapid mumbled speech, soft or inaudible speech, breathiness, hoarseness, and drooling.

People with dysarthria (primarily adults with cerebral palsy) report that they are often mistaken for "retarded" or deaf. If someone is unable to understand them, they may walk away, talk loudly, or talk to others about them.

Some people with dysarthria choose therapy to learn compensatory strategies for improving swallowing, improving the functionality, intelligibility of their speech or to learn augmentative, alternative methods of communication. To improve the functionality, intelligibility of their speech, someone may learn to talk slower and more deliberately. Also, communication partners may learn listening strategies (e.g., choose a quiet place, let the person know what part of the message you understood and parts you need clarified). Some people choose to use communication aids. If someone has difficulty producing adequate volume for speech, he or she may benefit from a speech amplifier. To clarify speech, people may learn to use letter or word boards to introduce the topic they want to talk about and/or to point to the initial letter of each word they say as they speak. People unable to produce speech may also consider an electronic augmentative communication device with voice output so that they can communicate on the phone and talk to unfamiliar people.

—Patricia A. Politano

See also Augmentative Communication; Cerebellar Ataxia; Dysphagia; Speech and Language Pathology; Stroke.

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DYSLEXIA

Dyslexia is characterized by an unexpected difficulty in reading in children and adults who otherwise possess the intelligence, motivation, and schooling considered necessary for learning to read. Dyslexia is the common and most comprehensively studied of the learning disabilities (LD). The prevalence of dyslexia is now considered to range between 5 to 10 percent of the school-age population.

The cardinal signs of dyslexia observed in school-age children are an inaccurate and labored approach to decoding and reading words either in isolation or in text. For example, when asked to read aloud, most children with dyslexia display a labored approach to decoding ("sounding out") unfamiliar words. This laborious and slow approach to reading words makes it difficult to understand what is read. This is because the more time spent in reading words the less time can be dedicated to remembering what is read. Typically, in contrast to the difficulties experienced in decoding single words, individuals with dyslexia have adequate vocabulary and listening comprehension abilities. Indeed, one sign of dyslexia is that the individual who has difficulty comprehending what is read because of labored reading can understand the same material when it is read aloud by another person. Parents of dyslexics frequently report that although their child enjoys the opportunity to be read to, reading aloud to the parent or reading independently is resisted.

In contrast to conventional wisdom, individuals with dyslexia do not see letters and words "backwards." The letter reversals that are observed in some children below age six or seven reflect normal variations in development. Persistent difficulties reading words and text, with or without letter reversals, are caused primarily by circumscribed language difficulties rather than deficits in visual perception. Rather, dyslexics have difficulties developing an understanding that words, both spoken and written, can be segmented into smaller elements of sound. This ability is termed *phonemic awareness* and is an essential ability given that reading an alphabetic language (i.e., English) requires that the reader map or link printed symbols to sound.

Children at risk for dyslexia can be identified as early as five years of age. Kindergarten assessments that measure awareness of phonemes and other language skills, such as rhyming ability and the rapid naming of letters and numbers, are highly predictive of later reading difficulties. Family history is also important in the diagnosis of dyslexia. Approximately half the children with a parent with dyslexia will also have reading difficulties. However, the specific mechanisms by which genetic factors predispose someone to dyslexia are not clear.

Effective intervention programs for school-age children with dyslexia provide direct, explicit, and systematic instruction in phonemic awareness, phonics, reading fluency, vocabulary, and reading comprehension strategies and ample opportunities for writing and reading. The teacher's knowledge and experience in assessing and treating dyslexia are critical.

The treatment of dyslexia in students in high school, college, and graduate school is typically based on accommodation rather than remediation. College students with a childhood history of dyslexia frequently require extra time in reading and writing assignments as well as examinations. Other accommodations include the use of laptop computers with spelling checkers, tape recorders in the classroom, access to lecture notes, tutorial services, alternatives to multiple-choice tests, and a separate and quiet room for taking tests.

—G. Reid Lyon

See also Educational Assistive Technology; Learning Disability.

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DYSPHAGIA

Dysphagia, or difficulty swallowing, is a common condition with many etiologies, including stroke, neurological disorders, and cancer. Dysphagia may cause malnutrition, weight loss, dehydration, airway obstruction, or aspiration pneumonia, resulting in potentially serious morbidity or mortality. Dysphagia due to oral or pharyngeal dysfunction is often amenable to rehabilitation and is the focus of this discussion.

Swallowing requires activity of 31 muscles and 6 cranial nerves and must be coordinated with breathing, speaking, and mastication. For descriptive purposes, the process of swallowing is commonly divided into four phases: oral preparatory, oral propulsive, pharyngeal, and esophageal. The oral preparatory phase includes mastication and oral food transport. In the oral propulsive phase, the tongue squeezes the food against the palate, pushing it through the faucial pillars into the oropharynx. In the pharyngeal phase, the bolus is transported to the esophagus during a rapid sequence of events that includes tongue base retraction, soft palate elevation, pharyngeal constriction, hyolaryngeal elevation, laryngeal closure, and opening of the upper esophageal sphincter (UES). During the esophageal phase, the bolus is transported downward by a peristaltic wave; the lower esophageal sphincter relaxes, allowing the bolus to enter the stomach.

Clinical evaluation of swallowing requires a comprehensive history and physical examination that includes assessment of cognition, voice, speech, cranial nerves, oral sensory and motor function, respiration, and trial swallows. If esophageal dysphagia is suspected, a routine barium swallow or endoscopy is generally indicated. The videofluorographic swallowing study or VFSS (also known as the modified barium swallow) is the "gold standard" for assessment of oral/pharyngeal dysphagia. This study is typically performed jointly by a physician (usually a radiologist or a physiatrist) and a speech-language pathologist. The purpose of the VFSS is to evaluate the structure and function of the oral cavity and pharynx. If aspiration is noted, compensatory maneuvers to reduce or eliminate aspiration are tested empirically during the VFSS, to determine the circumstances for safe and efficient swallowing. Fiberoptic endoscopic evaluation of swallowing (FEES) is often used to assess swallowing when VFSS is not feasible. Although it is a sensitive method for detecting aspiration, the FEES is less useful than VFSS because it omits assessment of critical aspects of the swallow (e.g., tongue base retraction, opening of the UES).

Rehabilitation of swallowing disorders aims at eliminating aspiration, improving oral intake so it is safe and adequate to maintain hydration and nutrition, and improving sensory and motor function to optimize the strength and speed of the swallow mechanism. Therapeutic exercises may address deficits in flexibility, strength, and coordination of oral, pharyngeal, and laryngeal structures. Compensatory maneuvers such as alterations in head position, respiration, or food consistency may eliminate aspiration and improve swallow efficiency. Designing the rehabilitation program requires understanding the underlying cause of the dysphagia and its unique manifestations in the individual with dysphagia.

—Jeffrey B. Palmer and Judy Haynos

See also Neurological Impairments and Nervous Disorders; Stroke.

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CHRONOLOGY

1500 BCE	Egypt: The Ebers Papyrus, a medical textbook, devotes an entire chapter to eye diseases. It also shows that deafness is well understood and that clinical knowledge has developed.
400 BCE	Graeco-Anatolian Hippocratic writings coin the word e*pilepsy* for a convulsive condition they view as a disease rather than a possession or punishment. Today, it is estimated that more than 80 percent of the 40 million people who currently have epilepsy throughout the world have little access or no access to contemporary treatments.
300 BCE	China: *The Yellow Emperor's Internal Classic* is the first text to outline acupuncture. Ordinances on emergency relief for the disabled date to the Han Dynasty, 206 BCE–AD 220. Fiscal and administrative disability classification date at least to the Tang Dynasty, 618–907.
1250–1350	High point of medieval medicalization during which theoretical explanations for conditions gain currency in Western Europe. Prior to this time, in the most general of terms, lay explanations held more sway, ranging from the superstitious to the spiritual to the vindictive. With the founding of the universities, medical theory, typified by the four humors, became more influential in governmental, legal, and elite social circles. Disabling conditions like epilepsy, strokes, and paralyses, as well as psychiatric conditions, increasingly fell under the social control of doctors.
1400	Turkey: Deaf people work in the Ottoman Court from the 15th to the 20th centuries. Sign language becomes a recognized means of communication among both hearing and deaf courtiers.
1593	England: The origins of disability as a social and political category emerge with the first state disability benefits being enacted by Parliament for those disabled in war.
1593	Europe and the United States: English Parliament initiates Europe's first national system of benefits for rank-and-file disabled veterans. The first veterans' homes—France's Hôtel des Invalides, Britain's Chelsea Hospital, and Frederick the Great's Invalidenhaus in Berlin—are established in 1633, 1685, and 1748, respectively. Following the American Civil War, the U.S. government responds with a system of homes, preferences in government hiring, land grants, free prosthetics, and pensions for disabled veterans (however, southern veterans were limited to usually scanty state pensions).
1601	England: The Poor Law is passed to provide family and community support for those unable to make a living for themselves.
1604	Laws on witchcraft in the colonies all evolve from a 1604 English Statute that makes "being a witch" punishable by death. During outbreaks of witch-hunting, the "different" body itself is targeted as a sign and symptom of one's confederation with demonic forces.
1697	England: The first English workhouse for people with mental and physical disabilities is established in Bristol in 1697.
1704	Bethlem Hospital in the United States has 130 residents housing the "furiously mad."

1714 Canada: The Bishop of Quebec opens the first building in Canada exclusively for the confinement of mentally disturbed individuals. It is adjacent to Quebec General Hospital.

1749 France and England: Denis Diderot pens one of the most influential treatises on the blind and education in his *Letter on the Blind* in which he argues that the blind can be educated. In 1784, Valentin Haüy opens the first school for the blind in Paris. He perfects a system of raised *letters* to enable the blind to read. In 1828, Louis Braille modifies a raised *dot* system invented by Charles Barbier, which is used today by blind persons to read and communicate. In 1847, William Moon, an Englishman, develops an embossed script based on Roman capitals that blind adults can learn to read in a few days. It is the first reading system for the blind to be widely adopted across the world, but because it is costly to print, the Braille system, which can be produced by blind individuals for themselves, overtakes Moon's system.

1755 France, the United States, and Germany: The Abbé Charles-Michel de l'Épée establishes the first state-supported school for the training of young deaf children, where he teaches sign language. The school serves as an inspiration for the establishment of other European schools and has a dramatic impact on social attitudes toward the deaf. In 1817, Thomas Gallaudet and Laurent Clerc establish the Asylum for the Deaf (now American School for the Deaf) in Hartford, Connecticut. Clerc imports the French sign system, which influences the makeup of contemporary American Sign Language (ASL). In 1778, Samuel Heinicke establishes a school in Leipzig, Germany, where the "oral method" is used.

1800 France: Victor of Aveyron, a "feral child" found in southern France, is brought to Paris. Jean Marc Gaspard Itard, a French physician, develops a systematic training program for the boy and works intensively with him for five years. Itard considered his attempt at educating Victor to be a failure because the boy did not learn to use a language. Nevertheless, Itard's disciples, including Edouard Séguin, Maria Montessori, and Alfred Binet, continue his work by establishing classes for children considered to be "mentally retarded."

1802 France: The world's first pediatric hospital, L'Hôpital des Enfants Malades, is founded.

1817 The American School for the Deaf is founded in Hartford, Connecticut. It is the first school for disabled children in the Western Hemisphere.

1817 James Parkinson, a London physician, describes what is to become known as Parkinson's disease.

1817 Thomas Gallaudet and Laurent Clerc open the American Asylum for the Education of the Deaf and Dumb in Hartford, Connecticut.

1828 Frenchman Louis Braille, blind from childhood, modifies a raised-dot system of code, one of the most important advances in blind education. It not only allows the blind to read at a much faster rate but also makes it possible for the blind to be teachers of the blind. UNESCO creates the World Braille Council in 1952.

1829 France: Louis Braille publishes an explanation of his embossed dot code.

1832 Samuel Gridley Howe is chosen to direct what is later to be called the Perkins School for the Blind in Boston. It becomes the model for schools around the nation. Laura Bridgman and Helen Keller attend Perkins. In 1837, Ohio establishes the first state-sponsored school for the blind.

1834 England: The English Poor Law Amendment stipulates five categories of those unable to work: children, the sick, the insane, defectives, and the aged and infirm. This sets the stage for the development of specialty institutions that isolate the disabled from the community.

1841 P. T. Barnum purchases Scudder's American Museum in New York City. This moment is considered to be the beginning of the "Golden Age" of freaks, which persists until the 1940s. The tension between freaks and disability rights comes to a head in 1984, when disability rights activist Barbara Baskin successfully lobbies the New York State Fair to remove Sutton's Incredible Wonders of the World Sideshow, featuring a limbless man who performs as the "Frog Boy," from the midway.

1843 ◆ Due to the influence of Dorothea Dix, an American social reformer, the Massachusetts legislature allocates funds to greatly expand the State Mental Hospital at Worcester. Dix also plays an instrumental role in the creation of 32 mental hospitals and becomes nationally known for her reform efforts. By the late 1840s, Dix focuses on developing a national plan that addresses the treatment of people with mental illness.

1846 ◆ William Thomas Green Morton discovers anesthesia and in 1867 Joseph Lister provides a model for antisepsis. These new technologies play a central role in the future of aesthetic surgery as well as surgical intervention for every type of disability that calls for it. Penicillin is discovered in 1929, cutting mortality rates in hospitals dramatically.

1848 ◆ The North Carolina School for the Deaf begins the first publication for Deaf persons with its school newspaper, *The Deaf Mute.* First published in 1907, the *Matilda Ziegler Magazine for the Blind* is an ongoing Braille publication.

1848 ◆ Samuel Gridley Howe founds the first residential institution for people with mental retardation at the Perkins Institution in Boston.

1851 ◆ In the United States there are 77 residential institutions for children, 1,151 by 1910, and 1,613 by 1933. By the 1950s and 1960s, family members and politicians throughout Western Europe, Canada, and the United States push for the deinstitutionalization of people with disabilities.

1851 ◆ The first International Sanitary Conference is held in Paris, France, with 12 countries participating. It leads to the World Health Organization, the WHO, which formally comes into existence in 1948.

1857 ◆ Edward Miner Gallaudet, youngest son of Thomas Hopkins Gallaudet, establishes the Columbian Institution for the Instruction of the Deaf, Dumb, and Blind, located in Washington D.C. Its college division, eventually known as the National Deaf-Mute College, is the world's first institution of higher education for deaf people. Abraham Lincoln signs its charter on April 8, 1864; today it is known as Gallaudet University.

1857 ◆ English philosopher Herbert Spencer is first to use the expression "survival of the fittest." The application of his idea in combination with Charles Darwin's theories in his 1859 book, *The Origin of the Species,* is called Social Darwinism. It is widely accepted and promoted in Germany in the 1920s and leads Adolf Hitler to express prejudice against the weak, sick, and disabled.

1863 ◆ Louis Agassiz, a significant American naturalist, advocates the permanence of different races and worries about the "tenacious influences of physical disability" if races were mixed.

1864 ◆ Germany: Karl Ferdinand Klein, teacher for deaf-mutes, and Heinrich Ernst Stotzner are considered the founding fathers of the *training school,* which calls for schools to be created for less-capable children with the goal of improving their lot. Training schools remain in effect today, but critics maintain that there is an over-representation of socially and economically underprivileged students in this type of setting experiencing little academic success.

1868 ◆ Sweden: The Stockholm Deaf Club is the first recorded organization of people with disabilities.

1870 ◆ England and Wales: Education for children with disabilities begins when universal elementary education is first introduced around this time. From 1895 onward, schools for "defective" children spring up. In 1899, Alfred Eichholz, an inspector of special education, draws up key recommendations, which leave their mark on the historic 1994 Education Act legislation. In 1978, the Warnock report introduces the term *special needs education,* which soon gains acceptance worldwide. With the 1994 UNESCO Salamanca Statement and Framework for Action on Special Needs Education, a major shift in organizing educational services for children with disabilities is confirmed internationally.

1876 ◆ Isaac Newton Kerlin, Edouard Séguin, and others establish the Association of Medical Officers of American Institutions for the Idiotic and Feeble-Minded Persons. Today, it is known as the American Association on Mental Retardation. Séguin, who staunchly believes in the educability of those with significant cognitive disabilities, is styled as "apostle to the idiots," by Pope Pius X, reflecting the attitude of the time.

1880 ◆ The United States National Association of the Deaf (NAD), the first organization of deaf or disabled people in the Western Hemisphere, is established. In 1964, the Registry of Interpreters for the Deaf (RID) is formed to establish a national body of professionals who are trained and certified to enable communication between deaf, signing persons and nondeaf, speaking persons.

1880 ◆ Helen Keller is born in Tuscumbia, Alabama. An illness at the age of 19 months leaves her totally deaf and blind. In 1887, Anne Sullivan, recently graduated from Perkins Institution for the Blind, joins the Keller household as Helen's teacher and remains Keller's companion for nearly 50 years. For many, Keller's story is the quintessential overcoming narrative.

1881 ◆ The Chicago City Council enacts the first American "ugly law" forbidding "any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view."

1882 ◆ The first major federal immigration law in the United States, the Immigration Act of 1882, prohibits entry to "lunatics," "idiots," and persons likely to become unable to take care of themselves. Most of the restrictions that apply specifically to disability are removed from U.S. law in 1990. Today, disabled immigrants are still denied an entry visa if they are deemed "likely to become a public charge."

1887 ◆ Walter Fernald serves as superintendent of the Massachusetts School for the Feeble-Minded (now known as the Fernald Center) from 1887 to 1924. Unlike most of his colleagues, Fernald moderates some of his earlier extreme views and eventually develops one of the country's largest "parole" systems for moving institutional residents back into smaller, community-based residences.

1887 ◆ The American Orthopaedic Association is founded. German and British counterparts are founded in 1901 and 1918, respectively.

1895 ◆ The chiropractic profession is founded. This type of care is used to relieve musculoskeletal pain, one of the most common causes of disability.

1899 ◆ Maria Montessori and a colleague open the Scuola Magistrale Ortofrenica in Rome, an educational institute for disabled children and a training institute for instructors. Her method relies on the concept of sensory-based instruction as a means for developing intellectual competence. Her methods allow the child the greatest possible independence in order to foster his or her own development (the child's own inner "building plan").

1904 ◆ Sir Francis Galton, half first cousin of Charles Darwin, defines the term e*ugenics* (which he coined in 1883) in a paper he presents to the Sociological Society on May 16. He argues for planned breeding among the "best stock" of the human population, along with various methods to discourage or prevent breeding among the "worst stock." Galton also develops the idea for intelligence tests. The term *feeblemindedness* is defined as broadly as possible and is widely used by eugenic social reformers to conflate myriad social problems. Further naming, classification, and labeling provides eugenicists with a troubling rationale for treating people with coercion, disrespect, and profound inhumanity. Persons within the various categories of sub-normality become particularly vulnerable to state-sanctioned segregation, institutional confinement, and enforced sterilization. Eugenics is widely practiced in Europe, the United States, and Canada, culminating in the systemic murder of more than 260,000 disabled people by the Nazis between 1939 and 1945. Today, the so-called new eugenics, known as "human genetics," appeals to the needs of the individual. Critics (some of the first in Germany), however, criticize individualistic eugenic approaches and disclose the connections between human genetics, national socialist racial hygiene, and eugenics.

1905 ◆ Alfred Binet and Theodore Simon publish the first intelligence scale, known as the Binet-Simon Test.

1908 ◆ The publication of Clifford Beers's *A Mind That Found Itself* initiates the mental health hygiene movement in the United States. Speaking out against mistreatment and neglect within the system, Beers establishes the Connecticut Committee of Mental Hygiene, which expands in 1909, becoming the National Committee for Mental Hygiene and is now known as the National Mental Health Association. In 1940 there are 419,000 patients in 181 state hospitals. In 1943, the patient-doctor ratio is 277:1, and by the mid-1950s in New York state alone, there are 93,000 inpatients. The Bazelon Center for Mental Health Law, founded in 1972 by a group of committed lawyers and professionals in mental health and mental retardation, attempt to improve mental health service provision through individual and class action suits. In 1980, a group of these lawyers form the National Association of Rights Protection and Advocacy (NARPA). One-third of its board of directors must identify themselves as current or former recipients of mental health care. The association is committed to the abolishment of all forced treatment.

1908 ◆ Pastor Ernst Jakob Christoffel establishes a home in Turkey for blind and otherwise disabled and orphaned children. This grows into Christoffel-Blindenmission (CBM), an independent aid organization of Christians of various denominations united to help disabled people in third world countries. Today, it supports more than 1,000 development projects in 108 countries. In 1999, CBM, other agencies, and the World Health Organization initiate VISION 2020: The Right to Sight, a global initiative for the elimination of avoidable blindness by the year 2020.

1909 ◆ Germany: The German Organization for the Care of Cripples is created as an umbrella organization for the care of the physically disabled. The Prussian Cripples' Care Law of 1920 for the first time provides a right to medical care and scholarly and occupational education for this group.

1912 ◆ Henry H. Goddard publishes *The Kadikak Family,* supports the beliefs of the eugenics movements, and helps create a climate of hysteria in which human rights abuse of the disabled, including institutionalization and forced sterilization, increases. In 1927, the U.S. Supreme Court, in *Buck v. Bell,* rules in favor of forced sterilization of people with disabilities, further fueling eugenics movements—the number of sterilizations increases.

1914 ◆ By this date, Sigmund Freud develops his most enduring influence on the study of disability, namely, the theory of psychosomatic illness in which a psychopathological flaw is given corporeal form as a symptom, thereby establishing the notion that people succumb to disease or disability because they feel guilty about past or present repressed desires.

1918 ◆ The Smith-Sears Veterans Rehabilitation Act passes, authorizing VR services for World War I veterans. In 1916, the National Defense Act marks the beginning of the U.S. government's supportive attitude toward rehabilitation. In 1920, the Smith-Fess Act marks the beginnings of the civilian VR program. The Social Security Act of 1935 establishes state-federal VR as a permanent program that can be discontinued only by an act of Congress.

1919 ◆ Edgar "Daddy" Allen establishes what becomes known as the National Society for Crippled Children. In the spring of 1934, the organizational launches its first Easter "seals" money-making campaign. Donors place seals on envelopes containing their contributions. The seal is so well-known that it becomes part of the organization's official name. Today, Easter Seals assists more than one million children and adults with disabilities and their families annually through a nationwide network of more than 500 service sites. During the 1920s, Franklin D. Roosevelt inspires the March of Dimes.

1920 At about this time, the Shriners open hospitals for the care of crippled children. President Herbert Hoover establishes a "Children's Charter" in 1928 highlighting the need to attend to the needs of crippled children.

1921 Franklin D. Roosevelt contracts poliomyelitis. Despite damage to his legs (which makes him a wheelchair user) and deep depression, through enormous rehabilitative effort, he eventually re-enters politics and becomes president of the United States. His triumph over personal disability becomes legendary. Critics, however, fault him for choosing to minimize his disability in what is called his "splendid deception." He establishes a center for the treatment of polio patients in Warm Springs, Georgia, called the Georgia Warm Springs Foundation (1927), which hires medical specialists from Atlanta to direct orthopedics. In 1937, President Roosevelt becomes the prime mover behind the National Foundation for Infantile Paralysis Research.

1921 Mary L. McMillan (Molly) establishes the American Women's Physical Therapeutic Association, which is known today as the American Physical Therapy Association (APTA).

1921 The American Foundation for the Blind is established.

1921 Canada: Researchers isolate the hormone insulin. In 1922, Frederick Banting, Charles Best, J. B. Collip, and J.R.R. Macleod produce and test the pancreatic extract on people with diabetes, for which they are awarded a Nobel Prize. Insulin becomes a wonderful treatment for diabetes, but not a cure.

1921 France: Three historical waves of advocacy movements can be identified beginning with the National Federation of Injured Workers (FNAT) in 1921 and other organizations that focus essentially on the protection of rights. Another factor that stimulates advocacy groups in the first wave is the wounded veterans of World Wars I and II. A second wave dates from the period after World War II. Many advocacy groups form between 1950 and 1970, such as the Union of Associations of Parents of Maladjusted Children (UNAPEI) in 1960. A third wave finds a gradual emergence of three types of associations: those that run specialized facilities (for example, Living Upright, which, in 1970, leads to the creation of the first group living facility); those interested in trade unions; and those represented by user-advocate associations. Financing comes in large part from public funds, thereby creating a government-association partnership.

1922 The founding of Rehabilitation International sets the stage for the establishment of other international organizations of and for people with disabilities that link together throughout the world. Later international organizations include, among numerous others, the World Federation of the Deaf (1951), Inclusion International (1962), the International Association for the Scientific Study of Intellectual Disability (1964), Disabled Peoples' International (1981), and the International Disability Alliance (1999).

1925 The American Speech-Language-Hearing Association, today the American Academy of Speech Correction, is established to provide high-quality services for professionals in speech-language pathology, audiology, and speech and hearing science, and to advocate for people with communication disabilities.

1928 Charles Nicolle is the first deaf person to be awarded a Nobel Prize.

1929 Seeing Eye establishes the first dog guide school in the United States.

1930 The Veterans Administration is created to administer benefits, promote vocational rehabilitation, and return disabled veterans to civil employment. There is a record of provision for disabled veterans in the United States since the Revolutionary War and the Civil War. After World War I, three agencies administer veteran's benefits.

1932 Herbert A. Everest, a mining engineer with a disability, and Harry C. Jennings collaborate to design and patent the cross-frame wheelchair, which becomes the standard for the wheelchair industry that exists today. Developed during World War I, the first powered wheelchair appears, but doesn't gain popularity for another 30 years.

1935 President Franklin D. Roosevelt signs the Social Security Act of 1935 on August 14. Beginning in 1956, SSA amendments provide disability benefits.

1935 By 1935, in the United States more than 30 states pass laws allowing for the compulsory sterilization of those deemed genetically unfit in state and federal institutions. By 1970, more than 60,000 people are sterilized under these laws.

1935 As a result of being denied participation in the Works Progress Administration (WPA), six young people with disabilities hold a sit-in at the offices of New York City's Emergency Relief Bureau, demanding jobs in non-segregated environments and explicitly rejecting charity. The League of the Physically Handicapped is born out of this activism and operates in New York from 1935 to 1938. The League identifies social problems that remain issues today.

1935 Peer support in the United States is traced to the establishment of Alcoholics Anonymous in this year. Interest in peer support increases in the 1960s and is adopted by the disabled community. Movements, such as the Center for Independent Living, and groups, such as the National Spinal Cord Injury Association, make peer support one of their major activities.

1936 The American Academy of Physical Medicine & Rehabilitation is founded, leading to the approval of the American Board of Physical Medicine & Rehabilitation by the American Medical Association in 1947.

1937 The Fair Housing Act of 1937 passes with a mandate to assist the poor, a group that includes people with disabilities, by creating public housing. However, it is not until the Rehabilitation Act of 1973 that housing law specifically deals with discrimination faced by individuals with disabilities in housing programs that receive federal funding. The 1988 amendment to the Fair Housing Act of 1968 extends protection for people with disabilities beyond those of Section 504 of the Rehabilitation Act to include private housing.

1939 The Nazi regime institutes the Aktion T4 program in Germany. Children and, later, adults with disabilities are selectively killed both in hospitals and in special centers. The program was officially terminated by Adolf Hitler in August 1941, but practitioners "informally" continued it through a phase historians have called "wild euthanasia."

1940 State activists for the blind, including Jacobus Broek, come together in Wilkes-Barre, Pennsylvania, to charter the National Federation of the Blind (NFB). In 1957, the NFB publishes the first edition of the *Braille Monitor,* which is still in print today. In 1960, dissatisfied NFB members form the American Council of the Blind (ACB).

1940 Paul Strachan establishes the American Federation of the Physically Handicapped, the nation's first cross-disability, national political organization.

1942 The American Psychiatric Association develops a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles.*

1943 The LaFollette-Barden Act, also known as the Vocational Rehabilitation Amendments, adds physical rehabilitation to federally funded vocational rehabilitation programs.

1943 The United Nations is established on October 24 by 51 countries. The global Programme on the Disability is the lead program concerning disability. Many other types of programs, activities, and instruments include the 1975 Declaration on the Rights of Disabled Persons, the 1981 International Year of

Disabled Persons, the 1982 World Programme of Action Concerning Disabled Persons, the 1983–1992 UN Decade of Disabled Persons, and the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In 1988, the first UN Disability Database (DISTAT) publishes statistics from 63 national studies covering 55 countries and the 2001 publication presents 111 national studies from 78 countries, indicating a growing interest worldwide for the collection of usable data. In 2005, a UN Ad Hoc Committee continues to consider a Convention on the Rights of Disabled Persons that is a legally binding human rights instrument. Today the UN membership totals 191 countries.

1943 Sweden: In possibly the first reference to the concept of normalization, the most significant driving force in the ongoing closure of state-run or state-funded institutions for people with a disability is made by the Committee for the Partially Able-Bodied, established by the Swedish Government. Through the advocacy of people such as Niels Erik Bank-Mikkelsen, normalization, with its profound positive effect on the lives of people who were once removed and segregated from society, remains relevant today.

1944 Richard Hoover invents long white canes known as Hoover canes that are used by many blind people.

1944 The word *genocide* first appears in a book by a Polish lawyer Raphael Lemkin titled *Axis Rule in Occupied Europe* in which he describes Nazi Germany's practices but also seeks the adoption of legal restrictions so that genocide will not occur. In 1948, the United Nations adopts a declaration and then a convention on genocide that describe both against whom genocide might be directed and acts constituting genocide. Article 6 of the Rome Statute of the International Criminal Court (ICC), established in 2002, uses language identical to that in the UN convention to define genocide. More than 90 countries are parties to the ICC, but not the United States.

1945 President Harry Truman signs into law an annual National Employ the Handicapped Week. In 1952, it becomes the Presidents' Committee on Employment of the Physically Handicapped, a permanent organization, which reports to the President and Congress.

1945 Canada: Lyndhurst Lodge, the first specialized rehabilitation center for spinal cord injury (SCI) in the world, and the Canadian Paraplegic Association, the first association in the world administered by individuals with SCI, are established.

1946 The first chapter of what will become the United Cerebral Palsy Association, Inc. is established in New York City. It is chartered in 1949, and along with the Association for Retarded Children, it becomes a major force in the parents' movement of the 1950s.

1946 The National Mental Health Foundation is founded by attendants at state mental institutions who aim to expose abusive conditions. Their work is an early step toward deinstitutionalization.

1946 The National Institutes of Mental Health (NIMH) are founded in the United States.

1946 Europe: The European Union is founded on September 17 in Paris. It consistently shows its commitment to eliminating discrimination on many fronts through joint declarations, resolutions, directives, and action programs. With regard to disability, the European Union supports actions in favor of people with disabilities, principally in the form of European Social Fund interventions. Action programs aim at facilitating the exchange of information between member states and nongovernmental organizations with a view to identifying good practices, integrating people with disabilities into society, and raising awareness of related issues. The EU Council of Ministers Recommendation on the Employment of Disabled People (1986) calls on member states to "eliminate negative discrimination by reviewing laws, regulations and administrative provisions to ensure that they are not contrary to the principle of fair opportunity for disabled people." Further steps are taken in 1996 when a communication on equality of opportunities for disabled people sets out a new European disability strategy that promotes a rights-based approach, rather than a welfare-type approach. This is strengthened in 1997 when the heads of state act to strengthen Article 13 of the European Community Charter of Fundamental Social Rights of Workers (1989), giving the European Community specific powers to take action to combat a broad spectrum of discrimination that includes disability.

1948 The National Paraplegia Foundation is established as the civilian branch of the Paralyzed Veterans of America.

1948 The World Health Organization is established. The WHO actively promotes human rights and the principle of equity in health among all people of the world, including persons with disabilities. Today it consists of 191 member states, but strives for universal membership. In 1980, the WHO publishes the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and issues a revised version in 2001, the International Classification of Functioning, Disability, and Health (ICF).

1948 The United Nations General Assembly adopts the "Universal Declaration of Human Rights," which promotes and affirms the fundamental rights to life, liberty, and security; to medical care and social services; and to the benefit from scientific progress and its uses.

1948 Sir Ludwig Guttmann organizes the first Stoke Mandeville (England) Games for the Paralysed, thus launching the Paralympic movement. The Games become international in 1952. In 1960, the first Paralympic Summer games are held in Rome and the first Paralympic Winter Games follow in 1976. The Paralympic Games are multi-disability, multi-sport competitions and have become the second-largest sporting event in the world, only after the Olympic Games.

1948 World War II bomber pilot and war hero Leonard Cheshire establishes what is to become the largest charitable supplier of services for disabled people in the United Kingdom. In the 1960s, the resistance of disabled people who live in one Leonard Cheshire home, Le Court, plays a major role in establishing the British disabled people's movement. In the late 1990s, the Leonard Cheshire organization establishes the Disabled People's Forum, which is run by disabled people and supports disabled people's involvement and empowerment.

1949 Timothy Nugent founds the National Wheelchair Basketball Association, and the first Annual Wheelchair Basketball Tournament takes place.

1949 Europe: The Council of Europe, an intergovernmental organization, is founded. Its activities cover all major issues facing European society other than defense. Human dignity, equal opportunities, independent living, and active participation in the life of the community form the heart of the Council of Europe's activities in relation to people with disabilities. The European Social Charter of 1961 and its revision in 1996 include specific wording and expand the rights of individuals with disabilities.

1950 The Social Security Amendments of 1950 provide federal-state aid to the permanently and totally disabled (APTD), which serves as a limited prototype for future Social Security assistance programs for disabled people.

1950 The National Mental Health Association is formed with the mission to continue 1908-advocate Clifford W. Beers's goals of "spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health."

1950 The National Association for Retarded Children (NARC) is established by families in Minneapolis. It is the first and most powerful parent-driven human-services lobby in the nation to emerge in the 1950s.

1950 ◆ Amniocentesis is developed by a Uruguayan obstetrician. Later, advanced prenatal testing provides a battery of powerful medical tools to predict risk of disability and provide information to parents about their pregnancies.

1951 ◆ With the founding of the World Federation of the Deaf, the deaf community becomes international.

1953 ◆ Francis Crick and James Watson propose a three-dimensional structure for the DNA molecule. The paper they publish also gives clues to genetic mechanisms. Today, more than 6,000 monogenic disorders have been identified, and these affect approximately 1 in 200 live births.

1955 ◆ The polio vaccine, developed by Dr. Jonas Salk, becomes available, thus ending polio epidemics in the Western world. A new oral vaccine, developed by Dr. Albert B. Sabin, is approved for use in 1961.

1956 ◆ Social Security Disability Insurance (SSDI) becomes available through amendments to the Social Security Act of 1935 (SSA) for those aged 50–64. Other important amendments to SSA include the following: 1958: provides for dependents of disabled workers; 1960: removes age limit; 1965: Medicare and Medicaid provide benefits within the framework of the SSA (until 1977); 1967: provides benefits to widows and widowers over the age of 50; 1972: Supplemental Security Income (SSI) establishes a needs-based program for the aged, blind, and disabled; 1984: the Social Security Disability Reform Act responds to the complaints of hundreds of thousands of people whose disability benefits have been terminated; 1996: President Clinton signs the Personal Responsibility and Work Opportunity Reconciliation Act, making it more difficult for children to qualify as disabled for SSI purposes.

1959 ◆ The UN Declaration of the Rights of the Child is adopted; the UN Convention on the Rights of the Child is adopted in 1989. A central principle of both documents is access to education for all children including those with disabilities. In 1993, a related UN document, the Standard Rules for the Equalization of Opportunity, extends this to preschool children, and in 1994, UNESCO's Salamanca Statement and Framework for Action specifies the provision of special education for children with disabilities or learning difficulties. These documents constitute a universal bill of rights that can serve as a framework in the development of national policies worldwide.

1961 ◆ The American Council of the Blind is established.

1961 ◆ Europe: The European Social Charter (ESC) protects "the right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement." In 1996, it is revised, updated, and expanded to take account of social changes.

1961 ◆ Michel Foucault's work *The History of Madness in the Classical Age* becomes obligatory reading for those concerned with the archaeology of madness and its treatments. It continues to be an academic *rite de passage.*

1962 ◆ Battered child syndrome is defined. Researchers estimate that the incidence of maltreatment of children with disabilities is between 1.7 and 3.4 times greater than of children without disabilities.

1962 ◆ Russia: The Moscow Theater of Mime and Gesture is the first professional deaf theater in the world. It has been in continuous operation for more than 40 years and has staged more than 100 classic and modern plays.

1963 ◆ Congress enacts new legislation to ensure funding for a comprehensive program of research on mental retardation through the National Institute on Child Health & Human Development. In 1965, the Office of Economic Opportunity launches the Elementary and Secondary Education Act (ESEA), commonly known as Project Head Start. The goal is to prevent developmental disability by providing increased opportunities for disadvantaged children in the preschool years.

1963 The Developmentally Disabled Assistance and Bill of Rights Act (DD ACT) is authorized, with its last reauthorization in 1996. It focuses on individuals with developmental disabilities such as intellectual disability, autism, cerebral palsy, epilepsy, and hearing and visual impairments, among others.

1964 The Civil Rights Act is passed. It becomes the model for future disability rights legislation.

1964 France: L'Arche is established. By the beginning of the twentieth-first century, it includes more than 113 communities in 30 countries. "The Ark" is a distinctive style of community living, based on "core members" and "assistants," who view their commitment as sharing life *with* people with disabilities, rather than as caregivers.

1965 Newly enacted Medicare and Medicaid provide national health insurance for both elderly (over 65) and disabled persons.

1965 The Vocational Rehabilitation Amendments of 1965 are passed. They provide federal funds for the construction of rehabilitation centers and create the National Commission on Architectural Barriers to Rehabilitation of the Handicapped.

1965 The Autism Society of America is founded.

1967 Deaf actors establish the National Theatre of the Deaf (NTD). It is the world's first professional deaf theater company and the oldest continually producing touring theater company in the United States. Today, after almost 40 years, the NTD chronicles over 6,000 performances. The National Theatre Workshop for the Handicapped begins in 1977 and the Other Voices Project in 1982. These groups are among the earliest groups formally to place the disability experience at the heart of their creative endeavors.

1967 Heart transplantation is introduced. This technology is preceded by open-heart surgery developed in the 1950s and coronary bypass and internal pacemakers in the1960s. The Framingham Heart Study begins in 1948. It collects data over the next decades that help identify major risk factors contributors to heart disease.

1967 Paul Lemoine in France in 1967 and Kenneth Jones and David Smith in the United States in 1973 independently describe the condition fetal alcohol syndrome (FAS), which comprises a recognizable pattern of birth defects attributable to the adverse effects of maternal alcohol abuse during pregnancy.

1967 England: St. Christopher's Hospice in South London opens. It is the first attempt to develop a modern approach to hospice and palliative care.

1968 Congress enacts the Architectural Barriers Act. The ABA requires access to facilities designed, built, altered, or leased with federal funds.

1968 The Fair Housing Amendments to the Civil Rights Act of 1968 guarantees civil rights of people with disabilities in the residential setting. The amendments extend coverage of the fair housing laws to people with disabilities and establish accessible design and construction standards for all new multi-family housing built for first occupancy on or after March 13, 1991.

1968 Sweden: The origins of People First® go back to a meeting of parents of children with intellectual disabilities whose motto is "we speak for them." However, the people with disabilities in attendance wish to speak for themselves and start their own self-advocacy group. Similar groups quickly spread to England and Canada. The name People First is chosen at a conference held in Salem, Oregon, in 1974. People First is an international self-advocacy organization run by and for people with intellectual disabilities to work on civil and human rights issues.

1970 ◆ Landmark legal cases such as *Diana v. State Board of Education* (1970; Latino students) and *Larry P. v. Riles* (1971–1979; minority students) challenge biases inherent in standardized testing procedures used to identify students as eligible for special education. Both cases call into question the widespread use of "scientifically" objective measures to gauge intellectual ability. Today, despite reforms, a disproportionate number of students from racial, ethnic, and linguistic minorities continue to be placed in special education classes.

1970 ◆ Japan: The Disabled Persons' Fundamental Law (DPFL) becomes one of the 27 fundamental laws that stipulate basic principles in each policy area. Major revision takes place in 1993 reflecting a progress of guiding principles in disability policy that are deeply influenced by international movements such as the International Year of Disabled Persons (1981) and the UN Decade of Disabled Persons (1983–1992). Disability Studies as well as modern disability movements are born this same year, when members of Aoi Shiba, a group of people with cerebral palsy, protest publicly for the first time against sympathetic views toward the killing of disabled children by their parents. Aoi Shiba and other disability movements join in the establishment of Disabled Peoples' International in 1981. In 1986, the Rehabilitation Engineering Society of Japan (RESJA) is established. In 1992, disability movements in Japan initiate the Asian and Pacific Decade of Disabled Persons 1993 to 2002. The Japan Society for Disability Studies is established in 2003 and a unified national organization, Japan Disability Forum (JDF), is established in 2004.

1970 ◆ United Kingdom: The Chronically Sick and Disabled Persons Act (CSDPA) strengthens the provisions in the 1948 National Assistance Act (NAA). Later, the Disability Discrimination Acts of 1995 and 2005, together with the Disability Rights Commission Act of 1999, constitute the primary source of antidiscrimination legislation for disabled people.

1971 ◆ A U.S. District Court decision in *Wyatt v. Stickney* is the first important victory in the fight for deinstitutionalization.

1971 ◆ WGBH Public Television establishes the Caption Center, which provides captioned programming for deaf viewers.

1971 ◆ Gerontologist M. Powell Lawton defines *functional assessment* as any systematic attempt to objectively measure the level at which a person is functioning in a variety of domains. Over 30 years later, functional assessment, in combination with *outcomes analysis,* is considered one of the "basic sciences" of rehabilitation. In 1980, the World Health Organization proposes a series of definitions, which have a profound impact on the assessment of functional status and outcomes in rehabilitation. It is modified and revised in 1993 and 2001.

1971 ◆ The Declaration on the Rights of Mentally Retarded Persons (UN 1971), the Declaration on the Rights of Disabled Persons (UN 1975), and the World Programme of Action Concerning Disabled Persons (UN 1982) indicate the emergence of a global discourse of rights for disability.

1972 ◆ A group of people with disabilities (including Ed Roberts, John Hessler, and Hale Zukas), known as the Rolling Quads, living together in Berkeley, California, formally incorporate as the Center for Independent Living (CIL). This first CIL in the country becomes the model for Title VII of the Rehabilitation Act of 1973. In the late 1980s and early 1990s the group's advocacy efforts help pass the Americans with Disabilities Act (ADA). CILs are always controlled by disabled people. Accepted by most people as the birth of the modern independent living movement, the Berkeley concept migrates to other countries. In 1999, a global summit on independent living is held in Washington D.C. The summit brings together more than 70 countries. The Washington Declaration that comes out of the conference establishes a set of basic principles. In 1996, the Ed Roberts Campus, an international center and a service facility, is created in Berkeley, California, in memory of Edward V. Roberts, founder of the independent living concept.

1972 ◆ A young television reporter for the ABC network, Geraldo Rivera, is given a key to one of the wards at Willowbrook State School on Staten Island, New York. Established in the late 1930s as a state-of-the-art facility for the "mentally deficient," by 1972, Willowbrook becomes a warehouse for the "socially undesirable" of New York City, with a substantial minority having no disability at all. The inhumane conditions deteriorate to the extent that a visitor remarks, "In Denmark we don't let our cattle live this way." Rivera's exposé leads to a lawsuit that results in the Willowbrook Consent Decree of 1975, which creates a detailed system of monitoring and oversight of all residents living there at that time, to be met until the last of the "class clients," as they are sometimes referred to, pass on. The property has since been sold to a college.

1972 ◆ Paul Hunt's call for a consumer group to promote the views of actual and potential residents of institutional homes for the disabled in the United Kingdom results in the establishment of the Union of the Physically Impaired against Segregation (UPIAS). The group's aim is to formulate and publicize plans for alternative forms of support in the community. Hunt is regarded by many disability activists as the founder of the modern disabled people's movement.

1972 ◆ New Zealand: Three key pieces of legislation pass have long-term effects on the disabled community: the 1972 no-fault Accident Compensation Act that provides monetary compensation to victims based on level of impairment suffered; the 1975 Disabled Persons Community Welfare Act, giving assistance to disabled people, parents, and guardians, as well as voluntary associations; and the Human Rights Act of 1977, which does not include disability as a recognized grounds for discrimination. Today, disabled populations in New Zealand continue to fight to establish an identity as disabled people rather than a group needing "welfare." One task is to promote legislation that includes disability as a group against whom discrimination is outlawed.

1973 ◆ The Rehabilitation Act of 1973 lays the foundation for the disability rights movement. Its Section 504 asserts that people with disabilities have equal rights that prevent discrimination based on their disability in programs or activities that receive federal funding. This is the first major nationwide antidiscriminatory legislation designed to protect disabled Americans. These rights are further protected with the landmark Americans with Disabilities Act (ADA) of 1990.

Section 501 of the Act requires affirmative action and nondiscrimination in employment by federal agencies of the executive branch. Section 502 creates the Access Board, which grows out of the 1965 National Commission on Architectural Barriers to Rehabilitation of the Handicapped. As a result of the commission's June 1968 report, Congress enacts the Architectural Barriers Act (ABA). Section 503 requires that to receive certain government contracts, entities must demonstrate that they are taking affirmative action to employ people with disabilities. The enduring hallmark of the act, Section 504, provides that no otherwise qualified individual with a disability shall, solely by reason of his or her disability, be excluded from the participation in, denied the benefits of, or subjected to discrimination under any program or activity receiving federal funds. However, it would take five years of lobbying and protesting before the American Coalition of Citizens with Disabilities (ACCD) wins the release of regulations that allow Section 504 to be implemented.

The Act is in many ways the direct predecessor to the ADA. However, the primary focus is vocational training and rehabilitation, and over the next half-century, disability law and advocacy move from the medical (medical issues) and vocational (often a justification for welfare and benefits) models to a civil rights model, which seeks to remove the barriers that impede the full integration of people with disabilities into society.

1973 ◆ The term *mainstreaming* emerges within the educational jargon associated with the Education for All Handicapped Children Act (EHA), the early U.S. legislation subsequently reauthorized as the Individuals with Disabilities Act (IDEA) in 1990.

1973 ◆ Ronald Mace is the driving force behind the creation of the first accessible state building code in the United States (North Carolina, 1974) and in the drafting of national accessibility codes and standards. He coins the term *universal design* to capture and promote his expanded philosophy of "design for all ages and abilities"—curb cuts being his favorite example.

1973 ◆ Washington D.C. introduces the first handicap parking stickers. The Federal-Aid Highway Act funds curb cuts.

1974 ◆ First Lady Betty Ford and investigative reporter Rose Kushner are diagnosed with breast cancer. They help break the public silence on this topic. In 1954, Terese Lasser begins Reach to Recovery, a program of volunteers who have previously undergone radical mastectomies who provide emotional support to hospitalized women who have just had the operation. Today, one in eight women is diagnosed with breast cancer during her lifetime.

1975 ◆ The Education for All Handicapped Children Act, the first separate federal legislation authorizing special education for children and youth, passes, due, in part, to the advocacy efforts of a group of parents. In 1990, it becomes known as the Individuals with Disabilities Education Act, or IDEA.

1975 ◆ The Developmentally Disabled Assistance and Bill of Rights Act, providing federal funds for programs that provide services for people with developmental disabilities, passes.

1975 ◆ The Association of Persons with Severe Handicaps (TASH) is founded. It calls for the end of aversive behavior modification and deinstitutionalization of people with disabilities.

1975 ◆ The UN General Assembly adopts the Declaration on the Rights of Disabled Persons, which states that all persons with disabilities have the same rights as other people. This document is not legally binding and can be attributed in part to a UN Ad Hoc Committee set up in 2001 to consider a Convention on the Rights of Disabled Persons that is legally binding.

1975 ◆ United Kindom: The Union of the Physically Impaired against Segregation (UPIAS) publishes a paper that redefines the term *disability,* which becomes known as the social model of disability as it radically transforms the way disabled people see themselves and their place in society.

1976 ◆ The Higher Education Act of 1965, which establishes grants for student support services aimed at fostering an institutional climate supportive of low-income and first-generation college students, is amended to include individuals with disabilities. In March 1978, the Association on Handicapped Student Service Programs in Post-Secondary Education is founded. It later becomes the Association on Higher Education and Disability (AHEAD).

1976 ◆ Sponsored by Ralph Nader's Center for the Study of Responsive Law, the Disability Rights Center is founded in Washington D.C.

1977 ◆ Protesting the federal government's delayed enactment of the rules and regulations for the implementation of the Rehabilitation Act of 1973, disabled activists on April 1 organize protests at the federal offices of the Department of Health and Human Services in various cities across the United States. In San Francisco, protesters hold the regional offices hostage for 28 days, gaining national attention and resulting in an agreement with federal officials for the rapid establishment of the rules and regulations to implement Section 504 of the Act.

1977 ◆ Max Cleland is appointed to head the U.S. Veterans Administration. He is the first severely disabled person to hold this post.

1977 ◆ S. Z. Nagi defines *disability* as an individual's performance of tasks and activities related to achievement of social roles—a distinct concept, different from *impairment*. It is further formalized with the introduction of the World Health Organization's International Classification of Impairments, Disabilities, and Handicaps in 1980 and further refined in 2001 in its International

Classification of Functioning, Disability, and Health. Nagi's model is used as the basis for the Americans with Disabilities Act, for almost all disability social policy in the United States, and for statistics at the United Nations and in Europe.

1978 ◆ The Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 and the Adoption Assistance and Child Welfare Act of 1980 promote the adoption of children with special needs, including disabilities.

1978 ◆ The Atlantis Community, the second independent living center in the country after Berkeley, is established in Denver, Colorado, in 1975. On July 5–6, 1978, twenty disabled activists from the Atlantis Community block buses with their wheelchairs and bodies and bring traffic to a standstill at a busy downtown intersection. This act of civil disobedience results in the American Disabled for Accessible Public Transit, the original name for the American Disabled for Attendant Programs Today, or ADAPT.

1978 ◆ Legislation creates the National Institute on Handicapped Research. In 1986, it is renamed the U.S. National Institute on Disability and Rehabilitation Research (NIDRR). Its mission is to contribute to the independence of persons of all ages who have disabilities. It is located in the Department of Education under the Office of Special Education and Rehabilitation Services.

1978 ◆ The World Health Organization starts to promote the concept of community-based rehabilitation (CBR) as a means of helping people with disabilities in the developing world. It emerges, in part, from the WHO primary health care campaign Health for All by the Year 2000. Around the same time, in Western countries, home-visiting programs in which a trained worker regularly visits the family to advise on ways of promoting child development become one of the success stories of modern disability services. Among the best-known programs are those based on a model originating in Portage, Wisconsin, and now used in many countries.

1978 ◆ England: The Warnock report introduces the term *special needs education.* It marks a major shift in organizing educational services for children with disabilities and results in the new conceptualization of special needs education. This change is confirmed internationally by the Salamanca Statement and Framework for Action on Special Needs Education at the UNESCO's Conference held in Salamanca in 1994. This theoretical shift is marked with the change of the term *integration* to *inclusion* or *inclusive education.*

1978 ◆ USSR: The Action Group to Defend the Rights of the Disabled is established to advocate for legal rights for Soviets with disabilities.

1979 ◆ The Disability Rights Education and Defense Fund (DREDF) establishes itself as a leading cross-disability civil rights law and policy center. It is founded by people with disabilities and parents of children with disabilities. Because its philosophy is closely aligned with other civil rights struggles, in 1981, DREDF is invited to join the executive committee of the national's largest coalition of civil rights groups, the Leadership Conference on Civil Rights. In 1987, DREDF establishes the Disability Rights Clinical Legal Education Program and begins teaching disability rights law at the University of California's Boalt Hall School of Law.

1979 ◆ The National Alliance for the Mentally Ill (NAMI) is founded. NAMI is an advocacy and education organization.

1979 ◆ Germany: The first Cripples' Group is founded as a cross-disability group with emancipatory aims. In an attempt to reinterpret disability in positive terms, the cofounders choose the term *Krüppel* over handicapped or disabled.

1979 ◆ Nicaragua: The Organization of the Revolutionary Disabled is set up in the wake of the Sandinista victory.

1980 ◆ The California Governor's Committee on Employment of People with Disabilities and entertainment and media industry professionals establish the Media Access Office (MAO).

1980 ◆ About the time Congress is considering passage of the ADA (1990), marketers begin to acknowledge the economic potential of the disabled community; consequently, the appearance of disabled characters in consumer goods advertising mushroom and ability-integrated advertising becomes much more commonplace. Organizations such as MAO and NOD (National Organization on Disability) provide advertising strategies and guidance.

1980 ◆ The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), an interdisciplinary association composed of individuals interested in technology and disability, is founded.

1980 ◆ The World Health Organization's International Classification of Impairments, Disabilities, and Handicaps (ICIDH), a groundbreaking, but controversial, classification system is tentatively released for trial purposes with the goal of uniform information collection worldwide. It has a negligible impact on disability statistics or data collection; however, researchers argue that it is a vast improvement over available tools. It is renamed and vastly revised in 2001.

1980 ◆ England: Graeae Theatre Group, composed of disabled actors, directors, and other theater professionals, is founded in London by Nabil Shaban and Richard Tomlinson. It takes its name from the the Graeae of Greek mythology, three gray-haired sisters who shared one eye and one tooth. Graeae's first production is *Sideshow*.

1980 ◆ Netherlands: The Liliane Foundation starts by assisting 14 children. In 2002, it helps 31,982 children spread over 80 countries. The Foundation's efforts are directed primarily toward children with disabilities living at home. Its aim is to have direct contact with the child within the home situation and to assist the personal growth and happiness of the child, thus providing "tailor-made" assistance.

1980 ◆ Taiwan: The Physically and Mentally Disabled Citizens Protection Law is promulgated. It guarantees legal rights for the disabled and creates a significant improvement in their welfare. Although most of the disabled people in Taiwan still struggle to earn their due respect, today, public awareness of this group is emerging gradually and significantly.

1980 ◆ United Kingdom and Europe: The Black Report (*Report of the Working Group on Inequalities in Health)* is published. Among other groups it targets disabled people for better conditions that lead to better health. The report does not find favor with the Conservative government, but begins to be implemented under the Labour government in 1997. With its central theme of equity, the report plays a central role in the shaping of the World Health Organization's Common Health Strategy of the European Region.

1981 ◆ The Reagan Administration begins to amend and revoke disability benefits, a policy that continues throughout his administration and leads several disabled people who are in despair over the loss of their benefits to commit suicide.

1981 ◆ Justin Dart, recognized as the founder of the Americans with Disabilities Act (ADA, 1990), is appointed to be vice-chair of the National Council on Disability. The council drafts a national policy on equal rights for disabled people; the document becomes the foundation of the ADA.

1981 ◆ The Committee on Personal Computers and the Handicapped is established in Illinois, an indicator of the disabled community's interest in information technology (IT) accessibility, but in order to stimulate the development of suitable products, activists lobby for legislative protections, which are included in the Americans with Disabilities Act of 1990. In 2000, a suit brought by the National Federation of the Blind against AOL is suspended when AOL agrees to make its software accessible by April 2001. The World Wide Web Accessibility Initiative (WAI) launches in 1997. It raises the level of awareness of disability accessibility issues within the Internet community, especially among those who design and implement web pages.

1981 ◆ The first reported cases of AIDS in the United States appear in June. Today, the World Health Organization estimates that worldwide, approximately 40 million people are living with HIV/AIDS; 22 million men, women, and children have died; and 14,000 new infections are contracted every day. Around the world, in the year 2003, the AIDS epidemic claims an estimated 3 million lives, and almost 5 million people acquire HIV, 700,000 of them children. Currently, 6 million people infected with HIV in the developing world are estimated to need access to antiretroviral therapy to survive, but only 400,000 have this access.

1981 ◆ Disabled Peoples' International (DPI) is officially founded at a meeting in Singapore. The establishment of such international organizations around this time represents the disability movement becoming a global social movement instead of a national one. DPI is directed by persons with disabilities working in human rights advocacy. It sponsors World Assemblies, which are held every four years to develop a multiyear action plan. The most recent one is held in 2002 in Sapporo, Japan, where delegates from more than 100 countries come together. A leading slogan for DPI and other disability groups, coined in the early 1990s, is "nothing about us without us."

1981 ◆ The International Year of Disabled Persons encourages governments to sponsor programs that assimilate people with disabilities into mainstream society. Despite the positive worldwide effects it has, the UN program also creates some angry activists with disabilities who protest against the charity approach officially adopted for the event. Consequently, the activists build their own infrastructure consisting of counseling and advocacy facilities as well as job creation programs.

1981 ◆ Australia: Australia's modern disability policy takes shape after the 1981 International Year of Disabled Persons. Examples: The 1980s see a shift away from institutional care; the Commonwealth Disability Service Act provides a framework for the provision of disability services; and in 1991, the federal Disability Reform Package maximizes the employment of disabled. In 1995, a legal decision represents a watershed in telecommunications policy for people with disabilities when a commission's inquiry finds the national carrier, Telstra, guilty of discrimination against people with severe hearing or speech impairments. The success of the action results in the Telecommunications Act of 1997, which includes new provisions for the deaf community.

1981 ◆ Mexico: The Program of Rehabilitation Organized by Disabled Youth of Western Mexico begins as a rural community-based rehabilitation program.

1981 ◆ Soweto: The Self Help Association of Paraplegics begins as an economic development project.

1981 ◆ United Kingdom: Disabled people set up the British Council of Disabled Persons (BCOPD), the United Kingdom's national organization of disabled people, to promote their full equality and participation in UK society.

1981 ◆ Zimbabwe: The National Council of Disabled Persons, initially registered as a welfare organization, becomes a national disability rights group.

1982 ◆ Disability Studies originates with the formation of the Society for the Study of Chronic Illness, Impairment, and Disability. In 1986, it officially changes its name to the Society for Disability Studies (SDS). Disability Studies is a critical field of study based in human and social science.

1982 ◆ *In re Infant Doe* (commonly known as the Baby Doe case) launches the debate as to whether parents or medical authorities should choose to let a disabled infant die rather than provide the necessary medical treatment and nourishment essential to sustain life. In response to this and other cases, the U.S. Department of Health and Human Services creates a rule maintaining it unlawful for any federally funded hospital to withhold medical treatment from disabled infants. In 1984, the U.S. Congress enacts the Child Abuse Amendments, which calls for the medical treatment of newborns with disabilities unless the child would die even with medical intervention. The issue makes it to the U.S. Supreme Court in 1986 with the *Bowen v. American Hospital Association* case. The Court holds that denying treatment to disabled infants does not constitute legally protected discrimination under Section 504 of the Rehabilitation Act and that hospitals and physicians are to implement the decision of the parents. The decision results in the passage of the Child Abuse Prevention and Treatment Act Amendments of 1984. In the year 2000, a scholar argues that the Amendments, presidential commission writings, and disability advocates "have all combined to ensure that most babies who can benefit from medical interventions do receive them."

1982 ◆ Disability Awareness in Action (DAA) and other groups such as the Disabled Peoples' International (DPI) and International Disability Alliance (IDA) are the driving force behind the globalization of disability issues through the World Program of Action (1982), the United Nations Standard Rules of Equalization of Opportunities for People with Disabilities (1993), the World Summit for Social Development (1995), and the Education for All Framework for Action (2000), as well as the current campaign to secure a UN convention on the rights of disabled people.

1982 ◆ The National Council on Independent Living (NCIL) is formed in the United States. It provides an excellent example of leadership for people with disabilities by people with disabilities.

1982 ◆ Canada: The Charter of Rights and Freedoms section of the Constitution provides protection to persons with disabilities.

1982 ◆ France: Handicap International is founded in Lyon. It is active in various areas associated with all the causes of handicaps, both traumatological (land mines, road accidents) and infectious (polio, leprosy). In the 1990s it begins working on mental disability issues as a result of experience with Romanian orphanages and the war in the Balkans. In 1992, Handicap International creates its first two mine clearance programs and in 1997 it is the joint winner of the Nobel Peace Prize for its leading role in the fight against landmines.

1983 ◆ Rights-based approaches to disability rapidly gain currency in many developing countries since the UN Decade of Disabled Persons, 1983–1992. UNESCAP's Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-Based Society for People with Disabilities in Asia and the Pacific sets the priorities for the extended Decade of Disabled Persons, 2003–2012.

1983 ◆ Access and accessibility are concepts discussed throughout the World Programme of Action Concerning Disabled Persons passed by the UN General Assembly. The General Assembly in 1993 passes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

1983 ◆ England: The first Covent Garden Day of Disabled Artists is held in London.

1983 ◆ Thailand: DPI-Thailand is established.

1984 ◆ The Access Board issues the "Minimum Guidelines and Requirements for Accessible Design," which today serves as the basis for enforceable design standards. The 1990 Americans with

Disabilities Act (ADA) expands the board's mandate to include developing the accessibility guidelines for facilities and transit vehicles. The Rehabilitation Act Amendments of 1998 give the Access Board additional responsibility for developing accessibility standards for electronic and information technology. In 2001, Section 508 of federal law establishes design standards for federal websites, making them accessible to individuals with disabilities.

1985 The U.S. Department of Health and Human Services issues the first comprehensive national minority health study, which shows racial disparity in health and concludes that the difference in mortality is not acceptable. In 1998, studies indicate that racial disparity has not improved as much as hoped; consequently, President Bill Clinton launches an initiative that sets a national goal of eliminating disparities in six key areas by the year 2010. Some of these areas include diseases and conditions considered to be disabling as well as life threatening.

1986 The Air Carrier Access Act (ACAA) passes. It requires the U.S. Department of Transportation to develop new regulations that ensure that disabled people are treated without discrimination in a way consistent with the safe carriage of all passengers. The relevant regulations, Air Carrier Access rules, are published in March 1990.

1986 The National Council on the Handicapped publishes its report *Toward Independence.* It recommends that "Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities" and suggests that the law be called "the Americans with Disabilities Act." In its 1988 follow-up report, *On the Threshold of Independence,* the council takes the somewhat unusual step of publishing its own draft of the ADA bill.

1986 The Equal Opportunities for Disabled Americans Act allows recipients of federal disability benefits to retain them even after they obtain work, thus removing a disincentive that keeps disabled people unemployed.

1986 Australia: The Disability Services Act provides that a person with disability has the right to achieve his or her individual capacity for physical, social, emotional, and intellectual development. In 1992, the Disability Discrimination Act supports nondiscrimination in education and training. It also makes it unlawful to discriminate in relation to access to premises, including public transportation.

1986 Canada: The Employment Equity Act mandates the institution of positive policies and practices to ensure that persons in designated groups, including persons with disabilities, achieve at least proportionate employment opportunities.

1986 England: The first issue of the magazine *Disability Arts in London* (DAIL) is produced in London.

1986 Southern Africa: The Southern Africa Federation of the Disabled is formed as a federation of nongovernmental organizations of disabled persons.

1988 The Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988 and its 1994 amendments), and, in 1998, the Assistive Technology Act (AT) provide financial assistance to states to support programs of technology-related assistance for individuals with disabilities of all ages. The1988 act defines *assistive technology* (AT). The Americans with Disabilities Act of 1990 prohibits discrimination against people with disabilities in employment, public institutions, commercial facilities, transportation, and telecommunications, which includes accessibility to all entrances, bathrooms, program areas, and parking spaces as well as interpreters for the deaf and Braille and large-print materials for the blind. The Telecommunications Act of 1996 requires the telecommunication industry to make equipment that will support transmission of information in forms accessible to people with disabilities including broadband and television program captioning. By 2000, approximately 10 percent of the U.S. population uses AT devices and/or modifications to their home, work, or school that allow them to participate in major life activities.

1988 ◆ Congress introduces a series of amendments to the Civil Rights Act of 1968, including a prohibition of housing discrimination against people with disabilities. These amendments are known as the Fair Housing Act Amendments of 1988.

1988 ◆ China: Deng Pufang, a wheelchair user and son of the late Chinese leader Deng Xiaoping, is the driving force behind a series of laws and programs initiated to improve life for the disabled. In 1984, he sets up the China Welfare Fund for Disabled Persons and, in 1988, the China Disabled Persons' Federation, which endeavors to improve public images of disabled people. Today, there are 60 million disabled people in China.

1989 ◆ The European Network on Independent Living (ENIL) is set up. It focuses on personal assistance as a key component of independent living.

1990 ◆ ADAPT, the American Disabled for Attendant Programs Today, originally called the American Disabled for Accessible Public Transit, continues to gain public awareness through tactics of civil disobedience until regulations are finally issued with the passage of the Americans with Disabilities Act (ADA).

The ADA passes, after ADAPT uses tactics of civil disobedience, in the tradition of other civil rights movements, in one of the largest disability rights protests to date (600 demonstrators), the "Wheels of Justice March," during which dozens of protesters throw themselves out of their wheelchairs and begin crawling up the 83 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day 150 ADAPT protesters lock wheelchairs together in the Capitol rotunda and engage in a sit-in until police carry them away one by one.

George H.W. Bush signs the ADA on July 26. It provides employment protections for qualifying persons with disability. It is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States, expanding the mandate of Section 504 of the Rehabilitation Act of 1973 to eliminate discrimination by prohibiting discrimination in employment, housing, public accommodations, education, and public services.

In June 2000, the National Council on Disability issues a report, *Promises to Keep: A decade of Federal Enforcement of the Americans with Disabilities Act,* which includes 104 specific recommendations for improvements to the ADA enforcement effort. On December 1, 2004, the council issues a final summary report, *Righting the ADA,* in order to address "a series of negative court decisions [that] is returning [Americans with disabilities] to 'second-class citizen' status that the Americans with Disabilities Act was supposed to remedy forever."

1990 ◆ The ADA requires public entities and businesses to provide effective communication to individuals with disabilities. Title IV of the ADA mandates that nationwide telecommunication systems be accessible to persons with speech or hearing disabilities. The Federal Communications Commission (FCC) requires relay services to be in place by July 26, 1993. The Telecommunications Act of 1996 adds provisions to the Communications Act of 1934 that requires manufactures and providers of telecommunications equipment and services to ensure accessibility to persons with disabilities. In 2000, President Bill Clinton establishes regulations governing the accessibility to people with disabilities of the electronic and information technology used within the federal government.

1990 ◆ The Individuals with Disabilities Education Act (IDEA) is enacted. It guarantees the right to free and appropriate education for children and youth with disabilities and focuses on higher expectations, mainstreaming students where possible, and an increased federal rule in ensuring equal educational opportunity for all students. IDEA requires schools to provide a free and appropriate public education to eligible children with disabilities. It also requires schools to develop an individualized education plan (IEP) for each child and placement in the least restrictive environment (LRE) for their education. IDEA is amended in 1997 and reauthorized again in 2004 as the Individuals with Disabilities Education Improvement Act.

1990 ◆ Legislation establishes the National Center for Medical Rehabilitation Research (NCMRR), whose mission is to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of persons with disabilities. It has primary responsibility for the U.S. Government's medical rehabilitation research that is supported by the National Institutes of Health (NIH).

1990 ◆ The World Declaration on Education for All (EFA) is adopted in Jomtien, Thailand, by more than 1,500 persons representing the international community. Article 23 of the UN Convention on the Rights of the Child states that disabled children have the right to a "full and decent life" and that member nations provide free education and training to disabled children whenever possible in order to provide the "fullest possible social integration and individual development." UNESCO is the lead UN organization for special needs education.

1990 ◆ Korea: The disability movement celebrates the passage of the Employment Promotion Act for People with Disabilities. The government imposes control over the disabled population in the 1960s and 1970s by forwarding institutionalization under the banner of "protection," promoting sterilization, and violating the rights of disabled people in general. The 1981 International Year of Disabled Persons influences the government, and new laws, such as the Welfare Law for Mentally and Physically Handicapped, are enacted, and the human rights of disabled people becomes the dominant rhetoric of the disability movement.

1990 ◆ United Kingdom: The National Disability Arts Forum is launched at the UK-OK Conference at Beaumont College in Lancashire, UK.

1991 ◆ The Resolution on Personal Assistance Services is passed at the International Personal Assistance Symposium. Personal assistance services are the most critical services for individuals. Critical aspects of these services are that they must be available up to 24 hours a day, 7 days a week, to people of all ages, and with access to governmental payments. In the United States alone, personal assistance services affect the lives of more than 9.6 million citizens with disabilities.

1991 ◆ Australia: The federal Disability Reform Package is introduced; the Disability Discrimination Act, which covers issues of discrimination in education, is enacted in 1992; and the Commonwealth Disability Strategy, designed to provide equal access to government services for people with disabilities, is first introduced in 1994 and then revised in 2000. During the 1990s similar discrimination legislation emerges in other countries, such as New Zealand's Human Rights Act, the U.K.'s Disability Discrimination Act, Israel's Disabled Persons Act, Canada's Human Rights Act, and India's Disabled Person's Act.

1991 ◆ China: The most important laws and initiatives reside in the 1991 Law on Protection of Disabled Persons and a series of National Work Programs for Disabled Persons (1988, 1991, 1996, 2001), which integrate disability into the government's Five-Year Plans. China participates heavily in the United Nations Decade of Disabled Persons, 1983–1992, and initiates the Asia Pacific Decade of the Disabled Persons, 1993–2002. China continues to collaborate with UN projects involving the disabled and will host the 2007 International Special Olympics in Shanghai.

1991 ◆ Serbia and Montenegro: From the 1960s to the 1980s, post–World War II Yugoslavia is lauded for being a socially advanced nonaligned nation, but the contemporary wars that decimate Yugoslavia begin in 1991, and today there are more than one million disabled citizens, refugees, and casualties due to the wars. Disabled people in Serbia and Montenegro (formally named the Federal Republic of Yugoslavia—FRY) are left with shattered pieces of the spent past with little hope for the near future. Although the FRY constitution prescribes special protection of disabled persons in accordance with legal provisions and Serbia is party to numerous UN documents and acts, a disabled expert in 2004 admits that discrimination against persons with disability in Serbia and Montenegro is a long-term problem that people without disability tend to ignore. Two of the most effective advocacy groups making in-roads today are the Association of Students with Disabilities and the Center for Independent Living in Belgrade.

1992 ◆ The UN Economic and Social Commission of Asia and the Pacific (ESCAP) proclaims a 10-year program known as the Asian and Pacific Decade of Disabled Persons 1993–2002 with goals of full participation and equality for persons with disabilities.

1993 ◆ The United Nations publishes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which becomes the international legal standards for disability programs, laws, and policies. Although not legally enforceable this instrument sets an inclusive and antidiscriminatory standard that is used when national policies are developed. It marks a clear shift from the rehabilitation and prevention paradigm to the human rights perspective on disability.

1993 ◆ Slovak Republic: The Czech and Slovak Republics separate into two independent countries. They both join the European Union in 2004. In Slovakia, a large number of highly innovative and resourceful grassroots nongovernmental organizations emerge to address the human rights, quality-of-life, and independent living priorities of citizens with disabilities. They pursue this mission, however, with extremely limited resources and with varying degrees of support from a multiparty parliament.

1993 ◆ Sweden: The Independent Living Institute (ILI) is founded.

1994 ◆ Two networks, one for elderly persons and the other for persons with disabilities, join together to form the U.S. National Coalition on Aging and Disability. In following years, policy makers and advocates begin to see the benefits of merging some services.

1994 ◆ Germany: The disability rights movement is successful in using for its own aims the reform of the German constitution, which is made necessary by the reunification process. An amendment to the constitution forbids discrimination on the grounds of disability. Other such laws as the Rehabilitation of Participation Law (2001) and the Federal Equal Rights Law (2002) are formulated with the active contribution of disability rights activists, and in 2003, the official German program of the European Year of People with Disabilities is organized by a prominent activist.

1994 ◆ Sweden: The Swedish Disability Act (LSS) comes into force. It expands the 1985 Special Services Act. The LSS is also more ambitious than its predecessor, calling for "good living conditions" rather than just an "acceptable standard of living."

1995 ◆ The National Council on Disability, a federal agency, makes recommendations to the president and Congress on disability issues. Among other issues, it calls for the end to the use of aversives (techniques of behavior control such as restraints, isolation, and electric shocks) because they are abusive, dehumanizing, and psychologically and physically dangerous. Other organizations follow, such as the Autism National Committee in 1999, TASH in 2004, and the International Association for the Right to Effective Treatment in 2003.

1995 ◆ The Commission for Case Management Certification (CCMC) incorporates. Case management is a process of care planning and coordination of the services and resources used by people with disabilities and their families.

1995 ◆ Europe: The Association for the Advancement of Assistive Technology in Europe (AAATE) is founded as an interdisciplinary association devoted to increasing awareness, promoting research and development, and facilitating the exchange of information. AAATE is composed of more than 250 members from 19 countries. It interacts with sister organizations in North America, Japan, and Australia to advance assistive technology worldwide. The Tokushima Agreement, signed in 2000 by AAATE, the Rehabilitation Engineering and Assistive Technology Society of North America

(RESNA), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation and Assistive Technology Association (ARATA), promotes exchange of information and collaboration.

1995 ◆ United Kingdom: The campaign for antidiscrimination legislation begins in earnest with the emergence of the disability movement in the late 1970s. The Disability Discrimination Act of 1995 (DDA) together with the Disability Rights Commission Act of 1999 constitute the primary source of antidiscrimination legislation for disabled people in the United Kingdom. The Disability Discrimination Act 2005 extends the protection.

1996 ◆ There are 1.4 million fewer disabled older persons in the United States than would have been expected if the health status of older people had not improved since the early 1980s.

1996 ◆ Advocates for mental health parity such as the National Alliance for the Mentally Ill (NAMI; 1979) believe that mental illnesses are real illnesses and that health insurance and health plan coverage for treatment should be equal with coverage of treatment for all other illnesses. Due in part to advocacy, the Mental Health Parity Act becomes law in 1996. In 1999, mental illness ranks first in causing disabilities among many industrialized nations, including the United States, which experiences a loss of productivity in this year of $63 billion. In the United States, 5 to 7 percent of adults suffer from serious mental disorders and 5 to 9 percent of children suffer from serious emotional disturbances that severely disrupt their social, academic, and emotional functioning.

1996 ◆ Costa Rica: Approval of a law called Equal Opportunities for People with Disabilities is a turning point for the population with disabilities, which is among the most excluded sectors of society. The law is inspired in part by the United Nations Standard Rules on the Equalization of Opportunities for Disabled People (1993). Disability experience in Costa Rica is definitely transformed as a result of the mandates of this generic law, as people with disabilities and their families start to use this legal instrument as a strategy to empower themselves.

1996 ◆ Europe: Created in 1996, the European Disability Forum (EDF) is today the largest independent, trans-European organization that exists to represent disabled people in dialogue with the European Union (EU) and other European authorities. Its mission is to promote equal opportunities for disabled people and to ensure disabled citizens full access to fundamental and human rights through its active involvement in policy development and implementation in the EU. The EDF has national councils in 17 European countries and has 127 member organizations. The European Year of People with Disabilities 2003 is one of the EDF's most important campaigns.

1996 ◆ India: The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, becomes law. It is the first legislation for equal opportunities for disabled people. Prior to this, disabled persons receive services but not legal protection. Improvements in conditions begin in 1981 with the International Year of Disabled Persons. India is a signatory to the UN resolution of 1976 establishing it and is thereby committed to improving the lot of the disabled. The Lunacy Act of 1912 is repealed and the National Mental Health Act is passed in 1987. Nonetheless, with approximately 70 million disabled people residing in India (in a population of over a billion), the government does not include the domain of disability in the 2001 census, which reflects the attitudinal barriers in acknowledging the disabled identity.

1997 ◆ Government expenditures on behalf of persons with disabilities may total as much as $217.3 billion (taking into account the costs that would be expected among persons with disabilities in the absence of the disability), the equivalent of 2.6 percent of the gross domestic product in the United States for 1997.

1997 ◆ The landmark 1997 UNESCO Universal Declaration on the Human Genome and Human Rights frames the actual application of the new scientific developments raised by genetics. As a policy statement, it provides the first signs that genetics will be applied in ways that maintain human rights. In 2003, the Council of Europe and the council's Steering Committee in Bioethics issue policy statements in a working document titled Application of Genetics for Health Purposes. In the case of gene therapy, in 1994, the Group of Advisors on the Ethical Implications of Biotechnology of the European Commission voices concern regarding equity, maintaining that all genetic services that are available for the entire population should be equally available for persons of disability. Today, UNESCO's Human Genome Organization's Ethics Committee, the World Health Organization, the Council of Europe, and consumer organizations such as Inclusion International, Rehabilitation International, and Disabled Peoples' International play major roles in translating genetic innovations into health service and public health fields, helping develop policies that focus on the general recognition, respect, and protection of the rights to which all people, whether disabled or nondisabled, are entitled. Concerns related to the possible undermining of human rights are expressed in 2003 when Disabled People's International demands a prohibition on compulsory genetic testing.

1997 ◆ Colombia: The General Act for People with Disabilities, also known as the Disability Act: Law for Opportunity, passes. The 2003–2006 National Plan of Attention to Persons with Disabilities estimates that 18 percent of the general population has some type of disability. Despite the existence of at least 37 disability-related legal policies (2001), the government provides limited spending on programs that protect the rights of people with disabilities, and the lack of enforcement of rights remains a major concern. Today's awareness efforts include marathons with the participation of the general population to raise money for educational programs for children with special needs, Special Olympics, new organizations such as the Colombian Association for the Development of People with Disabilities, and media awareness campaigns.

1998 ◆ President Bill Clinton issues an executive order ensuring that the federal government assumes the role of a model employer of adults with disabilities.

1998 ◆ President Clinton signs into law the Rehabilitation Act of 1973 Amendments. Section 508 requires that electronic and information technology (EIT), such as federal websites, telecommunications, software, and information kiosks, must be usable by persons with disabilities.

1998 ◆ Ireland: The Irish Employment Equality Act entitles all individuals, including disabled persons, equal treatment in training and employment opportunities. The Education Act of 1998 requires schools to provide education to students that is appropriate to their abilities and needs. The Education for Persons with Disabilities Bill passes in 2003. A Disability Bill published in 2001 fails to underpin a rights-based approach and is withdrawn amid a storm of protest in 2002; a redrafting of a new Disability Bill is suffering from continuing delays. Traditionally, Irish voluntary organizations play a reactionary role in the development of services for people with disabilities and a key role as pressure groups trying to keep disability issues on the political agenda.

1999 ◆ The National Center on Physical Activity and Disability (NCPAD) is established as an information and resource center that offers people with disabilities, caregivers, and professionals the latest information on fitness, recreation, and sports programs for people with disabilities.

1999 ◆ Established by a panel of experts brought together to evaluate the UN Standard Rules on the Equalization of Opportunities for Persons with Disability, the International Disability Alliance (IDA) encourages cross-disability collaboration and supports the participation of international disability organizations in the elaboration of a proposed UN convention on disability.

1999 ◆ England: The first disability film festival, Lifting the Lid, is held at the Lux Cinema in London.

2000 ◆ The National Telability Media Center collects documentation of 3,000+ newsletters, 200 magazines, 50 newspapers, 40 radio programs, and 40 television programs dedicated to disability in the United States alone. *The Ragged Edge, Mainstream* (Internet-based), and *Mouth* are examples of disability rights-focused publications.

2000 ◆ *Healthy People 2000,* the second edition of the Surgeon General's report on health promotion and disease prevention (the first edition published in 1979), includes some reference to the health and well-being of people with disabilities, but few data are available. In the mid-1990s, the U.S. Department of Health and Human Services begins a dialogue with the Centers for Disease Control and Prevention to include people with disabilities in the third edition, *Healthy People 2010.* The resulting report includes more than 100 objectives that include "people with disabilities" as a subpopulation for data gathering.

2000 ◆ The World Bank, increasingly concerned with how to include disabled persons in the economies and societies of developing nations, establishes an online clearinghouse to make documents concerning the disabled readily available to member nations and the general public and holds its first course on disability issues in 2004 in Guatemala.

2000 ◆ Africa: The African Decade of Persons with Disabilities, 2000–2009, is adopted by the Declaration of the Organization of African Unity. The African Network of Women with Disabilities (2001) and the community-based rehabilitation organization CBR Africa Network (CAN) are examples of the many activities that result from the African Decade.

2000 ◆ Brazil is one of the few countries to include an entire section on disability in its 2000 census. Results show that 14.5 percent of the population, roughly 24 million people, report having some form of disability, the poorest region, the northeast, reporting the highest percentage and the richest, in the south, the lowest. People with disabilities in the first half of the twentieth century have no voice or representation. In 1932, the first Pestalozzi Society, a community-based school for children with intellectual disabilities, is founded. By the end of the twentieth century, there are 146 Pestalozzi Societies and more than 1,700 chapters of the Association of Parents and Friends of the Exceptional. The first center for independent living is established in 1988 (CVI-RIO). In 1992 and 1995, CVI-RIO organizes two international conferences on disability issues called DefRio, out of which comes "Goals of the ILM," a document that delineates the basis for the independent living movement in Brazil; however, financial support is not provided by the government, creating a struggle for sustainability. Brazil has progressive policies toward disability. The constitution includes sections on the rights of people with disabilities, and laws have been passed with regard to accessibility, education, and employment.

2000 ◆ Europe: A European Community directive requires all member states to have introduced antidiscrimination laws in the fields of employment and training by the end of 2006. It seeks to establish a general framework for equal treatment in employment and occupation and to render unlawful discrimination based on, among other categories, disability. The European Union Charter of Fundamental Rights sets out in a single text, for the first time in the EU's history, the whole range of civil, political, economic, and social rights of European citizens. Disability is included in the general nondiscrimination clause (Article 21), but Article 26 specifically states that the Union recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.

2000 ◆ The Human Genome Project (HGP), an international effort to specify the 3 billion pairs of genes that make up the DNA sequence of the entire human genome, produces its first draft in June 2000. Formally begun in October 1990, it is completed in 2003.

2001 President Clinton declares in Executive Order No. 13217 the commitment of the United States to community-based alternatives for individuals with disabilities. This ensures that the *Olmstead v. L.C.* decision (1999), which mandates the right for persons with disability to live in the least-restrictive setting with reasonable accommodations, is implemented in a timely manner. The executive order directs federal agencies to work together to tear down the barriers to community living.

2001 In the United States, census data indicate that only 48 percent of citizens 25 to 64 years old with severe disabilities have health insurance compared with 80 percent of individuals with nonservere disabilities and 82 percent of nondisabled Americans. Women with disabilities in general are more likely to live in poverty than men. Minorities with disabilities are more likely to live in poverty than nonminorities with disabilities. In 2003, in the United States, about 28 percent of children with disabilities live in poor families compared with 16 percent of all children.

2001 A UN Ad Hoc Committee begins discussions for a legally binding convention under the draft title Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Its fifth session is held in early 2005.

2001 A new World Health Organization classification of people with disabilities, the International Classification of Functioning, Disability, and Health (ICF), replaces the old International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The ICF definition shifts the focus from disability as an innate deficit ("medical model") to disability as constructed through the interaction between the individual and the environment ("social model"). This shift encourages a focus on the kinds and levels of interventions appropriate to the needs of individuals.

2001 UNESCO launches pilot education projects for disabled children in Cameroon, the Dominican Republic, Egypt, Ghana, India, Madagascar, Mauritius, Nicaragua, Paraguay, South Africa, Vietnam, and Yemen. The global initiative Education for All 2000 has as its primary millennium development goal universal education by the year 2015.

2002 The U.S. Supreme Court rules that executing persons with mental retardation is unconstitutional.

2002 Disabled Peoples' International's 2002 Sapporo Platform, developed by 3,000 delegates from more than 90 countries, urges members to take every opportunity to seek publicity and awareness in order to change negative images of disabled people.

2002 Canada: The Canadian International Development Bank announces the approval of the Canada-Russia Disability Program, a four-year $4 million project, focusing on education, disability studies, social work practice, social policy, and information dissemination.

2003 A national survey that updates the Disability Supplement to the 10-year-old National Health Interview Survey highlights barriers to care among the uninsured. The uninsured are four times as likely to postpone care and three times as likely to go without needed supplies.

2003 The National Association of Social Workers (NASW) issues a policy statement that discusses their core values with respect to working with people with disabilities, including self-determination, social justice, and dignity and worth of the person. The statement emphasizes that social workers are responsible to take action with people who have disabilities in advocating for their rights to fully participate in society.

2003 The Disability Awareness in Action (DAA) database contains a total of 1,910 reports of known abuse affecting nearly 2.5 million disabled people. In the area of education alone, it documents

118 cases affecting 768,205 people in 67 countries. Responding to this documentation and other reports, the United Nations Commission on Human Rights creates the Global Rights campaign to address human rights abuses. Disability rights organizations use this information to insist on a UN convention on the rights of disabled people that would be legally binding on nation-states.

2003 The International Association for the Study of Pain has more than 6,700 members, representing more than 100 countries and 60 disciplinary fields. Chronic pain is one of the leading causes of recurrent and permanent disability in the developed world today, yet less than 1 percent of the U.S. National Institutes of Health's budget supports research into mechanisms and management of pain. The U.S. Congress declares 2000–2010 the Decade of Pain Control and Research.

2004 The *Journal of Gene Medicine* (January) reports that 636 gene therapy clinical trials are completed or ongoing, involving 3,496 patients. The first gene therapy clinical trials begin in the early 1990s.

Today Seventy to eighty percent—approximately 400 million—of the world's disabled people (600 million, or 10 percent of the world's population) live in the developing world, and of the world's poorest of the poor, 20 to 25 percent are disabled. In most countries, 1 out of 10 persons has a disability. Many international efforts are under way to address poverty and disability, such as those of the Action on Disability Development and the Chronic Poverty Research Centre.

Today E-health is the use of emerging interactive telecommunications technologies such as the Internet, interactive TV, kiosks, personal digital assistants, CD-ROMs, and DVD-ROMs to facilitate health improvement and health care services, including those with disabilities. E-health relies on environments that use a variety of technologies that can compensate for the lack of sensory ability. Telerehabilitation is an example of services delivered information technology and telecommunication networks.

Today Celebrating difference is the mantra and visible manifestation of disability culture in all regions of the world.

SEARCHING FOR AND EVALUATING WEBSITES

Anne Armstrong

The Internet, or Web, provides a vast number of channels through which researchers can find information on virtually any subject. The expansiveness of the Web can be daunting to new researchers. On the other hand, researchers often assume that they have mastered the Web in its entirety when indeed they have merely scratched the surface in terms of the numbers of resources they have consulted and searches they have performed.

Because the field of disability studies is continually evolving and inherently multidisciplinary, Web searchers can draw on previously conducted research from disciplines within the humanities, social sciences, and health sciences. This guide aims to expose beginning researchers to a mixture of general and subject-specialized Web-based search tools, as well as strategies for performing sophisticated Web searches and criteria for evaluating websites. In addition to its broad subject coverage, the field of disability studies differs from most fields in that many researchers may themselves have disabilities affecting their ability to perform research on the Web. For this reason, this description concludes with an overview of accessibility issues on the Web and suggestions for further reading.

OVERVIEW OF WEB-BASED RESEARCH TOOLS

When approaching Web searching, researchers should be aware of the multitude of search tools available to them, in addition to the varying purposes of these tools. Many users approach Web searching with the assumption that "everything is in Google," but this is a limiting misconception. No single search engine contains everything on the Web. Furthermore, all search engines function differently and rank results differently. Therefore, sampling various search tools increases the comprehensiveness of results on any topic. This discussion outlines multiple types of search tools available on the Web and offers potential starting points for Internet research on issues related to disability studies, whether from a health sciences, social sciences, or humanities perspective.

The Web-based search tools outlined in this chapter include general search engines, subject-specialized search engines, directories, indexes, catalogs, and Listservs. It is important to note that different types of search tools cover different parts of the Web. The Web is composed of layers. The top layer is detectible by general search engines, while a deeper layer termed "the invisible Web" can be penetrated only by specialized search engines, indexes, and catalogs. Readers should be aware that because the Web is in a constant state of flux, currently available resources may become obsolete over time, and newer, more sophisticated search tools will undoubtedly evolve.

General Search Engines

Most people who have searched the Web are familiar with sites such as Google, HotBot, or Lycos, which allow them to enter a string of keywords into a search box to retrieve a list of relevant websites (see Table 1). These sites, referred to as search engines, search the Web by means of a program called a *spider* (also

Table 1 Selected General Search Engines

Name	*URL*
AltaVista	www.altavista.com
Excite	www.excite.com
GO	www.go.com
Google	www.google.com
HotBot	www.hotbot.com
Lycos	www.lycos.com
Yahoo!	www.yahoo.com

called a *robot* or *crawler*). Since search engines tend to index millions of websites, they are most useful for entering specific search terms rather than broad concepts such as disability studies.

While Web searchers tend to pick a favorite search engine and return to it repeatedly, it is important to note that different search engines produce varying results, and that a truly comprehensive Web searcher should compare the results of multiple search engines. The variation between search engines can be attributed to differences between the spiders fueling the search engines as well as differences in the level of indexing and the order in which results are ranked. While some search engines index the full text of documents, others may index only the first page, or merely the *meta-tags*, which are lines of code containing keywords. Web searchers should be aware that developers of websites may intentionally increase their usage of certain words or meta-tags to increase the prominence of their website among search results. This practice has been referred to as *spamdexing* and is most prevalent among the developers of commercial websites advertising products and services. Due to the constant fluctuation of the Web, no search engine is entirely up-to-date; results produced by identical searches can vary greatly from one day to the next, even when one is using the same search engine.

Subject-Specialized Search Engines

Subject-specialized search engines (also referred to as subject portals) developed by educational institutions, associations, government agencies, and corporate entities narrow the broad scope of the Web, providing a focused channel by which researchers can search for information when they have determined the discipline from which their topic stems. Examples of such search engines are listed in Table 2. While subject-specialized search engines index considerably fewer websites and documents than general search engines, the information contained within them has been preselected, ideally by experts within a given field. Many subject-specialized search engines expose searchers to parts of the "invisible Web" not indexed by general search engines. Subject-specialized search engines can ease the research process by whittling down the Web to a more manageable size. However, researchers who use them should take the time to view the criteria for selection of

Table 2 Examples of Subject-Specialized Search Engines

Name	*URL*	*Subject Coverage*
Center for International Rehabilitation Research Information and Exchange (CIRRIE)	http://cirrie.buffalo.edu	Rehabilitation research
FamilyDoctor.org	http://familydoctor.org	Health sciences
FirstGov	www.firstgov.gov	Government
Google's Uncle Sam	www.google.com/unclesam	Government
Health*Web*	www.healthweb.org	Health sciences
Mayo Clinic	www.mayoclinic.com	Health sciences
MedlinePlus	http://medlineplus.gov	Health sciences
National Center for the Dissemination of Disability Research (NCDDR)	www.ncddr.org	Disability studies
Social Science Information Gateway (SOSIG)	www.sosig.ac.uk	Social sciences
Thomas	http://thomas.loc.gov/	Legislative information
Voice of the Shuttle	http://vos.ucsb.edu	Humanities
*Web*MD	www.webmd.com	Health Sciences

information contained within them. This information is usually posted within online "help" or "about" pages on the home page.

Table 3 contains search tools that have been developed distinctly for the purpose of locating specialized search engines by subject.

Directories

Directories are hierarchically arranged subject guides composed of websites chosen by or recommended to editors of the directory (Table 4). Usually, directories follow a template in which major subject categories such as health, sciences, social sciences, or humanities are posted on the top-level page. Each of these links leads to lists of narrower subcategories. The links on the second level lead to narrower subcategories, and so on. A sample hierarchy from the directory created by Google (available at http://directory.google.com) lists the following subject breakdown: Society → Disabled → Disability studies.

Directories provide Web searchers with the ability to browse recommended resources in various subject areas without having to enter specific search terms. Other useful attributes of directories are that they often contain summaries and evaluations of websites.

Table 3 Resources for Finding Subject-Specialized Search Engines

Name	*URL*
CompletePlanet	www.completeplanet.com
Direct Search	www.freepint.com/gary/direct.htm
InfoMine	www.infomine.com
Invisible Web Directory	www.invisible-web.net
Librarians' Index to the Internet	www.lii.org
Search Engine Colossus	www.searchenginecolossus.com

Table 4 Selected Directories

Name	*URL*
eBlast	www.eblast.com
Google Directory[a]	http://directory.google.com
Internet Public Library	www.ipl.org
LookSmart	www.looksmart.com
Yahoo! Directory[a]	www.yahoo.com

a. These sites contain both directories and general search engines.

Article Indexes

Article indexes allow researchers to search by topic for published articles in magazines and scholarly journals. Researchers could certainly locate journal and magazine articles using a freely available search engine such as Google, but they would merely be skimming the surface of what has been published. While the Web provides access to *more* content, it does not provide comprehensive access to research published in journal articles. Article indexes are for the expressed purpose of finding journal articles. With a few exceptions (such as PubMed, an article index of health sciences journals developed and maintained by the National Library of Medicine), article indexes are not freely available on the Web. Libraries purchase subscriptions to multiple article indexes covering a wide spectrum of disciplines. The indexes available through a given library are often dictated by the curriculum of the college or university that the library serves. Thus, large research institutions offer a greater number of specialized article indexes than smaller institutions and public libraries. Due to licensing agreements between article index providers and libraries, off-site access to indexes is usually limited to faculty and students of a college or university. However, there are many libraries that allow members of the public to use their article indexes from within the library. A local public library would be a good starting place for those not connected with academic or commercial organizations.

Since article indexes are proprietary products developed by companies for sale to libraries, they tend to offer specialized search features that are not always available on freely available search engines. These features include subject headings, thesauri, abstracts (summaries of articles), and frequently the full text of articles. Researchers should familiarize themselves with online tutorials, "help" screens, and "about" pages to increase the effectiveness of their searching.

Freely available article indexes relevant to disability studies include the following:

- PubMed: A product of the National Library of Medicine, which includes more than 14 million citations for biomedical articles dating back to the 1950s. URL: http://www.ncbi.nlm.nih.gov/entrez

- CIRRIE: Center for International Rehabilitation Research Information and Exchange, a database containing more than 24,000 citations of international research published from 1990 to the present. URL: http://cirrie.buffalo.edu

Catalogs

While researchers can search indexes to find articles on specific topics, they can search online catalogs to find books. Some catalogs list the books available at individual libraries, while others contain the holdings of multiple libraries and institutions. The individual catalogs of public libraries and universities are usually freely available on the Web. The most comprehensive catalog is called WorldCat, developed by an organization called OCLC (Online Computer Library Center). WorldCat lists books available at public and academic libraries throughout the world. Like most article indexes, WorldCat is not freely available on the Web and must be accessed through a library.

Listservs

Listservs are mailing lists on the Internet that facilitate online discussions on various subjects. They allow researchers within a given field to communicate about scholarly issues via email. People customarily sign up for Listservs by sending an e-mail to the Listserv address stating that they wish to subscribe. Several Listservs related to disability studies are listed in Table 5. In addition, Web searchers can perform a search on a database called tile.net to search for Listservs by topic.

Table 5 Disability Studies Listservs

Name	*URL*
ADA-LAW	http://listserv.nodak.edu/archives/ada-law.html
Disability-Research Discussion List	http://www.leeds.ac.uk/disability-studies/discuss.htm
Disability Studies at Yahoo.com	http://www.groups.yahoo.com/group/disabilitystudies
Disabled Student Services in Higher Education (DSSHE-L)	http://listserv.acsu.buffalo.edu/archives/dsshe-l.html
Women's International Linkage on Disability (D-WILD)	http://groups.yahoo.com/group/d-wild

SEARCH STRATEGIES

Since search capabilities vary from site to site, Web searchers should use online "help" screens and tutorials to learn search tips and strategies for improving their search results. Some search techniques common to several Web-based search tools are summarized below.

Quotation Marks

When entering a search, users should enter phrases in quotation marks to stipulate that they would like the results to contain a specific word combination and order. For instance, multiword concepts such as "disability studies," "adaptive technology," and "section 508" should be entered within quotation marks. Proper names can also be entered within quotation marks.

Truncation

Truncation symbols allow Web searchers to simultaneously search for multiple endings of a given word. For instance, assuming that the asterisk is the designated truncation symbol in a search engine, entering the word "impair*" would produce results including all forms of the word after the root, including "impair," "impaired," "impairment" and "impairments." In addition to adding truncation symbols to the end of words, users may also insert internal truncation symbols if there are potential variations for the spelling of the middle of a word. For instance, entering the word "colo*r" would simultaneously search for the words "color" and "colour." "Help" screens or "search tips" usually list the designated truncation symbol for a given database.

Boolean Logic

Developed by the English mathematician George Boole, Boolean logic is a mathematical framework that Web searchers can apply to broaden or refine their searches. There are three words, or *operators*, that Web searchers can use to combine their keywords to perform more complex searches: AND, OR, and NOT. The three Boolean operators are summarized below, along with potential applications. It is important to read the online "help" section of a database before performing a Boolean search, as Boolean searching does not work in all databases.

Using the Boolean Operator "AND"

Combining words with "AND" narrows a search, as the database retrieves only items that contain *all* the words entered. The second search example below will produce fewer results than the first, since there are three keywords that must appear within the content of each result.

"disability studies" AND theory
"disability studies" AND theory AND history

Using the Boolean Operator "OR"

Entering the term "OR" between keywords stipulates that any, but not all, of the words entered must appear within the search results. Using "OR" is a way of searching for synonyms or related terms when there are multiple words for the same concept. The example below shows how you could broaden your search if you wanted to search for multiple adaptive technology applications in a search engine. The second search example will potentially produce more results than the first, since there is an additional keyword that the results could include.

JAWS OR "Ruby OpenBook"
JAWS OR "Ruby OpenBook" or "window eyes"

Using the Boolean Operator "NOT"

Entering the Boolean operator "NOT" after a word stipulates that the word should not appear within the results. Using "NOT" in a search can be particularly useful if a word is frequently used in multiple contexts and you wish to eliminate results dealing with a particular topic. In the example below, the second search will ideally eliminate items relating to the state of New Mexico, given that the researcher is looking for information on legislation related to disabilities in the country of Mexico. The use of NOT can be too limiting. The second search would eliminate results that discussed both Mexico and New Mexico.

Disabilities AND legislation AND Mexico
Disabilities AND legislation AND Mexico NOT "new mexico"

Nesting

Nesting allows Web searchers to simultaneously search for multiple search terms relating to the same topic. The grouping of synonymous terms within parenthesis is referred to as nesting, as multiple terms relating to the same idea are clustered together as a single concept. When using nesting, the words within the parenthesis are connected by the Boolean operator "OR."

To find information about software for people who are visually impaired, search results are increased by using nesting to group multiple words for each facet of the topic:

(software or "adaptive technology") AND ("visually impaired" or blind)

Plus and Minus Signs

Most general search engines allow users to enter plus or minus signs before a particular word. Entering a plus sign before a word (e.g., +ADA) stipulates that the word must appear within the search results. A minus sign before a word (e.g.,–mobility) stipulates that the word should not appear within the results. Since some search engines also use plus and minus signs as substitutes for Boolean operators, it is important to view online "help" or "search tips."

Search Limits

Most search engines allow users to limit their results by date, language, or document type. Limiting capabilities vary from site to site and are customarily outlined in online "help" screens. In general, article indexes have more sophisticated limiting capabilities than search engines that are freely available on the Web.

EVALUATING WEBSITES

A researcher weighing the quality of a journal article faces a lesser challenge than a researcher considering a website as a potential resource. The publishing industry applies labels to periodicals of varying type: Scholarly journals, popular magazines, trade publications, and newspapers comprise the major categories. Articles submitted to scholarly journals undergo a peer review process by experts in a given field. If in doubt as to the suitability of journal for scholarly purposes, a researcher can consult a directory of periodicals such as *Ulrich's Periodicals Directory,* which indicates whether or not a journal is peer reviewed.

The fact that the Web has no comparable methods of control complicates the task of determining whether a website is appropriate for research purposes. While websites produced by certain types of agencies and organizations certainly undergo a form of *internal* review, the Web is a free forum; people can post anything they want, and no one has the right to force to take it down if it fails to meet certain standards of quality or accuracy. To complicate the matter, inaccurate or inexpert information can hide like a wolf in the sheep's clothing of sophisticated graphics, layout, and design. The Web has no peer review process to ensure quality. While none of the evaluation criteria outlined below can provide the final word as to the suitability of a website for scholarly use, a researcher who searches the Web with multiple evaluation criteria in mind expedites the process of finding quality information.

Authorship

When determining the credibility of a website, researchers should use multiple techniques to determine the credentials of the author as well as the character of the organization hosting, or sponsoring, the site. If individuals are listed as authors, researchers should take steps to determine their credentials and reputation in the field by performing a search in a general search engine to find biographical information or other documents written about the author. This will also produce references to the author on the sites of other authors within a field. Researchers can also consult a number of biographical sources available at libraries, such as *Who's Who in the America* or sources tailored to particular fields of study, such as *Who's Who in Science and Engineering.*

Website addresses, or URLs (Uniform Resource Locators) can also provide hints as to author affiliations and potential bias. Personal websites are often hosted on commercial ISP (Internet Service Provider) Web servers such as aol.com, or geocites.com. URLs of personal websites often contain first or last names, as well as percent (%) or tilde (~) signs. While personal websites may contain authoritative information, researchers should question why the same content does not appear on a site sponsored by an educational or research organization.. Was the site created as a pastime or to serve as a forum for airing personal views? Or does the site reflect serious scholarship backed up by other credentials and research published in scholarly publications?

Every website URL ends with a *domain name*, usually a series of three letters preceded by a period. The domain name denotes the type of institution that hosts the website and can often provide clues as to the purpose or potential bias of a site. Common domain names include the following:

Educational sites: .edu
Government sites: .gov, .mil, or country codes (e.g., .uk = United Kingdom, .au = Australia, .do = Dominican Republic)
Nonprofit organization sites: .org
Commercial sites: .com

Most URLs contain multiple levels separated by slashes (e.g., http://www.nod.org/stats/). To learn more about the sponsor or publisher of a particular site, you can remove levels of the URL one by one to see where the site is hosted and determine the character of the sponsoring entity. For instance, if a site is hosted on the site of an association, viewing the mission statement on the home page of the association can provide clues as to the bias or purpose of the content. When judging the credentials of the publishing entity, researchers should look for contact information and institutional logos. In general, sites devoid of identifying information or contact numbers and addresses should raise suspicion.

Audience

When evaluating a site, researchers should determine whether the content succeeds in addressing the stated audience through tone and presentation. Sites for adults should not have a childlike appearance or tone. Likewise, sites may be deliberately overrun by technical language or jargon to confuse or mislead a particular audience. High-quality sites clearly define their intended purpose.

Currency

Medical research findings or population statistics may become obsolete at a faster rate than research in the humanities. Web researchers should check sites for copyright dates and the date of the last update. Broken links are a sign of neglect, as they may indicate that URLs have changed or become obsolete since the last update of the site. To verify the currency of information on a site, researchers should check for several sites covering the same subject matter.

Accuracy

Determining accuracy involves further research to ensure that the claims or findings on a site are substantiated by other sources. If a site presents original research, the methods of the research and instruments used should be clearly explained, as well as potential limitations of the research. If authors make claims or conclusions, they should cite their sources, and these sources should be tracked down to ensure their existence and authenticity. Websites should contain a list of works cited or footnotes on par with any print book or article. Since websites sometimes include fabricated resources, and erroneous or incomplete citations, sources should be verified using library tools such as indexes and catalogs. Lists of works cited with multiple errors reflect irresponsible research. If a website contains links, the links should be checked. Researchers should be wary of websites populated by broken links or links to defunct websites.

Quality

In general, sites that are poorly organized or sloppy should be approached with caution. Shoddy design may point to further weaknesses. Poor grammar and spelling errors are also red flags.

Bias

While bias is not always a negative attribute, Web searchers should be cognizant of bias as the search for information. The bias of a website can be partially discerned by the domain name (as discussed above under "Authorship"). Commercial websites may be motivated by the goal to market a product or service. Nonprofit organizations may promote a political agenda. While bias may be clearly stated in mission statements and "about" pages, many websites deliberately shroud their bias. Thorough research involves consulting additional sources to determine the history and activities of a particular organization. If a site contains links to other sites, those links should be checked to discern the character and activities of the other organizations listed. If a site is sponsored by other organizations, researchers should consider the relationship between the sponsors and the creators of the site.

Special Considerations for Evaluating Health Information on the Web

The American Medical Association (AMA) has published "Guidelines for Medical and Health Information Sites on the Internet" outlining evaluation criteria for websites publishing health information, whether for consumers or health professionals. While these guidelines are technically enforced only on sites sponsored by the AMA or affiliated organizations, they could be applied to all sites containing health information. Many of these guidelines mirror the previously outlined criteria for evaluating all websites, but there are certain factors that are heavily emphasized in the AMA guidelines, including the importance of peer review by experts in the field, the importance of clearly identifying sources of funding, an explanation of the relationship between individual researchers and the institutions sponsoring the research, the importance of clearly stating the purpose and intended audience of a site, and the need to address the stated audience in a consistent and effective tone. Seven criteria for assessing the quality of health information on the Internet have been developed by the Health Summit Working Group (Health Information Technology Institute 1999).

Information on health-related websites should be verified by checking sources such as journal articles, books, and other websites. These measures are needed as health information on the Web frequently includes unsubstantiated claims.

OVERVIEW OF ACCESSIBILITY ISSUES ON THE WEB

Disability studies research is unique in that many scholars in the field have disabilities that may impact their ability to effectively search the Web. While in many ways the Web "evens the playing field" by making a vast number of resources available electronically, inaccessible design frequently places barriers on Web searchers with disabilities.

Principles of Web accessibility have been developed by the World Wide Web Consortium's (W3C) Web Accessibility Initiative (WAI). The WAI establishes guidelines for creating accessible websites, browsers, and authoring tools to increase the ease of use of the Web for users with disabilities. Multiple scenarios outlining potential challenges to Web searchers with disabilities are summarized in a W3C working draft titled "How People with Disabilities Use the Web" (2001). Among other scenarios, the document emphasizes that many Web searchers with cognitive or visual disabilities use OCR (optical character recognition) software, which reads Web page text and transmits the information to a speech synthesizer and/or refreshable Braille display. Many users with visual disabilities use text-based Internet browsers instead of standard graphical browsers. The successful use of these tools requires that images on websites be accompanied by descriptive text and *ALT tags*. ALT tags are textual labels that appear on the computer screen when a mouse moves over an image. Since visually impaired

Web searchers often enlarge Web-based text using screen magnification programs, Web designers must create pages with nonfixed font sizes that can be altered as necessary. These are only a few of the issues facing Web searchers with disabilities. Other population groups with disabilities discussed in the guidelines include individuals with cognitive disabilities, hearing impairment, and mobility-related disabilities. Readers should consult the WAI website for the complete guidelines (http://www.w3.org/WAI/).

To support the goals of WAI, an online tool called Bobby™ helps website developers test the accessibility of their sites and adhere to accessibility guidelines. By entering a URL into the Bobby website, a Web developer can generate a report outlining which features of the site need to be adjusted to make it "Bobby compliant" and adhere to both W3C accessibility guidelines and guidelines established by the U.S. government's Section 508, a 1998 amendment to the Rehabilitation Act requiring that all federal agencies make their electronic and information technology accessible to people with disabilities. Complete information about these guidelines can be found on the Section 508 website (www.section508.gov).

CONCLUSION

While "one-stop shopping" in Google may be tempting, there is no single search engine leading to everything on the Web. Comprehensive and effective research in disability studies involves consulting multiple search tools, including but not limited to general search engines, subject-specialized search engines, directories, and indexes. In addition to using multiple search tools, Web searchers should experiment with multiple search strategies to maximize the effectiveness of their searching. As there are no standards of quality on the Web, researchers should apply multiple evaluation criteria to every website, verifying that research findings posted on sites are supported by other sources. Web accessibility is a crucial component to disability studies, as the Web has the potential to deliver equal content to all users but frequently presents barriers to people with disabilities by failing to adhere to standards of accessible design. Researchers can develop an awareness of accessibility issues on the Web by familiarizing themselves with the standards outlined by W3C's Web Accessibility Initiative and Section 508.

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