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E

EARLY CHILDHOOD INTERVENTION

Early childhood intervention is defined by services for infants and young children to prevent or reduce disability and to promote their development and general well-being. It seeks to identify actual or potential risks for disability as soon as possible and initiate interventions to minimize limitations related to individual, social, and environmental factors. Early childhood intervention recognizes the central role of the family in the child's development and is based on the provision of individualized intervention for the child and family in the proximal environment. Interventions focus on reducing and/or removing physical, cognitive, emotional, social, and environmental barriers and promoting the child's growth, development, and health through stimulation and provision of support. Early childhood intervention builds on biomedical, behavioral, and social and educational research and requires the contributions of specialists from many disciplines. It is a complex and continually evolving field with broad, interdisciplinary involvement including psychologists, early childhood educators, social workers, pediatricians, nurses, child psychiatrists, physical and occupational therapists, speech and language pathologists, and professionals in public health and social policy.

Children with diagnosed conditions such as Down syndrome, autistic spectrum disorders, cerebral palsy, and communication disorders were initially the primary recipients of early childhood intervention. However, children with developmental delays and children with risk factors associated with low birth weight, disadvantaged environments, and neuromotor problems are increasingly likely to be served in early-intervention programs.

Early childhood intervention was established in the United States and in some countries in Europe in the 1970s. The interest for early childhood intervention is increasing around the world since it covers common issues that transcend national boundaries. Researchers, clinicians, parents, program developers, and policy makers from many countries contribute to the rapidly expanding knowledge base of early childhood intervention. The International Society for Early Intervention (ISEI) with members from 50 countries representing all continents, provides a forum for professionals to communicate about advances in the field of early intervention. In Europe, Eurlyaid (European Association on Early Intervention), a European working party of professionals and representatives of parent associations from more than 15 countries, is involved in promoting early intervention for children at risk or with developmental disabilities. The European Agency for Special Education is also involved in promoting early childhood intervention in Europe. There are national organizations working for early childhood intervention in many countries all around the world, for example, in Australia, India, Hong Kong, South Africa, and Russia.

The age of entry to the early childhood intervention services varies from country to country. In North

America, early childhood intervention covers the years from birth to three, whereas in Europe it covers the ages from birth to five or six. The form of early childhood intervention services provided varies as a function of the system of services existing in each country. In some countries, early childhood intervention is included in general health care and educational services for all children. In other countries, special programs for early childhood intervention are provided that may be center based, home based, hospital based, or a combination. Services may include identification, assessment, and the provision of direct intervention. Variability may be found in eligibility criteria and accessibility to early childhood intervention as well as the extent of involvement of parents in the intervention process.

The universal framework of early childhood intervention relies on recognition of the individuality of all children in terms of abilities and disabilities, and a comprehensive approach encompassing the child's health and well-being. It relies on the knowledge that children are born active and are ready to communicate and learn and that stimulating and responsive social and physical environments are essential for development. The growth of the field of early childhood intervention is influenced by the declarations of the United Nations and the World Health Organization (WHO). Key sources are the 1959 UN Declaration of Rights of the Child and the 1990 Convention of the Rights of the Child, where the responsibility of society to ensure children's health and development is underlined. Article 23 recognizes the importance of meeting needs of children with disability. WHO declarations serve as a premise for advocacy and legislative initiatives concerning health and disability. Parent associations have also to a great degree influenced the evolving field of early childhood intervention advocating the rights and needs of children with disability.

Early childhood intervention is influenced by theory and developmental science. Universal features include an ecological framework, a systems theory approach, a focus on the family and the proximal environment for intervention, individualization of services and supports, and a preventive perspective. An underlying assumption is that early intervention can prevent or reduce later manifestations of delay and disability. The ecological base and a family systems approach builds on the assumption that developmental problems must be addressed in the environmental context of the child. It focuses on interventions addressing the child, the family, and other proximal environments and intervention providers. A basic premise is that the unique and complex needs and resources of each child and family are met best by an interdisciplinary approach in collaboration with the family. A systems approach recognizes that the family and child are influenced by the world of work, the preschool, available services for health, and other major social systems. On the macro level, early childhood intervention is influenced by broader factors of laws, culture, attitudes, values, geography, and economy.

Developmental science has had a major influence on the philosophy and practices in early intervention. A fundamental assumption in child development literature is that the child is seen as active in constructing his or her world and that development occurs through the ongoing transactions over time between the child and his or her social and physical environment. Another foundation for early childhood intervention is the centrality of relations and of the environment in early development.

As research on early childhood intervention continues to evolve, a distinction has been made between first- and second-generation research. In first-generation research, focus has been on the child and methods to assess and intervene with the child's impairment and disability. In second-generation research, issues that are of value in the daily activities of children, families, other proximal environments, clinicians, and teachers are in focus broadening the scope of the discussion about assessment and intervention. Second-generation research addresses the questions about what intervention, for what child, under which circumstances, and with what desired outcomes?

The basic philosophy in early childhood intervention relies on a number of basic assumptions that define the essential elements in processes and outcomes of early childhood intervention. To reach the goal of preventing disabilities and promoting growth, development, and well-being of infants and young children, interventions must take individual differences

into account. The focus for interventions is thus the child's health, development, and well-being in both assessment and intervention. To meet the goals of early childhood intervention, services must be designed that are personalized for the child and family as a unit and in their specific social and cultural context.

—Eva Björck-Åkesson and Mats Granlund

See also Children with Disabilities, Rights of; Developing World; Education and Disability; Infant Stimulation Programs.

Further Readings

De Moor, J. M. H., B. T. M. Van Waesberghe, J. B. L. Hosman, D. Jaeken, and S. Miedema. 1993. "Early Intervention for Children with Developmental Disabilities: Manifesto of the Eurlyaid Working Party." *International Journal of Rehabilitation Research* 16:23–31.

Guralnick, M. J. 1997. *The Effectiveness of Early Intervention.* Baltimore: Paul H. Brookes.

Odom, S. L., M. J. Hansson, J. A. Blackman, and S. Kaul. 2003. *Early Intervention Practices around the World.* Baltimore: Paul H. Brookes.

Shonkoff, J. and S. Meisels. 2000. *Handbook of Early Childhood Intervention.* New York: Cambridge University Press.

Simeonsson, R. J. 2000. "Early Childhood Intervention: Toward a Universal Manifesto." *Infants and Young Children* 12:4–9.

Websites

Eurlyaid, http://www.eurlyaid.net/

International Society of Early Intervention, http://depts.washington.edu/isei/index.html

EASTER SEALS

Easter Seals has been helping individuals with disabilities and special needs, and their families, live better lives for more than 85 years. From child development centers to physical rehabilitation and job training for people with disabilities, Easter Seals offers a variety of services to help people with disabilities address life's challenges and achieve personal goals.

In 1907, Ohio businessman Edgar Allen lost his son in a streetcar accident. The lack of adequate medical services available to save his son prompted Allen to sell his business and begin a fund-raising campaign to build a hospital in his hometown of Elyria, Ohio. Through this new hospital, Allen was surprised to learn that children with disabilities were often hidden from public view. Inspired by this discovery, in 1919 Allen founded what became known as the National Society for Crippled Children, the first organization of its kind.

In the spring of 1934, the organization launched its first Easter "seals" campaign to raise money for its services. To show their support, donors placed the seals on envelopes and letters. Cleveland Plain Dealer cartoonist J. H. Donahey designed the first seal. Donahey based the design on a concept of simplicity because those served by the charity asked "simply for the right to live a normal life."

The lily—a symbol of spring—was officially incorporated as Easter Seals' logo in 1952 for its association with springtime, renewal, and new life, and it has appeared each year as part of a fund-raising campaign.

Public support for the Easter Seals' "seals" campaign triggered a nationwide expansion of the organization and a swell of grassroots efforts on behalf of people with disabilities. By 1967, the Easter Seals' seal was so well recognized that the organization formally adopted the name "Easter Seals."

Easter Seals assists more than 1 million children and adults with disabilities and their families annually through a nationwide network of more than 500 service sites. Each center provides high-quality, family-focused and innovative services tailored to meet the specific needs of the particular community it serves. In the United States, Easter Seals' services for children and adults with disabilities include medical rehabilitation, job training and employment, inclusive child care, adults and senior day care and in-home care, and camping and recreation programs.

Easter Seals also advocates for the passage of legislation to help people with disabilities achieve independence, including the Americans with Disabilities Act (ADA). At the core of the Easter Seals organization is a common passion for caring, shared by its 13,000 staff members and thousands of volunteers, and by those who support its mission.

See also Advocacy.

Websites

Easter Seals National Headquarters, http://www.easterseals.com/site/PageServer

EATING DISORDERS

Eating disorders (anorexia nervosa, bulimia nervosa, and binge eating disorder) have been identified by some clinicians as an emerging public health crisis. Rates of eating disorders are difficult to gauge because of underreporting and misdiagnosis, but the *DSM-IV-TR* (American Psychiatric Association 2001) estimates lifetime prevalence to be 0.5 percent for anorexia and 1–3 percent for bulimia, with data still being collected on the newly designated binge eating disorder. Over 90 percent of those affected by eating disorders are women. An estimated 20 percent of all college females actively struggle with either anorexia or bulimia.

Eating disorders have long been viewed as a "culture-bound syndrome," as they have been historically observed in white, upper-middle-class teenage girls in the United States. Eating disorders have often been interpreted as expressions of conflicted feminine identity in the wake of capitalist expansion and as the embodied representation of conflicting cultural discourses regarding individualism and dependency. Recent reports, however, note increasing rates of incidence in other ethnic groups, persons of diverse economic backgrounds, boys and men, and non-Western cultural contexts. This diversification of the "typical" profile, coupled with increases in reported cases, produces something of a conundrum. On the one hand, the appearance of eating disorders in such a wide range of people across the globe might seem to lend credence to studies suggesting a biological basis for the disorders. On the other hand, the apparent coincidence of these increases with the expanded reach of western cultural ideology suggests cultural factors as a precipitating factor.

Regardless of where one locates causation, the fact remains that individuals who suffer from eating disorders are significantly impaired in their abilities to care for themselves, to interact with others, and to pursue school or employment. Their bodies are often ravaged by the disorder, leaving their bones brittle and weak, their teeth fragile, their heart and other organs often permanently damaged. Given this, and the increasing numbers of people struggling with these illnesses, one might legitimately argue that eating disorders should be classified as a "disability," and their sufferers afforded all the rights and protections given to other disabled individuals.

But there is something perhaps unsettling about this, and it speaks to the precarious situating of eating disorders in the cultural and clinical landscape: Do eating disorders reflect individual pathology, or should they be understood as crystallizations of pathological cultural dynamics? Are eating disorders inevitable given the presence of certain causal factors, or do they reflect individual choices within a given social context? How one answers these questions has direct implications for where one places responsibility for these illnesses, and, consequently, how they are understood vis-à-vis other disabling conditions. Put another way, we might ask: Can and should we recognize a condition as a "disability" that in many ways—through its emphasis on self-control, efficiency, and personal achievement—makes manifest our most treasured social values?

In strict definitional terms, eating disorders do meet the criteria for "disability." In its biopsychosocial model of health and illness, the International Classification of Functioning, Disability, and Health (ICF) defines *disability* as an outcome of interactions between health conditions and contextual factors that involves dysfunctioning (given certain qualifiers) at one or more of the three levels of human functioning: body or body part, whole person, and whole person in context (World Health Organization 2001). Eating disorders in their active phases certainly impair an individual on each of these three levels in ways substantial enough to disrupt everyday life. The Americans with Disabilities Act of 1990 states that an individual is considered to have a disability if he or she has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment. Again, eating disorders (viewed either from the perspective of mental illness or from the perspective of their physical consequences) would easily meet these criteria. But while conditions such as attention deficit hyperactivity disorder (ADHD), schizophrenia, major depression, and bipolar disorder are legally recognized as disabling conditions worthy of accommodation, eating disorders are not. What

makes eating disorders different? The aim of this entry is not to argue either for or against classifying eating disorders as a disability, but rather to briefly outline some of the issues at stake when a disabling condition unfolds within a social context that explicitly values many of the features of that condition.

Few would argue that a person who has schizophrenia or bipolar disorder would (and should) qualify as "disabled" according to these criteria. But many eating-disordered individuals do not, at first glance, appear to be substantially limited in their ability to function in society (at least those with anorexia nervosa or bulimia nervosa). (There has also been increasing pressure in recent years to classify obesity as a disability. See LeBesco 2004 and Braziel and LeBesco 2001 for discussions of this and related issues.) One reason for this is that, as noted above, the heightened self-control, anxiety about not being good enough, and ambivalence about overconsumption characteristic of eating disorders, while perhaps pathological in their extreme expressions, are nevertheless "in sync" with our cultural ideology in a way that hearing voices or staying in bed for a week are not. And it is perhaps more difficult to view a condition as disabling if it appears (on the surface at least) to garner significant social and cultural capital for the person involved. Girls often *do* get more positive attention when they are thin; physical fitness and attractiveness *are* often linked to success in the business world (see, e.g., Bordo 1995; Wolf 2002). Indeed, the social perks that can accompany the attainment of the slim, fit ideal can easily transform eating-disordered individuals into objects of envy rather than of sympathy. This situation is complicated by the recent rise of "pro-anorexic" websites with names such as "Emaciate me," "Little Baby Nothing," "Ana By Choice," "Anorexic wit' Attitude," and "Beautifully Insane," which insist that being anorexic is a "life choice" and an avenue for empowerment. This would seem to lend credence to the position that people with eating disorders *choose* to be sick, and, by extension, could just as easily choose to be well.

But such a position obscures the everyday, soul-wrenching struggle many eating-disordered individuals endure as they work to pull themselves, inch by excruciating inch, out of the depths of their illness. In the throes of an eating disorder, one does not feel pretty or popular or successful or powerful. On the contrary, one feels hollowed out, hopeless, emotionally decimated. And the most debilitating aspects of the illness do not entirely go away with recovery. For most eating-disordered people, food and eating always remain wrought with anxiety, one's body is always to some degree the enemy, and the temptation to return to eating-disordered behaviors (horrible as they are) swells in the face of periods of stress (see Hornbacher 1999 for a particularly gripping personal account of these issues). The "disability" of eating disorders, then (should we choose to call it that), is perhaps more elusive and subtle than other forms of disability, such as blindness or cerebral palsy. It is more like a sustained vulnerability than a physical limitation in functioning. And unlike these other conditions, accommodations cannot be made for the eating-disordered person. On the contrary, recovery often proceeds *in spite of* social interventions (with its contradictory passions for super-sizing food portions, on the one hand, and fad diets, liposuction, and 24-hour gyms, on the other) rather than because of them.

What *can* be gained from exploring eating disorders as a form of disability, however, is an increased awareness of the lifelong, everyday struggle those in recovery must face as they navigate cultural expectations of control, success, and achievement through the attainment of the perfect body. This might also lead us to a critical revisiting of the notion of disability as a condition that prevents full participation in society. In some cases, it seems, this full participation itself can be implicated in both the causes and consequences of what often becomes a lifelong battle.

—Rebecca Lester

See also Normality; Obesity; Osteoporosis.

Further Readings

American Psychiatric Association. 2001. *Diagnostic and Statistical Manual of Mental Disorders,* 4th ed. Washington, DC: American Psychiatric Association.

Anderson-Fye, Eileen and Anne Becker. 2003. "Sociocultural Aspects of Eating Disorders." In *Eating Disorders and Obesity: A Comprehensive Handbook*. New York: Guilford.

Bordo, Susan. 1995. *Unbearable Weight: Feminism, Western Culture and the Body*. Berkeley: University of California Press.

Braziel, Jana Evans and Kathleen LeBesco. 2001. *Bodies Out of Bounds: Fatness and Transgression*. Berkeley: University of California Press.

Gremillion, Helen. 2003. *Feeding Anorexia: Gender and Power at a Treatment Center*. Durham, NC: Duke University Press.

Hornbacher, Marya. 1999. *Wasted: A Memoir of Anorexia and Bulimia*. New York: HarperCollins.

LeBesco, Kathleen. 2004. *Revolting Bodies? The Struggle to Redefine Fat Identity*. Amherst, MA: University of Massachusetts Press.

Nasser, Mervat, Melanie A. Katzman, and Richard A. Gordon. 2001. *Eating Disorders and Cultures in Transition*. New York: Taylor & Francis.

Wolf, Naomi. 2002. *The Beauty Myth: How Images of Beauty Are Used against Women.* New York: Perennial.

World Health Organization. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

Websites

Academy for Eating Disorders, http://www.aedweb.org/newwebsite/index.htm

Eating Disorders Coalition, http://www.eatingdisorderscoalition.org/

ECONOMIC ANALYSIS OF DISABILITY

Studies of the economic impact of disability have been conducted from the perspective of government and society at large. Government expenditures on behalf of persons with disabilities may total as much as $247 billion (in 1997 terms), with all but $4 billion due to medical care expenditures or disability transfer payments. The costs of disability from the perspective of society may be as much as $345 billion (in 1997 terms); even after taking into account the costs that would be expected among persons with disabilities in the absence of the disability, the costs may total as much as $217.3 billion (in 1997 terms), the equivalent of 2.6 percent of the gross domestic product (GDP) in the United States for that year.

METHODS OF COST OF DISABILITY STUDIES

Estimates of the economic impact of reduced health or functional status have been produced with regularity since the mid-1960s. Most have concerned the cost to society of the prevalent cases of individual medical conditions, but the methods have been adopted by those interested in estimating the impact of disability on the national economy. In these studies, analysts enumerate the resources consumed as a result of having a medical condition (or disability), encompassing the costs of procuring medical services (including assistive technology and personal assistance), labeled "direct costs," and those associated with reduced ability to participate in activities, labeled "indirect costs."

Indirect costs might include the wage losses incurred by those who would be expected to work in the absence of the disability or of their household members who reduced work to care for them. Indirect costs would also include the economic costs associated with reduced functioning in other spheres of activity, such as parenting, as well as the harder-to-measure costs associated with the psychological impact of not being able to function as well as one would like. A full accounting of the costs of disability, of course, might include some gains as well. On the tangible side, there is some evidence that persons with disabilities use fewer medical resources than expected because they learn to consume medical care more judiciously. Similarly, some persons with disabilities are actually able to find more remunerative work after the onset of their disabilities or are able to replace paid help in family roles such as child care because of their reduced work time. Finally, some report personal growth through the experience of having a disability and, thus, would not report psychological deficits, but the opposite.

There are two principal methods to assess the costs of illness or disability. The first, the human capital approach, was devised by Dorothy Rice and colleagues. The human capital approach provides estimates of the economic value of services or goods purchased to take care of oneself (principally medical care) as well as the economic value of losses to society when individuals function more poorly, principally, the wage losses of those who stop or reduce work effort and the equivalent in wages for those one would hire to replace other kinds of function, for example, the costs associated with paying someone else to do the tasks associated with being a homemaker.

In the other principal method, the willingness-to-pay approach, one accounts for the tangible and intangible impacts of lost function by asking respondents how much they would be willing to pay to forgo an illness or disability. As a practical matter, because the obstacles to implementing the willingness-to-pay approach are so numerous (including the fact that individuals have trouble completing the exercise of stating their willingness to pay, are far more willing to pay after the onset of illness or disability than before, and the amount they are willing to pay is proportional to income, suggesting that some lives are worth more than others), there are no cost-of-disability studies using this method.

Even among the studies using the human capital approach to estimate the cost of disability, most have enumerated the direct and indirect costs incurred by persons with disabilities, regardless of whether the disability status accounts for the costs, rather than estimating the actual economic impact of disability above and beyond what would be expected in the absence of the disability. (Table 3, below, provides summary estimates of the latter below.)

RESULTS OF PRIOR ANALYSES

Table 1 reviews the results of the principal studies of the economic impact of disability over the past several decades. The studies differ in their perspective (with some providing estimates of the costs to government; some to disability insurers, including those in government and the private sector; and some to society as a whole) and the range of costs enumerated (with some limited to medical care expenditures as well as those for disability-specific services such as rehabilitation, some to disability insurance benefits [called income transfers when provided by government], and others encompassing both). In addition, the studies differ in the populations studied—from all persons with disabilities to only those of working ages or only children. Moreover, the results of the studies using different perspectives cannot be compared. For example, studies of the costs of disability from the perspective of society would necessarily omit an enumeration of disability transfer payments to avoid double-counting the impact of lost wages.

The first comprehensive assessment of the economic impact of disability was completed by Berkowitz and Johnson in 1970 and concerned the magnitude of disability transfer payments by the federal government in 1967: $43 billion ($207 billion in 1997 dollars). Burkhauser and Haveman provided a thorough review of government and private disability expenditures in several years; Table 1 provides the estimates for the last year for which they have complete data, 1978. They reported that government and private disability expenditures totaled $82 billion in that year (or $202 billion in 1997 terms). Disability transfers, worker's compensation, and medical services comprised most of the total. Snook and Webster estimated the magnitude of disability transfer payments, by kind, for 1981. Social Security Disability Insurance payments totaled $17 billion, worker's compensation payments were $16 billion, while private disability payments amounted to $5 billion. In 1989, Berkowitz and Greene updated the earlier estimates for 1986, finding that disability transfers (including those from the private sector) were $87 billion (or $127 billion in 1997 terms). The real value is actually less than their earlier study due, in part, to differences in services and income transfers enumerated as well as errors in adjusting for inflation. In addition, medical care expenditures on behalf of persons with disabilities totaled $79 billion in 1986 ($116 billion in 1997 terms) while expenditures on disability-specific services amounted to $3 billion ($4 billion in 1997 terms). The total of government and private expenditures on behalf of persons with disabilities in 1986 of $169 billion amounted to 3.8 percent of the GDP for the United States in that year. More recently, Aarts and colleagues provided estimates of government disability expenditures. Although they provided the estimates in terms of the percentage of GDP, we have translated the figures into billions of dollars. In 1991, government disability expenditures totaled $45 billion, of which all but $3 billion was due to disability transfer payments.

Several analysts have calculated the magnitude of medical care expenditures for persons with disabilities in both the public and private sectors. In the first of these, Newacheck and McManus estimated that expenditures on behalf of children with disabilities totaled $2 billion in 1980, or $4 billion in 1997 terms.

Table 1 Prior Studies of the Costs of Disability

Study	*Publication Year*	*Perspective*	*Population Studied*	*Scope of Study*	*Findings Study Year*	*% GDP*	*Current $ (billions)*	*1997 $ (billions)*
Berkowitz, Johnson	1970	Government disability insurers	All persons with disabilities	Disability transfers	1967		43	207
Burkhauser, Haveman	1982	Government and private expenditures	All persons with disabilities	Disability transfers	1978		29	71
				Workers' compensation			9	21
				Medicaid/Medicare			43	106
				All other			1	3
				Total			82	202
Snook, Webster	1987	Government and private disability insurers	Working-age persons with disabilities	Social Security disability	1981		17	30
				Workers' compensation			16	28
				Private disability benefits			5	9
				Total			38	67
Newacheck, McManus	1988	Government and private expenditures	Children with disabilities	Medical care expenditures	1980		2	4
Berkowitz, Greene	1989	Government and private expenditures	Persons ages 18–64 with disabilities	Disability transfers	1986		87	127
				Medical care expenditures			79	116
				Disability services			3	4
				Total			169	247
Chirikos	1989	Society	All persons with disabilities	Direct costs	1980		91	177
				Indirect costs of persons with disabilities			68	132
				Indirect costs of family members of persons with disabilities			18	35
				Total			177	345
Rice, Laplante	1992	Government and private medical expenditures	All persons with disabilities	Persons with one limiting condition	1980		49	95
				Persons with two or more limiting conditions			14	27
				Total			63	123
Trupin, Rice, Max	1995	Government and private medical expenditures	All persons with disabilities	Out of pocket	1987		29	41
				Private insurance			42	59
				Public programs			80	113
				Other			6	8
				Total			157	222

Table 1 (Continued)

Study	*Publication Year*	*Perspective*	*Population Studied*	*Scope of Study*	*Findings Study Year*	*% GDP*	*Current $ (billions)*	*1997 $ (billions)*
Institute of Medicine	1997	Society	Persons ages 18–64 with disabilities	Indirect costs	1994		159	172
				National Health Interview Survey—without adjustment				
				National Health Interview Survey—with adjustment			111 133	120 144
				Current Population Survey—without adjustment				
				Current Population Survey—with adjustment			93	101
Aarts, Burkhauser, De Jong	1998	Government disability expenditures	All persons with disabilities	Vocational rehabilitation[a]	1991	0.05	3	4
				Direct job subsidies[a]		—		
				Transfer payments[a]		0.70	42	49
				Total[a]		0.75	45	53

Note: Current year estimate updated to 1997 terms by the Consumer Price Index for all items.

a. Article states costs as percentage of gross domestic product (GDP). Transformed back to $billions by multiplying percentage GDP by 1991 GDP.

Table 2 Direct and Indirect Costs Incurred by Persons with Disabilities

	Mean ($)	*% of Direct*	*% of Indirect*	*% of Total*	*Sum (billions of $)*
Direct costs					
Office Based/Ambulatory Care	1,722	22		9	39.9
Inpatient/ER	3,691	47		19	85.5
Home Health	1,024	13		5	23.7
Prescriptions	991	13		5	23.0
Devices/Home Alterations	222	3		1	5.1
Other	178	2		1	4.1
Total	7,879	100		40	182.6
Indirect costs					
Loss of Employment	8,489		72	43	96.0
Earnings Losses among Employed	3,252		28	17	19.0
Total	11,741		100	60	115.0
Total	19,620				297.6

Source: Author's analysis of 1997 Medical Expenditures Panel Survey.

Similarly, Rice and LaPlante estimated that medical care expenditures for persons with disabilities of all ages for the year 1980 totaled $63 billion, or $123 billion in 1997 terms. Trupin and colleagues calculated the magnitude of medical care expenditures for persons with disabilities for 1987, by source of payment. Of the total expenditures of $157 billion ($222 billion in 1997 terms), out-of-pocket expenditures were $29 billion, private insurance paid for $42 billion, public insurance paid for $80 billion, while other sources paid for $6 billion.

In 1989, Chirikos made the first comprehensive assessment of the costs of disability from the perspective of society using data from 1980. He reported that direct costs for medical care and disability services amounted to $91 billion in that year, indirect costs due to lost wages of persons with disabilities were $68 billion, while indirect costs of lost income among family members were $18 billion, for a total of $177 billion ($345 billion in 1997 terms). Using these figures, the cost of disability to society was the equivalent of 6.3 percent of GDP for 1980. Since the Chirikos study was published, no similarly comprehensive estimates of the costs of disability have been completed. However, the Institute of Medicine provided estimates of the indirect costs associated with disability for 1994 using two different data sources with and without adjustment for differences between persons with and without disabilities in demographic and health characteristics. The institute estimated that the indirect costs associated with disability ranged from $93 to 159 billion ($101 to $172 billion in 1997 terms). Thus, despite the passage of time since the Chirikos study, his estimate and that of the Institute of Medicine of the indirect costs associated with disability were of similar magnitude.

RESULTS OF NEW ANALYSES

The authors of this entry have used the Medical Expenditures Panel Survey (MEPS) to develop estimates of the economic impact of musculoskeletal conditions, the subset including various forms of arthritis, and respiratory conditions. The MEPS, jointly administered by the Agency for Healthcare Research and Quality and National Center for Health Statistics, is an annual survey of medical care utilization and attendant costs and functional status among the U.S. noninstitutionalized population. In these prior studies, we have estimated the direct and indirect costs incurred by persons with the aforementioned medical conditions regardless of whether the condition in question was responsible for those costs. In addition, we have used regression techniques to estimate the increment in direct and indirect costs associated with the specific condition being studied.

In the analyses reported here, we replicate the methods of the prior studies to provide estimates of

the direct and indirect costs incurred by persons with disabilities as well as of the increment in such costs specifically associated with disability for 1997. For the analyses, we defined *disability* as the presence of a limitation in work, household, or school activities or a limitation in social or recreational activities or the presence of confusion or memory loss, difficulty making decisions, or the need to have one's activities supervised by someone else for one's safety due to cognitive impairment. All told, about 23.2 million persons (8.6 percent of the noninstitutionalized population) met one or more of these criteria for disability, of whom about 10.2 million were men and 13.0 million were women.

Table 2 shows the distribution of all direct and indirect costs incurred by persons with disabilities, by kind. Overall, direct and indirect costs for persons with disabilities averaged $19,620 per case, for a total of $297.6 billion (the equivalent of 3.6 percent of the GDP for 1997). Of the $19,620 average, $7,879 per case, or $182.6 billion (40 percent of all costs) was associated with direct costs and the remainder, $11,741 per case, or $115.0 billion, with indirect costs. Lost wages among persons who had stopped working altogether was by far the single largest component of costs ($8,489 per case, or 43 percent), while inpatient or ER costs and lost wages among those still employed represented 19 and 17 percent of total costs, respectively. To put the 3.6 percent of GDP figure in perspective, the economy is said to be in a recession when the overall economy contracts by 1 percent or more for two consecutive quarters. So the economic impact of the direct and indirect costs incurred by persons with disabilities would have an effect of a severe and ongoing recession.

The results of the analysis of the increment in direct and indirect costs associated with disability indicate that most of the costs incurred by persons with disabilities are the result of the disability itself rather than the other characteristics of persons with disabilities (Table 3). Accordingly, total costs associated with disability averaged $16,113 per case, or $217.3 billion (2.6 percent of GDP for 1997). However, the increment is disproportionately attributable to indirect costs as a result of lost wages. Whereas 40 percent of all costs incurred by persons with disabilities were for direct costs, only 18 percent of the increment associated with disability was due to direct costs. Prevention of work disability, one of the principal goals of the Americans with Disabilities Act, is essential to limiting the economic impact of disability.

Table 3 Direct and Indirect Costs Associated with Disability

	Mean ($)	*Sum (billions of $)*	*% of Total*
Direct Costs			
Total	2,953	68.4	18
Indirect Costs			
Total	13,160	148.9	82
Total	16,113	217.3	100

Source: Author's analysis of 1997 Medical Expenditures Panel Survey.

Note: Direct costs estimated for all persons age 18 and older; indirect costs for all persons ages 18–64.

Interestingly, the increment in the earnings gap is larger than the raw earnings gap. The implication is that persons with disabilities earn more than expected on the basis of their disability and their other characteristics; the results are inconsistent with the charge that persons with disabilities may not persevere at work because of the availability of disability benefits.

—Edward Yelin and Laura Trupin

See also Disability Policy: United States; Financial Costs of Disability; Health Management Systems.

Further Readings

Aarts, L., R. Burkhauser, and P. De Jong. 1998. "Convergence: A Comparison of European and United States Disability Policy." In *New Approaches to Disability in the Workplace*, edited by D. Hyatt and J. Burton. Ithaca, NY: IIRA Research Proceedings.

Berkowitz, E. and C. Greene. 1989. "Disability Expenditures." *American Rehabilitation,* pp. 7–15, 29.

Berkowitz, E. and W. Johnson. 1970. "Towards an Economics of Disability." *Journal of Human Resources,* pp. 271–297.

Burkhauser, R. and R. Haveman. 1982. *Disability and Work: The Economics of American Policy*. Baltimore: Johns Hopkins University Press.

Bodenheimer, T., K. Lorig, H. Holman, and K. Grumbach. 2002. "Patient Self-Management of Chronic Disease in Primary Care." *Journal of the American Medical Association* (November 20): 2469–2475.

Brandt, E. and A. Pope. 1997. *Enabling America: Assessing the Role of Rehabilitation Science and Engineering.* Washington, DC: National Academy Press.

Chirikos, T. 1989. "Aggregate Economic Losses from Disability in the United States: A Preliminary Assay." *Milbank Memorial Fund Quarterly,* pp. 59–91.

Cohen, S. 2000. *Sample Design of the 1997 Medical Expenditure Panel Survey Household Component.* Rockville, MD: Agency for Healthcare Research and Quality.

Cooper, B. and D. Rice. 1979. "The Economic Cost of Illness Revisited." *Social Security Bulletin* 39:21–35.

Lubeck, D. and E. Yelin. 1988. "A Question of Value: Measuring the Impact of Chronic Disease." *Milbank Quarterly* 66:444–464.

Newacheck, P. and M. McManus. 1988. "Financing Health Care for Disabled Children." *Pediatrics,* pp. 385–394.

Rice, D. 1966. *Estimating the Cost of Illness*. Hyattsville, MD: National Center for Health Statistics, Health Economic Series.

Rice, D., T. Hodgson, and A. Kopstein. 1985. "The Economic Costs of Illness: A Replication and Update." *Health Care Finance Review* 7:61–80.

Rice, D. and M. LaPlante. 1992. "Medical Expenditures for Disability and Disabling Comorbidity." *American Journal of Public Health* (May): 739–741.

Snook, S. and B. Webster. 1987. "The Cost of Disability." *Clinical Orthopaedics and Related Research* (August): 77–84.

Thompson, M. 1986. "Willingness to Pay and Accept Risks to Cure Chronic Disease." *American Journal of Public Health*, pp. 392–396.

Trupin, L., D. Rice, and W. Max. 1995. *Medical Expenditures for People with Disabilities in the United States, 1987.* Washington, DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

Yelin, E., M. Cisternas, D. J. Pasta, and L. Trupin. 2003. *Direct and Indirect Costs of Musculoskeletal Conditions in 1997: Total and Incremental Estimates*. Report on Project for Aging Studies Branch. Atlanta, GA: Centers for Disease Control and Prevention.

Yelin, E., A. Herrndorf, L. Trupin, and D. Sonneborn. 2001. "A National Study of Medical Care Expenditures for Musculoskeletal Conditions: The Impact of Health Insurance and Managed Care." *Arthritis and Rheumatism* 44:1160–1169.

Yelin, E., L. Trupin, M. Cisternas, M. Eisner, B. Katz, and P. Blanc. 2002. "A National Study of Medical Care Expenditures for Respiratory Conditions." *European Respiratory Journal* 19:414–421.

ECONOMIC AND SOCIAL DEVELOPMENT

Disability is linked to development in a manner that is neither obvious nor well established. For instance, increased disability may be the result of advances in health signaling broad-based welfare improvements, or societies may be in such economic or political disorder that continued poverty or war conflict leads to a rise in the prevalence of disability. At the same time, disability seems to impede development through the constraints it places on individuals' productivities and earning capacities. These complications combined with a dearth of comparable data may explain why the link between disability and development has been the subject of very little research in both the disability and development literatures. More attention has been granted to the link between disability and poverty, widely accepted as a vicious circle. The relation between development and disability may be understood as a two-way street, where development affects disability and vice versa. Disability and development are intertwined, and we seek to understand both strands of the relationship. The major part of this review explores aspects of the relationship at a macro level, while touching on micro- and policy-level links as well.

This entry is organized as follows. I first clarify the concepts of development and disability. The entry then analyzes the two-way relation between development and disability. At the micro level, the entry explains the vicious circle between poverty and disability. Finally, I review disability policies of international development agencies such as the United Nations and the World Bank.

TWO CONCEPTS: DEVELOPMENT AND DISABILITY

We all have intuitive notions of *development* and *disability*. Yet these two concepts are complex and cannot be used without clarifying their definitions and measurements. Development typically refers to the structural transformation from a subsistence economy to an urban industrial economy, and to the sustained rise in income and productivity that follows. The transformation takes place in various aspects of the economy and society, including in the structure of consumption, production, investment, and trade and in demographic trends and economic institutions. While development is typically understood in its narrow economic sense, it also has human and political dimensions. Human development is the process of expanding

the education, health, and other conditions of human life. In its political sense, development refers to the process that provides individuals with improved civil rights and with the opportunity to determine who should govern. It refers to entitlements and institutions one usually associates with democracies.

In this broad sense, development refers to the enhancement of individuals' capabilities and freedoms. This concept of development is far more difficult to measure than the conventional economic view of development captured in the per capita gross domestic product (GDP), growth, or industrialization measures. However, several measures have been developed to capture this broader approach of development including the Human Development Index of the United Nations Development Programme (UNDP). *Development* is thus a multifaceted term. We understand it as a broad concept with economic, human, and political dimensions when we attempt to understand its link to disability.

Disability has proved to be a very controversial and complex concept to define and measure, and analyzing its definitional problems is beyond the scope of this entry. In brief, different conceptual models have been created to define disability. For instance, the medical model considers disability as a problem of the individual that is directly caused by a disease, an injury, or other health conditions and requires medical care in the form of treatment and rehabilitation. An individual with an impairment is considered disabled (where *impairment* is the term used for an individual's condition) irrespective of whether the person experiences limitations in his or her life activities. The medical model is usually opposed to the social model. Overall, the social model sees disability purely as a social construct and a human rights issue. Disability is not the attribute of the individual; rather it is created by the social environment and requires social change. In the social model, disability is generally understood as the result of social oppression, and this oppression can start in the form of poverty and later on lead to disability.

Recently, S. Mitra used A. K. Sen's capability approach that was developed to analyze concepts of the standard of living, poverty, and development in order to define disability. Here, disability is understood as a deprivation of capabilities where capabilities refer to practical opportunities. Disability occurs when an individual with an impairment is deprived of practical opportunities. Such deprivation may result from the interaction between the resources available to the person, personal characteristics (e.g., impairment, age, gender), and the environment (physical, social, cultural, political, economic). Poverty is a factor that, while interacting with the individual's characteristics and environment, may lead to disability.

The development and disability concepts may overlap depending on the approach we adopt to define each concept. Development and disability do not intersect when they are understood in their narrow economic and medical senses, respectively. However, if development is defined as a broad-based process that enhances human capabilities, then it may well intersect with disability. If we place ourselves in the social model where disability is a human rights issue, or if we adopt the capability approach where disability may be considered as a capability deprivation for persons with impairments, then development and disability are entwined. Clearly, if being disabled means being deprived of capabilities, reducing disability can be conceived as an integral part of the development process. Development can be considered as a process that, among other things, curbs disability by enhancing human capabilities. Development and disability are then two intrinsically linked concepts.

In the remainder of this entry, we leave the complexities of the relation between the concepts of disability and development. We use the term *disability* as a two-facet concept that refers to both disability and impairment, and we understand *impairment* as a physiological, mental, or anatomical loss. Instead, we focus on the dynamic relation between disability and development, and between disability and poverty: How does development affect disability prevalence? How does disability affect the development process? How does disability relate to poverty?

DEVELOPMENT AND DISABILITY: A TWO-WAY RELATION

There are four fundamental questions relating to the relationship between development and disability: (1) How does development affect the prevalence of disability? (2) How does development affect the distribution

of disability within the population? (3) How does development impact the major causes of disability? and (4) How does disability impact development itself?

The Impact of Development on Disability Prevalence

To attempt to address the first question, we introduce the notion of disability transition. Disability transition is a concept that is meant to capture the changing pattern of disability as a country develops. As there is a "population transition" apparent in reduced birth and death rates, one may wonder if there is a "disability transition" that accompanies development. There is no definite answer to this question, whether at the theoretical or empirical level. There are mainly three theories about the link between the effect of increased life expectancy and changing morbidity associated with development on disability prevalence. The first one, and probably the most widely accepted theory, is that development leads to increased disability prevalence. The basic rationale is that the demographic and medical changes associated with development, increased longevity and survival from disabling accidents and conditions, lead to increased disability prevalence. Second, in what is often called the compression of morbidity theory, it is argued that with medical improvements, the proportion of life lived with a disability decreases and the prevalence of disability also decreases. A third theory predicts a reduction in severe disabilities through enhanced medical intervention and a rise in mild disabilities.

Is there any empirical evidence of a disability transition? While we realize that country-level estimates are not comparable because different definitions and methods are used, available disability rates seem to show a higher disability prevalence in developed countries than in developing countries. On the basis of United Nations data, for developed countries, disability rates are in the 14 to 20 percent range, while they are generally below 5 percent in developing countries. However, one needs to be very cautious when analyzing this apparent correlation between disability and development. Many factors, in particular those related to perception and measurement, contribute to higher prevalence rates in developed countries.

There are several types of factors related to development that may have an increasing or a decreasing impact on disability prevalence. First, there are factors related to demographic and health changes associated with development. For instance, improved survival rates from conditions causing illnesses and impairments would lead to an increase in disability prevalence, whereas an increase in prevention care would generally be expected to reduce disability prevalence. Second, there are aspects in the environment that would be affected by development and would in turn affect disability prevalence. Wars and political unrest are surely not limited to developing countries, but it is in the developing world that the effects are widely borne by populations, in particular through disabling injuries. It is also in developing countries with mass poverty that there are impairments resulting from inadequate nutrition and hazardous modes of living. Such impairments resulting from political unrest or poverty would be expected to decrease with development.

Third, there are factors related to the way impairments and disabilities are perceived and reported. These include increased knowledge and awareness of impairments, increased diagnosis and screening, medicalization of problems, change in perceived standard of good health, and eligibility to social benefits based on disability. All these factors lead to an increase in perceived disability and would therefore explain a higher reported disability prevalence in developed countries compared to developing countries.

Finally, fundamental differences in measuring instruments also affect prevalence estimates across developed and developing countries. Developed countries typically use disability screens that assess activity limitations, whereas developing countries tend to use impairment screens. Activity limitation screens generally lead to higher rates of reported disability than impairment screens. Indeed, individuals are more likely to identify activity restrictions because they immediately connect with daily experience, whereas an impairment may be only vaguely familiar and its nomenclature may be unknown.

The first two types of factors mentioned above indicate that some factors associated with development changes per se (medical, demographic, environmental changes) are expected to have a negative

impact on disability prevalence, others a positive one. In contrast, factors related to perception and measurement all seem to have a positive association with development. Altogether, these factors probably argue in favor of higher reported disability rates in developed countries compared to developing countries. This analysis is consistent with the much higher rates of disability prevalence that we find in country-level estimates for developed countries versus developing countries.

However, this analysis and these country estimates are not consistent with global estimates of disability prevalence. The United Nations estimates that 10 percent of the worldwide population have a disability and that two-thirds live in developing countries. In 1984, the UN secretary general reported that an average of 20 to 25 percent of the population of developing countries is disabled. This number is likely to have increased because of wars and other forms of violence, inadequate medical care, and natural and other disasters. The empirical evidence on the impact of development on disability is thus inconclusive: The lack of comparable data across countries prevents us from providing any clear and supportive evidence to any of the theories on a disability transition.

The World Health Organization (WHO) has recently released the International Classification of Functioning, Disability, and Health (ICF), which should provide a more unified and standard framework for the recording of disability in the context of development if it is implemented successfully. It is astonishing that disability data have been rarely collected in the human development literature. Since 1990, as part of the Human Development Reports, UNDP reports annually on the health access and profile of populations as part of its human development indicators and for the compilation of a human development index. Health profile indicators include, among others, incidence of malaria, HIV/AIDS, tuberculosis, cigarette consumption, and access to nurses and physicians; rarely has it included data on the numbers of persons with disabilities. One exception is the Human Development Report of 1999.

Despite these limitations due to the dearth of comparable data, we can make some general statements regarding the distribution of disability by age and causes across developed and developing countries. The distribution of disability causes across developing and developed nations is well-known. Disabilities resulting from land mines and wars, tuberculosis, malaria, anemia, HIV/AIDS, and diarrheal diseases are more prevalent in developing countries, while disabilities resulting from road accidents, heart disease, and pulmonary diseases are typical of developed countries. The distribution of disability by age is also well established. In developing as in developed countries, age-specific disability rates and the severity of disablement increase with age. However, because in developed countries the elderly represent a larger share of the total population than in developing countries, disability seems to be more concentrated in older age groups. In addition, in developing countries, the proportion of disabled children is higher than in developed countries.

The Impact of Disability on Development

We tackle the last question that we set out at the beginning of this section, what are the implications of disability for the process of development? This relationship is typically thought to be negative. A large disabled population means that there is a lower supply of productive labor, leading to a reduction in income and production. However, this question is somewhat more subtle than appears at first glance. There are many ways in which disability can influence economic and social outcomes and development in particular, ways that will vary given a country's resource endowments and its social, cultural, and institutional environment.

Simple economic arguments suggest that disability worsens social and economic outcomes and impedes development. Indeed, disability places constraints on individuals' productivities and earnings capacities. As such, there is an economic loss attributable to disability, and the extent of this loss has been assessed in some countries. For instance, a study by Cooper and Rice found productivity losses due to disability amounting to 3.5 percent of the gross national product (GNP) of the United States. Of course, this economic loss associated with disability is reduced in countries that have effective vocational rehabilitation programs

in place that promote the labor force participation of persons with disabilities.

The economic and social implications of disability are also apparent in public expenditures and disability-related sectors of the economy. This is mainly the case though in developed counties, where disability has given rise to specific markets in the health care, rehabilitation, insurance and legal fields, and where government disability expenditures tend to be significant. For instance, estimates of public expenditures on disability-related programs stand at about 5 percent of GDP for the Netherlands and Sweden, and 1.5 percent for the United Kingdom. The net impact of disability on the overall economy depends on how the loss in productivity and potential earnings compares to disability-related expenditures in the private markets and the public sector. In developing countries, because government expenditures and markets related to disability are very limited, the main economic implication of disability seems to be the economic loss from reduced productivity and earnings. Thus, while disability seems to hold back development through the economic loss it brings about, the impact of disability on this process evolves and becomes more complex as a country develops and establishes public policies and private markets related to disability.

The economic loss resulting from disability points toward the importance of prevention and employment policies as part of the development agenda as well as toward the link between disability and poverty at the micro level.

DISABILITY AND POVERTY

Poverty is the most visible characteristic of underdevelopment. There is little controversy nowadays over the fact that the fundamental purpose of development is poverty eradication. Hence, the relation between poverty and disability is an important consideration. If the relation between disability and development is complex and ambiguous, what can be said about that between disability and poverty?

Poverty and disability have been linked through a "vicious circle" that has been described in several sources. For instance, it has been described as a two-way relationship with disability contributing to an increased risk of poverty and vice versa, resulting in persons with disabilities being part of the poorest of the poor.

From Disability to Poverty

The fact that disability may lead to poverty is common sense. Disability places constraints on an individual's earnings capacity and adds costs related to the disability in terms of health care for instance. The economic well-being and poverty status of persons with disabilities has received limited attention in both developed and developing countries.

The few studies on the economic well-being of persons with disabilities in the United States have assessed trends in incomes whether from work or public benefits for persons with disabilities. However, such studies do not take into account the costs that may be associated with a disability at an individual or a household level. There is a need to assess the costs of a disability in terms of both forgone earnings and direct costs at the individual and household levels to gain a better insight into the poverty status or risk of such individuals and households. Such costs include medical expenses, equipment, adaptations to housing, and means of transportation and personal care. One study by Erb and Harris-White found, based on a village-level survey in southern India, that the direct cost of a chronic illness or an impairment in terms of equipment and treatment averaged three months of a person's income. This does not include forgone earnings due to an inability to work, nor the opportunity costs borne by other members of the household. The costs to caregivers, particularly in terms of forgone work earnings, are increasingly recognized and have been evaluated in the United Kingdom. The cost of personal care on the household may be more important in developing countries than in developed countries since the former generally do not offer income maintenance programs and other funded entitlements as the latter do. In developing countries, families are typically considered as being responsible for persons with disabilities. The direct costs of disabilities and the forgone earnings they entail warrant more research in developing countries. Assessments of such costs would allow researchers to evaluate if the minimum standard of living encapsulated in the

poverty threshold is sufficient to meet the needs of persons with disabilities and would aid the formulation of poverty reduction strategies for persons with disabilities. An obstacle to such research is the lack of sources of reliable data on both disability and poverty in developing countries.

From Poverty to Disability

Poverty itself can be the catalyst of a disability; this is particularly the case in developing countries where disability largely results from preventable impairments associated with communicable, maternal, and perinatal diseases and injuries. Poor individuals and families do not have enough resources to satisfy their basic needs, and their sanitation and shelter are inadequate. They may contract some diseases, which, with a lack of access to health care, make them become disabled. Malnutrition in its various forms is a cause of disability for adults and children. Malnourished mothers have low-birth-weight babies who are more at risk of debilitating diseases than healthy babies. Malnourished children are also more prone to impaired intellectual development. UNICEF notes that the incidence and severity of disability are the greatest in countries at earlier stages of development as a consequence of factors that are mainly related to poverty.

Poverty and disability are also linked through the general level of awareness and education of the poor. Parental awareness, access to information, and maternal education have been found to have a great preventive effect. In addition, poverty and disability are linked through the working environment of the poor given that poor people tend to work in more risky physical environments.

While this link from poverty to disability is usually addressed in the context of developing countries, it does not disappear with development. For instance, empirical evidence on the association of poverty and poor health or disability is clear in the United States. The link between poverty and disability is expected though to be more pronounced in developing countries with mass poverty.

Overall, it is obvious that poverty and disability are strongly correlated. Poverty may influence disability and disability may influence poverty. Understanding such relationships is essential for the design of poverty reduction strategies.

INTERNATIONAL DEVELOPMENT AGENCIES

Despite the strong but complex link between disability and development, international development agencies have paid marginal attention to disability. The emphasis has generally been on prevention of impairments and rehabilitation with additional initiatives in data collection efforts and rights-based initiatives. The United Nations has taken the leadership in providing assistance in the field of disability and development. Several UN agencies support or operate community-based programs providing rehabilitation or vocational training programs. In 1982, the United Nations adopted the World Programme of Action Concerning Disabled Persons as a global strategy to prevent disability, promote rehabilitation, and provide for the full participation of persons with disabilities. In 1993, the United Nations introduced the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which are not legally enforceable but do set an inclusive and antidiscriminatory standard that is used when national policies are developed. There is currently a campaign by disability organizations to have a UN convention on the rights of persons with disabilities.

The lack of comparable data on disability is an obstacle to research on development and disability as well as for international organizations to form disability policies and to evaluate policies aimed at tackling both disability and poverty. In 1993, the World Bank developed the disability adjusted life year (DALY) to provide comparable data on the burden of disease and disability. The DALY was strongly criticized on various grounds, including that disability is considered as a burden on society and that disability is equated to disease without recognizing the numerous factors that lead to disability including environmental ones. The WHO has taken several initiatives to develop comparable data sources, the latest being the development of the ICF. In the ICF, functioning refers to body functions and structures, activities, and participation, while disability includes impairments, activity limitations, and

participation restrictions. The ICF is a model of disability that offers a concrete classification system of individuals, and it is thus expected to provide comparable data across countries if it is implemented successfully.

Thus, there is a very limited record of disability work in prominent development organizations. We are very far from having a disability paradigm in the development field as there has been a health or gender paradigm in the recent past. It is encouraging to note though that a new Office of the Advisor on Disability and Development was created in 2002 at the World Bank as a result of which the disability dimension of poverty reduction programs is starting to receive some attention and several data collection and gathering efforts in relation to development are under way.

CONCLUSION

It is evident that there is a strong link between disability and development. Despite this, disability remains a marginal area of interest in development research and practice. Certainly, efforts to improve the quality and comparability of disability statistics will help clarify some of the complex relationships we have pointed out in this entry and demonstrate the importance and relevance of disability issues in the context of development.

—Sophie Mitra

See also Citizenship and Civil Rights; Developing World; Economic and Social Development, International; Poverty; United Nations; World Bank; World Health Organization.

Further Readings

Cooper, Barbara and Dorothy Rice. 1976. "The Economic Cost of Illness Revisited." *Social Security Bulletin* 39(2): 21–36.

Department for International Development. 2000. *Disability, Poverty and Development.* London: Department for International Development.

Elwan, Ann. 1999. *Poverty and Disability: A Survey of the Literature.* Social Protection Discussion Paper Series 9932. Washington, DC: World Bank.

Erb, S. and Barbara Harris-White. 2001. "The Economic Impact and Developmental Implications of Disability and Incapacity in Adulthood in a Village Study from S. India." Paper presented to the Workshop Welfare, Demography and Development, September 11–12, Downing College, Cambridge, UK.

Harris-White, Barbara. 2003. "The Political Economy of Disability and Development: With Special Reference to India." Working paper, Conference on Staying Poor: Chronic Poverty and Development Policy, Chronic Poverty Research Centre, University of Manchester, April 7–9.

International Labour Organization. 2002. "Disability and Poverty Reduction Strategies." Discussion paper, Disability Programme. Geneva: International Labour Organization.

Mitra, Sophie. Forthcoming. "The Capability Approach and Disability." *Journal of Disability Policy Studies*.

Murray, Christopher and Alan Lopez. 1997. "Regional Patterns of Disability-Free Life Expectancy and Disability-Adjusted Life Expectancy: Global Burden of Disease Study." *Lancet* 349:1347–1352.

Organization for Economic Cooperation and Development. 2003. *Transforming Disability into Ability: Policies to Promote Work and Income Security for Disabled People.* Paris: Organization for Economic Cooperation and Development.

Sen, Amartya K. 1985. *Commodities and Capabilities.* Professor Dr. P. Hennipman Lectures in Economics: Theory, Institutions, Policy 7. Amsterdam: Elsevier.

———. 1999. *Development as Freedom.* New York: Alfred A. Knopf.

Shirley, Oliver, ed. 1983. *A Cry for Health: Poverty and Disability in the Third World.* London: Third World Group for Disabled People.

Stienstra, Deborah, Yutta Fricke, and April D'Aubin. 2002. *Baseline Assessment: Inclusion and Disability in World Bank Activities.* Retrieved July 22, 2003 (www.disabilitystudies.ca/baselinehtml.html).

United Nations. 1990. *Disability Statistics Compendium*. New York: United Nations.

———. 2000. *The United Nations and Disabled Persons: The First 50 Years.* Division for Social Policy and Development. Retrieved July 16, 2003 (http://www.un.org/esa/socdev/enable).

United Nations Development Programme. 1999. *Human Development Report.* New York: Oxford University Press.

Yeo, Rebecca and K. Moore. 2003. "Including Disabled People in Poverty Reduction Work: 'Nothing about Us, without Us.'" *World Development* 3:571–590.

ECONOMIC AND SOCIAL DEVELOPMENT, INTERNATIONAL

"Disability" is a complex, global phenomenon. The number of persons with disabilities in the world is estimated to be 500 million. In most countries, at least 1 out of 10 persons has a disability with physical, mental, or sensory impairment (United Nations Enable 2004). What is disability? Though they are different, terms such as *functional impairment*, *disability*, and *handicap* often are used interchangeably. The World Health Organization (WHO) offered a comprehensive

International Classification of Functioning, Disability, and Health (ICF) as an operational standard (adopted by 191 member states of WHO) to facilitate policy development, economic analyses, and research uses involving disability (WHO 2002). ICF is complementary to WHO's International Classification of Diseases (ICD-10). ICF offers core classification on function, while ICD offers core classification of health condition and diagnosis. ICF is organized around body function and structure, individual activities and task participation, and environmental factors.

Countries gather data on disability and estimate prevalence rates. But due to differences in the concepts (or definitions) and methods used in collecting data on disability, prevalence rates are not comparable across countries. Differences in definition or method can lead to different prevalence rates even *within* a country. Inconsistency in definitions of disability can cause a problem in the administration of programs for persons with disabilities. For example, acknowledging this problem, Australia has been working toward national consistency in disability definition and data collection (Australian Institute of Health and Welfare 1997).

From a *traditional perspective,* many cultures associated disability with sin, shame, and feelings of guilt. Persons with disabilities were socially ostracized and excluded from participation in community activities. The presence of an impairment coupled with negative attitude and behavior of family and community led to rejection or isolation of children and adults. From a *medical perspective,* disability is regarded as a sickness or disease that can be cured through medical intervention. From a *humanitarian perspective,* disability is viewed as a function of the interaction between the individual with impairment and the environmental demands (cultural, social, architectural, and technological). From a *workforce perspective,* disability is viewed as a functional limitation preventing equal rights and full participation in an employment setting. Appropriate job accommodations may be used to increase the employability of persons with disabilities and create equal opportunities (Job Accommodation Network 2003).

Increasing numbers of persons with disabilities are linked to factors such as poverty, hunger, epidemics, violence, war, living conditions, illiteracy, health care, rural/urban geography, age shifts, accidents, natural disasters, environmental pollution, drug/alcohol abuse, and HIV/AIDS. The correlation between disability and poverty has been well established. In developing countries, 80 percent of persons with disabilities live in isolated rural areas and are extremely poor (Chaliand 2004). How a person responds to a disability depends on *intrinsic factors* such as the type/severity of impairments (e.g., diabetes, total blindness) and personal characteristics (e.g., gender, age, education, skills, interests) as well as *extrinsic factors* such as environmental variables (e.g., high unemployment area, dysfunctional family). Social, cultural, and economic disadvantages restrict access to health care, education, training, and employment. Progress in life expectancy and overall physical and mental fitness is related to contemporary social and cultural forces. Advancements in knowledge and practice in the areas of health care, technology, and management of economies have led to substantial improvement in physical fitness, mental health, and life expectancy.

Population and adult mortality rates for males and females for some of the developing and developed countries in different regions of the world are highlighted in Table 1. The WHO (2003) indicated that generally, the adult mortality rate for women in all of the countries (both developing and developed) is lower than the adult mortality rate for men. For example, in Zimbabwe, the adult mortality rate (AMR) for females (F) is 789 deaths per 100,000 in a year. For males (M), the AMR is 821. But the AMRs for men and women in developing countries are substantially higher compared to developed countries. For example, in Japan (Developed), the AMR (F) is 46, and in Cambodia (Developing) the AMR (F) is 298. The developing countries are, of course, at various levels of economic development. Much of their economic growth is linked to natural resources such as oil (e.g., Saudi Arabia, Libya), copper (e.g., Chile, Peru, Zaire, Zambia), and bauxite (e.g., Guinea, Guyana, Jamaica). Technologically developing nations of Asia, Africa, and Latin America generally are characterized as poor and with high rates of illiteracy, disease, and population growth. The technological and economic development promotes health, education, and quality of life of a nation and tends to reduce mortality rate.

Table 1 Population and Adult Mortality Rate (AMR) (Female and Male) in Developing and Developed Countries, by Region, 2002

Country	*Population (000)*	*AMR (F) (000)*	*AMR (M) (000)*
Africa *(Developing)*			
Zimbabwe	12,835	789	821
Swaziland	1,069	707	818
Botswana	1,770	745	786
Zambia	10,698	654	700
Burundi	6,602	563	692
Central African Republic	3,819	566	620
Mozambique	18,537	519	613
Namibia	1,961	529	605
Rwanda	8,272	474	605
South Africa	44,759	482	598
Angola	13,184	481	594
Democratic Republic of the Congo	51,201	449	585
Liberia	3,239	471	582
Tanzania	36,276	512	561
Uganda	25,004	431	505
Niger	11,544	443	497
Ethiopia	68,961	422	487
Chad	8,348	402	477
Congo	3,633	410	474
Ghana	20,471	303	354
Americas			
(Developed)			
United States	291,038	83	140
Cuba	11,271	89	138
Canada	31,271	58	95
(Developing)			
Haiti	8,218	438	493
Honduras	6,781	150	269
Bolivia	8,645	209	260
Bahamas	310	153	248
Brazil	176,257	136	246
Colombia	43,526	99	236
Peru	26,767	144	205
Uruguay	3,391	88	182
Venezuela	25,226	97	182
Argentina	37,981	90	177
Paraguay	5,740	120	171
Jamaica	2,627	121	162
Panama	3,064	84	146
Chile	15,613	67	134
Southeast Asia			
(Developing)			
Myanmar	48,852	236	335
Nepal	24,609	290	301
India	1,049,549	220	291
Thailand	62,193	153	279
Bangladesh	143,809	258	251
Indonesia	217,131	208	244

(Continued)

Table 1 (Continued)

Country	*Population (000)*	*AMR (F) (000)*	*AMR (M) (000)*
Sri Lanka	18,910	121	238
Republic of Korea	47,430	61	166
Europe			
(Developed)			
Russian Fed.	144,082	168	464
Ukraine	48,902	139	378
Latvia	2,329	118	327
Hungary	9,923	112	256
Azerbaijan	8,297	122	231
Bulgaria	7,965	97	219
Poland	38,622	82	204
Turkey	70,318	112	177
Albania	3,141	94	167
France	59,850	60	133
Spain	40,977	47	120
Germany	82,414	60	118
Greece	10,970	48	118
United Kingdom	59,068	67	107
Norway	4,514	60	100
Italy	57,482	49	96
Netherlands	16,067	65	94
Sweden	8,867	53	83
Eastern Mediterranean			
(Developing)			
Somalia	9,480	418	534
Afghanistan	22,930	413	494
Sudan	32,878	278	379
Yemen	19,315	228	286
Pakistan	149,911	201	227
Iran	68,070	132	213
Lebanon	3,596	139	201
Saudi Arabia	23,520	112	192
Jordan	5,329	121	191
Syria	17,381	127	190
Kuwait	2,443	63	81
Western Pacific			
(Developed)			
New Zealand	3,846	63	98
Japan	127,478	46	95
Australia	19,544	52	91
Singapore	4,183	53	90
(Developing)			
Cambodia	13,810	298	400
Philippines	78,580	133	258
Vietnam	80,278	129	200
Malaysia	23,965	106	192
China	1,302,307	104	165

Source: *World Health Report* (WHO 2003).

High mortality rates are associated with various types of diseases and injuries. The three major categories used by WHO are (I) Communicable Diseases, (II) Non-Communicable Conditions, and (III) Injuries (World Health Organization 2003). Table 2 shows the rankings for these three categories within each of the

Table 2 Ranking of Diseases, Conditions, and Injuries Associated with High Mortality Rates within the Three Major Categories Used by WHO, by Region, 2002

Disease/Condition/Injury	*Africa VHAM*	*Americas HAM*	*E-Medit. HAM*	*Europe HAM*	*S-E Asia HAM*	*W-Pacific LAM*
I. Communicable Diseases	**1**	**2**	**1**	**3**	**2**	**2**
HIV/AIDS	1	2	6	2	5	5
Diarrheal diseases	4	4	3	4	3	3
Childhood diseases	5	5	4	–	4	4
Malaria	2	–	5	–	6	6
Respiratory infections	3	1	1	1	1	1
Perinatal conditions	6	3	2	3	2	2
II. Non-Communicable Conditions	**2**	**1**	**2**	**1**	**1**	**1**
Malignant neoplasm	2	2	2	2	2	2
Cardiovascular diseases	1	1	1	1	1	1
Respiratory diseases	3	4	4	4	3	3
Digestive diseases	4	3	3	3	4	4
Diabetes	5	5	5	5	5	5
III. Injuries	**3**	**3**	**3**	**3**	**3**	**3**
Road traffic injuries	1	1.5	1	1.5	1	1
Violence	2	1.5	2	1.5	2	2

Source: *World Health Report* (WHO 2003).

Note: VHAM = very high adult mortality; HAM = high adult mortality; LAM = low adult mortality. The three major categories (I, II, and III) are ranked based on the number of deaths that occurred in each category in 2002 in various regions of the world. Within each major category, the diseases or health conditions that caused mortality are ranked based on the number of deaths that occurred in each region (1 = highest rank, 6 = lowest rank).

six regions of the world (Africa, Americas, Eastern Mediterranean, Europe, Southeast Asia, and Western Pacific). For example, Communicable Diseases ranked highest (no. 1) in Africa, ahead of Non-Communicable Conditions (no. 2), and Injuries (no. 3). Within each major category, diseases or injuries are listed as subcategories. For instance, in Africa, HIV/AIDS was the highest-ranking communicable disease (no. 1), followed by malaria (no. 2), respiratory infections (no. 3), diarrheal diseases (no. 4), childhood diseases (no. 5), and perinatal conditions (no. 6). Ranks within the regions based on Table 2 show that Communicable Diseases rank highest in Africa and Eastern Mediterranean, whereas Non-Communicable Conditions rank highest in Americas, Europe, Southeast Asia, and Western Pacific. Furthermore, HIV/AIDS is the greatest contributor to mortality in Africa, but HIV/AIDS is the smallest contributor to mortality in the Eastern Mediterranean region.

Though diabetes does not rank high as a major cause of deaths, diabetes has been rapidly increasing and having a great impact on adults of working age around the world, especially in the developing countries. In 2000, there were 171 million people with diabetes worldwide, and by 2030 this figure is expected to more than double (366 million), and most of this increase will occur in developing countries such as India and China. And a global partnership spearheaded by WHO, Rotary International, the U.S. Centers for Disease Control and Prevention (CDC), and UNICEF supports the efforts of national governments to eradicate polio. The partnership includes private foundations, donor governments (developed countries), and humanitarian and nongovernmental organizations (NGOs).

The WHO promotes collaboration among health, education, social, and labor sectors to ensure that persons with disabilities receive all available services to assist them in achieving equal opportunities. WHO encourages the involvement of persons with disabilities as an essential feature of all program areas (health, education, social, labor). WHO holds that empowerment of persons with disabilities in community-based rehabilitation is necessary to achieve full social integration within their communities. Many developing

countries have taken important steps during the past 10 years. Recognizing that inclusion and integration of persons with disabilities into their communities can be achieved only through political and social action, many developing countries have enacted legislation to guarantee the rights of persons with disabilities. For example, in 1991, Thailand passed its first governmental act, the Rehabilitation of Disabled Person Act, focusing on the rights of people with disabilities (Constantine 2000). Philippines has legislation known as the Magna Carta for Disabled Persons. In 1995, Philippines partnered with the Danish Society of Polio and Accident Victims, and initiated projects establishing Therapeutic Activity Centers serving 5,700 children with disabilities. In 1991, Bangladesh established (1) the National Forum of Organizations Working with Disabled and (2) the National Council for the Blind, both under the Ministry of Health (Economic and Social Commission of Asia and the Pacific [ESCAP] 2002).

In 1992, the ESCAP proclaimed a 10-year program known as the Asian and Pacific Decade of Disabled Persons 1993–2002 (ESCAP 2002). The program adopted an agenda for action to achieve the goals of full participation and equality for persons with disabilities. The ESCAP agenda called for a multisectoral approach reflecting the following 12 policy categories: national coordination, legislation, information, public awareness, accessibility and communication, education, training and employment, prevention of causes of disability, rehabilitation (community-based rehabilitation, and health/social development), assistive devices, self-help organizations, and regional cooperation. The program has produced initiatives of good practice in the ESCAP region by governmental and nongovernmental agencies (self-help organizations of persons with disabilities). For example:

- Bangladesh and Cambodia focused particularly on increasing public awareness of disability issues and outreach.
- Hong Kong, China demonstrated that legislation is effective with a built-in implementation and enforcement mechanism.
- Malaysia illustrated that general public awareness of disability issues must be accompanied by specific action to achieve necessary change.
- India stressed that determination and continued advocacy were necessary to achieve accessibility, and a project in India showed that a firm commitment to the education of all children was essential (increased enrollment of children with disabilities from 8 in 1981 to 31,000 in 2000).
- Thailand demonstrated (1) how appropriate and adequate training to rural people with disabilities (blindness) can help reduce poverty, and (2) how practical capacity building for training on productive small enterprise activities (e.g., mushroom production) could offer both improved food security and income generation for people with disabilities.
- Philippines and Bangladesh (using local organizations) underscored the importance of community-based effort as an integral part of rehabilitation as well as prevention of disability.
- Vietnam established importance of training on issues of policy, decision making, and mobilization of a self-help group.

Rehabilitation of individuals with disabilities facilitates their participation in the global marketplace. As formal and informal communication among countries increase, attitudes toward people with disabilities, government policies on disability, and rehabilitation programs are acquiring commonalities across counties. Targeted legislation, adequate service delivery programs, appropriate professional preparation, and continuing research and development will promote economic and social independence, leading to better quality of life for all citizens of the global community.

—Ranjit K. Majumder, Sita Misra, and Richard T. Walls

See also Developing World; Disability in Contemporary Africa; Disability in Contemporary India; Economic and Social Development; Globalization; Poverty; World Health Organization.

Further Readings

Australian Institute of Health and Welfare. 1997. "The Definition of Disability in Australia: Moving towards National Consistency" [Summary]. Disability data briefing (occasional series). Canberra, Australia: Australian Institute of Health and Welfare.

Chaliand, G. 2004, May 5. "Third World: Definitions and Descriptions." (http://www.thirdworldtraveler.com).

Constantine, G. 2000. "Where the Stroke Community Clicks: Stroke Awareness for Everyone." Retrieved May 3, 2004 (http://www.strokesafe.org/resources).

Economic and Social Commission of Asia and the Pacific. 2002. "Pathfinders: Towards Full Participation and Equality of Persons with Disabilities in the ESCAP Region." Social Policy Paper No. 2. New York: United Nations. Retrieved May 6, 2004 (http://www.unescap.org).

Job Accommodation Network. 2003. *Accommodation Ideas, Suggestions, and Research Findings.* Morgantown, WV: International Center for Disability Information, Job Accommodation Network, a program of the U.S. Department of Labor, Office of Disability Employment Policy.

United Nations. 1983. *U.N. Decade of Disabled Persons: World Programme of Action Concerning Disabled Persons*. New York: United Nations.

United Nations Enable. 2004, May 5. "World Programme of Action Concerning Disabled Persons." (http://www.un.org/esa/socdev/enable).

World Health Organization. 2002. "Towards a Common Language for Functioning, Disability, and Health." Retrieved June 10, 2004 (http://www3.who.int/icf/beginners/bg.pdf).

———. 2003. *World Health Report, 2003.* Geneva. World Health Organization. Retrieved May 10, 2004 (http://www.who.int/en).

ECONOMIC DECISION MAKING BY THE DISABLED

Disabled people face many difficult decisions about how to best cope with their disabilities and plan for the future. In recent decades, policy makers have become increasingly interested in understanding how such decisions are affected by public policy. Until the 1960s, disability was primarily viewed as a clinical concept. As the federal disability rolls expanded rapidly during the 1960s and 1970s, researchers began to consider disability more broadly as a partly behavioral phenomenon influenced by economic, psychological, and social factors. A purely clinical view of disability was decidedly inconsistent with large observed variation in work patterns and public program participation among disabled people with the same observed medical conditions and sociodemographic backgrounds.

Often one of the most difficult decisions confronting a disabled person involves whether to remain employed in the current job, change occupations, or withdraw from the labor force altogether. The timing of changes in employment status depends on a variety of considerations including the type and severity of the medical condition, its prognosis, and the possibility of employer accommodations to improve access. Employment outcomes also depend on tastes for continued employment (which may be influenced by pain or difficulty in commuting), savings, income support from family members, other private sources of income, and the extent to which monetary and in-kind public transfers might substitute for forgone labor earnings.

Given sufficiently unattractive labor market prospects, a disabled person may decide to apply for disability benefits. The two dominant federal disability programs in the United States are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Participation in SSDI is comparable to early participation in the Social Security retirement program. After a five-month waiting period, eligible beneficiaries receive monthly cash payments equal to the retirement benefits they would receive if they were 65. After two years, SSDI beneficiaries gain access to Medicare; the value of these medical benefits varies substantially across recipients depending on their specific health conditions and private health insurance status. SSI is a means-tested program targeted to low-income aged, disabled, or blind people. In contrast to SSDI, there is no waiting period or work history requirement. Beneficiaries have immediate access to medical care through Medicaid.

Much academic attention has focused on estimating how a disabled person's choice whether to continue work or apply for disability benefits depends on policy parameters (e.g., benefit levels, award standards, waiting periods) and personal characteristics (e.g., age, occupation, medical conditions). Economic theory assumes that people will make choices that maximize their expected well-being, given their constraints. Statistical models based on this assumption attempt to quantify a disabled person's expected level of well-being under various scenarios. The methods recognize that decisions are made in an environment of imperfect information, including uncertainty about the evolution of the work limitation, the path of potential wages, the quality of leisure time, and the government's decision about whether to approve a disability application. The methods also recognize that while some

important personal characteristics can be observed in the data (e.g., age and years of schooling), others are unobservable to the researcher (e.g., motivation, the severity of a condition, and potential discrimination). Empirical estimates obtained from these models have been used to assess the degree of work disincentives associated with various policies and to forecast the extent to which policy changes would affect economic decision making. Researchers generally agree about the directions but not the magnitudes of these policy effects.

—Brent Kreider

See also Decision Making; Disability Policy: United States; Job Retention.

Further Readings

Bound, John and Richard V. Burkhauser. 1999. "Economic Analysis of Transfer Programs Targeted on People with Disabilities." Ch. 51 in *Handbook of Labor Economics,* Vol. 3c, edited by O. Ashenfelter and D. Card. Amsterdam: Elsevier Science.

Danzon, Patricia M. 1993. "The Economic Implications of Public Disability Insurance in the United States." *Journal of Labor Economics* 11:S170–S200.

Haveman, Robert and Barbara Wolfe. 2000. "The Economics of Disability and Disability Policy." Ch. 18 in *Handbook of Health Economics,* Vol. 1, edited by A. J. Culyer and J. P. Newhouse. Amsterdam: Elsevier Science.

Websites

Rehabilitation Research and Training Center for Economic Research on Employment Policy for Persons with Disabilities (RRTC), Cornell University, http://www.ilr.cornell.edu/ped/dep/rrtc.html

EDISON, THOMAS (1847–1931)

American inventor

Thomas Edison, the most prolific U.S. inventor, has appealed to the popular imagination since the late 1870s. Among the most enduring stories are those about Edison's lack of formal education. Generations of schoolchildren have learned these as object lessons in perseverance. In recent years, Edison's name has been used to encourage persons diagnosed with disabilities such as attention deficit hyperactivity disorder (ADHD) and dyslexia. Although there is no evidence that Edison, a prolific reader, was dyslexic, opinions are divided regarding ADHD. The affirmative case rests partly on his short school career, anecdotes about inattention and mischievousness, his restless creativity, and ability to work on several projects simultaneously. More likely is that economic hardship made it difficult for Edison's family to pay school fees; his mother, a former teacher, was manifestly capable and made use of the family's ample library. Edison's mind was distinctive and fecund, but there is no clear evidence of functional impairments, which an ADHD diagnosis requires. Rather, his combination of originality, energy, and learning through experience epitomizes the divergent thinking that psychologist Lucy Jo Palladino has termed "the Edison Trait."

Edison's hearing impairment was incontrovertible. Its origin is unclear; he seems to have recognized it as a youth and it grew progressively worse. When newspapers reported it in 1878 following his invention of the phonograph, Edison received many letters seeking advice and hearing aids, which he made some effort to develop. Even as normal conversation became more difficult, Edison remained sociable and enjoyed the theater, taking care to sit near the front. He had a lifetime love of poetry and music. In his 60s, he insisted on selecting artists and recordings for his phonograph business, to the company's detriment. He said that by biting into the wooden horn he could "hear better than anybody else" because the sound went directly to his inner ear, which had been "protected from the millions of noises that dim the hearing of ears that hear everything."

—Louis Carlat

See also Hearing Impairment.

Further Readings

Baldwin, Neil. 1995. *Edison: Inventing the Century.* New York: Hyperion.

Israel, Paul. 1998. *Edison: A Life of Invention.* New York: John Wiley.

Jenkins, Reese V. et al., eds. 1989–1998. *The Papers of Thomas A. Edison*, Vols. 1, 4. Baltimore: Johns Hopkins University Press.

Palladino, Lucy Jo. 1997. *The Edison Trait: Saving the Spirit of Your Nonconforming Child.* New York: Random House.

EDUCATION, COLLEGE AND UNIVERSITY

> *Indeed, attempting to fit the problem of discrimination against the handicapped into the model remedy for race discrimination is akin to fitting a square peg in a round hole.*
>
> *Garrity v. Gallen*,
> 522 F. Supp. 171, 206 (DNH, 1981)

> *Section 504 and the ADA should be welcomed for the opportunities they offer to postsecondary education for rewarding self-examination. No other set of laws so entreats academia to take its own temperature, examine its traditions, and thoughtfully deliberate about which of its standards are essential and which are merely unexamined habits.*
>
> Paul D. Grossman (2001)

Support for students with a disability in higher education has both a long and a short history, an approach-avoidance relationship that both reflects and shapes the views of the larger social milieu. In the latter half of the nineteenth century, a national philosophy of educational egalitarianism began to influence colleges and universities in the United States. This movement was reflected in the Morrill Acts of 1862 and 1890, which created the land grant colleges, increasing both the diversity of the student body and the fields of study available.

During this same period, the Columbia Institution for the Deaf, Dumb and Blind was founded in Washington, D.C., by William Kendal. Kendal hired Edward Miner Gallaudet (the son of Thomas Hopkins Gallaudet, who founded the first school for deaf students in the United States) as the first superintendent. By 1864, Congress authorized the Columbia Institution to grant college degrees. The following year, the nine blind students at the institution were transferred to the Maryland Institution for the Blind, and the Columbia Institution for the Deaf and Dumb became the National Deaf-Mute College by an act of Congress.

In 1866, the National Deaf-Mute College conferred its first bachelor's degree, 21 years later the first women were admitted, and 28 years later the name of the college was changed to Gallaudet College. During Gallaudet College's first 30 years, numerous elementary, secondary, and vocational "schools for the deaf" or "schools for the blind" were established but did not lead to the spread of specialized institutions at the postsecondary level as it had for colleges founded to educate African Americans.

At the beginning of the twentieth century, the first dozen historically black colleges and universities had been established. Gallaudet would stand unique until 1965 when the Rochester Institute for the Deaf was established by Congress. This was not because individuals with disabilities were attending "mainstream" institutions in large numbers; they were as unique to postsecondary education as Gallaudet and would remain so for most of the century.

War, or more precisely returning veterans, became one of the driving forces in U.S. disability policy. Legislation supporting disabled veterans returning after World War I combined with early vocational rehabilitation programs aimed at injured workers began to increase participation in higher education. In 1943, the inclusion of assistance to disabled veterans in the Vocational Rehabilitation Act and the passage of the GI Bill in 1944 significantly increased this trend.

Similar to the latter half of the nineteenth century, the second half of the twentieth century oversaw a period of rapid expansion and democratization in education. In 1954, *Brown v. Board of Education* mandated desegregation of public education. In addition, college enrollments increased, the community college system was established, and open admissions programs were begun. By 1965, the Higher Education Act established grants for student support services aimed at fostering an institutional climate supportive of the success of low-income and first-generation college students. Eleven years later, the act would be expanded to include individuals with disabilities.

Beginning with the increasing presence of disabled veterans on campuses, services for students with disabilities began to emerge. By 1948, the University of Illinois at Urbana–Champaign had a formal program for students with disabilities. In a speech at the 25th anniversary of the program, Timothy Nugent, its founder, stated:

> The University of Illinois was the ideal place to bring about the total rehabilitation and integration of individuals with disabilities with its varied academic, social, cultural opportunities and challenges along with the resources and research capabilities to give credence to what we were doing. It was difficult and took time but it was well worth the pain and suffering. Very few of the young people today would tolerate or endure what many of my early students went through but they knew that they were building for the future. Of all of our facilities and programs the most effective was the development and participation in normalized competitive sports. To the individual participant, it helped overcome self-consciousness and develop self-confidence. There were many common denominators in our sports programs and those of the general population that all people could understand, appreciate, and respect. They began to recognize the normalcy of those with disabilities—their desires, skills, competitiveness, and emotions. They were athletes, and good ones too! (LaMere and Labanowich 1984)

The University of Illinois at Urbana–Champaign was typical of a few dozen programs that emerged as a result of the GI Bill. This university in particular provides a good example because of its better than average documentation over the years. With an emphasis on wheelchair users, programs applied the vocational rehabilitation model to higher education. Such programs offered adapted sports, housing, and transportation. The program at Illinois and the program helped to found the National Wheelchair Basketball Association, established a service fraternity for students with disabilities (Delta Sigma Omicron), introduced curb cuts on campus, and had lift equipped fixed-route buses by 1952. A transitional living program for students with severe disabilities needing assistance in the performance of daily living activities was established in 1959, and a study-abroad program for university students with disabilities was in place by 1965.

About that time, another model was developing in California. In 1962, Ed Roberts, who used a wheelchair by day and respirator by night, wanted to attend University of California, Berkeley. After a series of meetings between Roberts, his mother, and the administration, Ed Roberts was allowed to move on campus but in the campus' health facility, Cowell Hospital, not the residence hall. Word of this spread and by the end of the 1960s there were a dozen students on the third-floor Cowell Hospital.

In 1969, the students began moving from the hospital to apartments on the south edge of the Berkeley campus. In the spirit of the 1960s, the students organized. Calling themselves the Rolling Quads the organization gave voice to student concerns, negotiated with the college administration, and proposed the formal establishment of services for disabled students.

In 1970, the students were awarded a federal Department of Education grant of $80,000, and the Physically Disabled Students' Program was established. Its first director was John Hessler, one of the original students living in Cowell Hospital. By 1986, the program had grown to approximately 350 students; today it employs 30 staff members and serves more than 850 students.

By the early 1970s, there were isolated programs serving students with disabilities. Gallaudet and the Rochester Institute for the Deaf, established by Congress, stood at one end of the spectrum; a few dozen programs similar to the University of Illinois at Urbana–Champaign might be seen as a midpoint; and a handful of programs that were student driven along the lines of the program at Berkeley stood at the other end. Beyond these exceptions at most of the 3,000 or so accredited colleges in the United States there were no structured supports for individuals with disabilities, and if participation was encouraged it was based on individual circumstances and advocacy. This was about to change.

The disability rights movement was taking shape. When the Rehabilitation Act of 1973 was passed it included Section 504, and for the first time civil rights were legislated for people with disabilities in the United States. Section 504 prohibits programs receiving federal funds, which includes most colleges and universities, from discriminating against otherwise qualified "handicapped" individuals. It would take five years of lobbying and protesting before the American Coalition of Citizens with Disabilities (ACCD) won the release of regulations that would allow Section 504 to be implemented.

The full impact of Section 504 on higher education is not the focus of this entry, but it is important to note that

the regulations for Section 504, subpart E, specifically covered postsecondary education and required that postsecondary education operate its programs (specifically identifying recruitment, admissions, academics, housing, research, financial aid, counseling, physical education, athletics, transportation, and employment assistance) in a nondiscriminatory fashion.

It is also important to note that Section 504 required institutions to make academic adjustment (modifications to policy procedure and practice) and provide auxiliary aids and services to students to provide equitable access to their programs. These adjustments and aids, commonly referred to as reasonable accommodations, must be provided unless they fundamentally alter the program or service in which the student participates. Balancing these competing equities, the individual right to participate and maintain the essential nature of programs became a part of the role and fabric of disability services in higher education.

In 1975, the Education for All Handicapped Children Act (P.L. 94-142) was passed and established the right of children with disabilities to a free and appropriate education in the public school systems. This increased the number of college students with disabilities prepared for colleges.

In 1976, the Higher Education Act was amended to include students with disabilities as one of the eligible populations for Student Support Services grants. This provided funding for the growth in disability service programs across the country. In March 1978, the Association on Handicapped Student Service Programs in Post Secondary Education was founded, which later became the Association on Higher Education and Disability (AHEAD).

The passage of the Americans with Disabilities Act (ADA) in 1990 did not substantially alter higher education's legal obligation because nearly all colleges and universities receive federal funds. From the early 1980s to the early 1990s, there was a growth in the enrollment of students with disabilities. A survey of first-time freshmen at four-year institutions indicated approximately 1.8 percent in 1980 reported a disability. In 2000, over 6 percent reported having a disability. The largest growth has been in the number of students with learning and psychological disabilities.

Shifting demographics has affected services. Today, disability services offices divide their work between two sets of tasks: accommodations and services. As accommodation decision makers, they review students' disability-related needs, relying heavily on documentation for students with learning and other "nonvisible" disabilities, and determine accommodations appropriate to the students' needs. Typically, they arrange for the conversion of print material into accessible formats, advise on facilities' access issues, provide proctoring for modified test conditions (extended time, reduce distractions), and provide adaptive equipment. In addition, they may provide awareness and training to faculty and staff, provide advising and counseling to students, and host support groups and student organizations.

—L. Scott Lissner

See also Accessibility; Gallaudet University; Rehabilitation Act of 1973 (United States); Ed Roberts.

Further Readings

Berkowitz, Edward. 1987. *Disabled Policy: America's Programs for the Handicapped.* New York: Cambridge University Press.

Cremin, L. A. 1982. *American Education: The National Experience 1783–1876.* New York: Harper and Row.

Gallaudet, E. M., L. Fischer, and D. de Lorenzo, eds. 1983. *History of the College for the Deaf, 1857–1907.* Washington, DC: Gallaudet University Press.

Grossman, Paul D. 2001. "Making Accommodations: The Legal World of Students with Disabilities, 87." *Academe: Bulletin of the American Association of University Professors* (November-December): 41–46.

Henderson, Cathy. 2001. 2001 College Freshmen with Disabilities: Biennial Survey." Heath Resource Center. Washington, DC: American Council on Education (http://www.heath.gwu.edu/PDFs/collegefreshmen.pdf).

LaMere, T. J. and S. Labanowich. 1984. "The History of Sports Wheelchairs—Part I and Part II." *Sports 'n Spokes* (March and May).

Thelin, J. R. 2004. *A History of American Higher Education.* Baltimore: Johns Hopkins University Press.

Websites

Association on Higher Education and Disability, http://www.ahead.org

EDUCATION, INTERNATIONAL

Education is universal and occurs wherever people interact and communicate with each other. Educational

practice in all cultures and societies is a mirror reflecting the ways in which people relate to each other. While education may be a global occurrence, education systems are continuously shaped by local beliefs, customs, and history in diverse nations. The differing beliefs on educability remain deeply entrenched in the cultural values and attitudes of particular societies. Thus, the education of children with disabilities can best be understood if the precise historical and cultural contexts in which they are raised are well understood. Therefore, international perspectives on the education of persons with disabilities may focus on global issues, as the established universal values in education or on the diversity in education, fashioned by the prevailing principles and demands of various societies.

The manner in which societies exploit their distinct human resources is an acknowledgment and measure of the power of education. The education of persons with disabilities therefore provides a glimpse into the essential understanding of humanity as perceived by a particular culture. Schools are the vehicles that societies employ to advance their aims of education. The culture and philosophy of schools therefore reflects a view on education embedded in a particular historical and cultural context. The systems countries design, for educating their children with disabilities, characterizes their general outlook on the human character and spirit. Throughout history, children with disabilities have been regarded as nature's mistakes and cruelly neglected and often killed. Recently, better understanding of disabling conditions and more promising practices among practitioners have led to fruitful international exchanges and meaningful dialogue among professionals in this field.

Comparative special education attempts a description of similarities and differences in various systems and provisions engaged in the education of children and youths with disabilities. More recently, comparative approaches also examine trends in educational provision across the lifespan, including early education programs as well as adult education for persons with disabilities.

While comparative special education contrasts practices in various countries, international special education seeks to identify paradigms and models beyond the instructional practices in individual countries. More recently a global perspective as to the best methods for providing quality education for children with disabilities has developed alongside scientific enquiries into education in general. The international discourse on disability and education has been fashioned by the scientific community, on the one hand, and by international organizations, on the other.

Historically, educational services for people with disabilities developed from practices and traditions of the medical profession as well as the religious and charitable institutions. Today's international perspectives on education for persons with disabilities are more systems oriented and invite the education system to promote greater social cohesion, inclusive practices, and equitable access for all children and youths.

INTERNATIONAL PERSPECTIVES IN EDUCATION

International exchanges of views about good educational practices are often initiated by parents or professionals working with children with disabilities. Recommendations regarding the handling of complex and challenging situations as well as the most pragmatic methods for coping with everyday situations have cross-national legitimacy. Pioneer efforts are usually embraced by education systems once their intrinsic worth is established. Usually, such international exchanges tend to focus on specific issues such as the efficacy of "sensory training" or early intervention programs for children with specific disabilities. Other practices shared internationally are approaches to alternative and augmentative communication or ways in with children with cerebral palsy can be supported.

On the other hand, comparative special education does not concentrate on the individual successes of children, but rather on the achievements of the education system. These revolve around such issues as the types of provision in the various countries and their delivery systems. Comparative special education may entail simple descriptions of the manner in which states organize their education or present multidimensional facets of their pupils, resources, and attainments. The comparison of provision for children with disabilities in the various countries is not always straightforward because of the lack of precision in the definition of disability and limited information about the reasons for failure to join the regular schools.

A country's ability to integrate children with a hearing loss, for example, may be due to a wider definition of hearing impairment—leading to an overidentification, compared to procedures in other countries. Measures used for assessing the accomplishments of special education in various countries are the level of resource investment (attributes and qualifications of teachers, financial support, and the availability of auxiliary services), the quality of educational processes (assessment procedures, teaching practices, and team collaboration), and outcomes (academic performance, pupil and teacher satisfaction, personal well-being, and transition to work and other settings). The apparent differences between countries lead to cross-national collaboration, joint programs, and assistance to less developed countries. Some disadvantaged countries may have only insignificant provision; others may offer good facilities for the children of upper-class parents or those living in affluent urban districts, but have few services available to the poor in rural areas. Considerable sensitivity needs to be exercised in this exchange lest the superimposition of the donors' values on the recipient country undermines their trust and integrity of their own society.

An international discourse does not merely focus on educational practices in different countries, but is also concerned with theories and research results that underpin practices. Since the issues surrounding the education of persons with disabilities are so many-sided and complex, it is hardly surprising that a large variety of scientific workers (doctors, psychologists, sociologists, academics) and practitioners (teachers, therapists, social workers) are drawn to the study of disability. In its early years, the international dialogue centered on the educability of children with disabilities and methods to be applied to their education. The present discourse gives greater attention to societal and system transformations that may be necessary to ensure successful outcomes of education. Currently, there is a swing away from a medical model to a social model, which emphasizes the importance of social structures to support the independence and rights of people with disability. Presently, robust debates can be observed, particularly at international congresses when scientists and theoreticians freely exchange their respective views on burning issues of disability and education.

While academics base their position in accordance with their specific theoretical framework, international organizations pay more attention to changing practices according to their general mission. Recent emphasis on disability issues is also the result of a growing interest in human capital, lifelong learning, and understandably also in the education of persons with disabilities. Many major international governmental organizations initiating educational, economic, social, or cultural development are today concerned with issues about disabilities. Some of them have recently formed a common platform to discuss and coordinate their disparate endeavors with a view to reducing waste and overlap. The International Working Group on Disability and Development is one such initiative designed to coordinate the various internationally active organizations such as the Organization for Economic Cooperation and Development (OECD), the United Nations Educational, Scientific, and Cultural Organization (UNESCO), or the World Bank.

Nongovernmental organizations (NGOs) created by interest groups lobby strenuously to further their respective causes and make strong representation to governments. Several international NGOs unite national interest groups to further their objectives, such as Inclusion International and Rehabilitation International. The development and relevance of such international private bodies were facilitated by the United Nations when the organization conferred official status to international NGOs representing a relevant and substantial interest group.

DEVELOPMENT OF INTERNATIONALITY IN EDUCATION

Famous individuals have contributed to the theory and practice of educating children with disabilities across the centuries. In England, the writings of Charles Darwin may have influenced the view that only the fittest should survive. Indeed, Darwin's illustrious cousin Francis Galton, the geneticist, advocated the segregation and sterilization of children and adults with intellectual weaknesses. His contemptuous and callous description of even the mildly retarded as "polluters of the noble stock of humanity, too silly to take part in general society and easily amused with

some trivial harmless occupation" relegated the disabled to institutions or asylums or placed in the care of hospitals or charitable organizations. Abroad in France and Italy, for example, a more optimistic view of the modifiability of human behavior was evidenced. The outstanding proponent of this view was enunciated by Jean Gaspard Itard, who rescued a "feral" so-called wild boy, Victor, found wandering in the forests of Aveyron in France. Itard designed and applied a systematic training program for the boy and made remarkable progress despite several vicissitudes. His disciples Edouard Séguin, Maria Montessori, and Alfred Binet continued his work by establishing classes for children with "mental retardation." Montessori, a doctor, recognized that the more effective "treatment" for such children was pedagogical, not medical. Today, most reformers accept the principle that through the promotion of education of persons with disabilities, critical insights into the makeup of a civilized society are discovered.

The philosophy underlying attempts to educate children with disabilities goes back several decades. It was, however, the influence of the English philosopher John Locke, who advanced the concept that knowledge was gained through the senses in his notable *Essay Concerning Human Understanding*, that aroused interest in the disabled. Jean-Jacques Rousseau emphasized that the "child's curiosity was the origin of learning" and that instruction should be based on its nature and not the demands of an artificial society. The climate of despair present in many countries of the nineteenth century was further improved by illustrious and legendary individuals and dedicated teachers such as Itard, Montessori, and Binet. They influenced educational practice for generations of children, by their practices and philosophy of teaching and interacting with children with disabilities. These individuals have in the past inspired parents and professionals and given them strong motivation to continue the quest for quality education. They are well-known internationally, having shaped our idea of education and changed restricted views people held on the educability of persons with disabilities. The story of Helen Keller and her devoted teacher Anne Sullivan has inspired countless parents, teachers, and professionals alike. However, it is necessary to avoid raising the hopes of parents and teachers when untested and bogus treatments and educational programs are advertised and marketed for parents and educationists. Rigor and scientific veracity are the watchwords to safeguard the welfare of this vulnerable group. The complex disorders of autism, cerebral palsy, hyperactivity, and other baffling conditions tend to be the targets of unfounded claims for effective treatment and cure.

Comparative special education began with contrasts between various state practices in dealing with persons with disabilities. In several countries, state institutions were founded in the late nineteenth and early twentieth centuries to care for the mentally ill or intellectually disabled. The regime in many cases was custodial, harsh, restrictive, and dismal. The isolation and lack of stimulation of the regime worsened the mental and emotional states of the "inmates" as they were referred to. These individuals were under the auspices of either health or social welfare departments/ministries. As a result of pressure exerted by professionals, parents, and other groups, the responsibility for such children was transferred to the ministry or department of education. Today, in all Western countries, the education of children with disabilities is the responsibility of education departments/ministries. However, in many developing countries the education of such children is still the under the authority of departments/ministries of social affairs or welfare.

It is of interest to learn that the earliest chair of special education in Europe was established at the University of Zurich in the 1920s and the first international conference on special education was held in Geneva in 1938. Since then, studies related to the education of children with disabilities have had contributions from general education, sociology, medicine, philosophy, and psychology. The international movement toward normalization occurring in the 1970s was led by Sweden and other Scandinavian countries. It spread to several Western countries making a deep impact on their education systems. For example in Italy, the antipsychiatry movement led by Franco Basaglia led to the rapid dismantling of special schools and the integration of most disabled children into the regular education system.

Today, there is a prevalent demand for increasing the number of children with disabilities to receive

their schooling side by side with their nondisabled peers. This trend is now acknowledged and welcomed by the major education providers. It reflects a general world movement toward equity and educational opportunity for such a minority group. The growing conviction that all people have equal intrinsic value has permeated the thinking of those responsible for organizing and delivering educational services for children with disabilities.

In recent times, the recurring theme of "integration" has captured the attention of educationists, political activists, parents, and governments. This led to the promulgation of the Salamanca Statement and Framework for Action at the UNESCO conference in 1994, which invited all governments to embrace the philosophy of integration. More recently, the recurring theme of "inclusion" has captured the international attention of everyone working in the field. However, there is currently a major debate as to the efficacy of a particular form of social organization over another. The challenge facing the protagonists is to demonstrate that children with disabilities are meaningfully served in either the regular or special school system.

Critics of "segregated" (an unfair and pejorative term according to some) schooling claim that such placement denies children with disabilities the opportunities to access the full range of normal experiences and rich interactions available in the regular school. These strictures are strongly challenged, and it is argued that special education can and is offered in an array of integrated and special educational settings. In several countries, many segregated institutions for the education and well-being of children with disabilities were founded by parents or pioneers. These establishments often pioneered new and improved techniques and teaching methods for children who were deaf or visually impaired or had other disorders and maladies. With the spread of compulsory education, children with disabilities were now drawn into the sphere of the public education system and were in receipt of education as well as ancillary services. This might serve as a timely reminder that sensitivity toward local needs often serves the needs of children with disabilities preeminently.

Today, international scientific journals with interdisciplinary contributions help establish cross-national and international perspectives on issues affecting the education of children with disabilities. In addition, countries form alliances to tackle problems together. In Europe, for example, the education ministries of member countries have established a joint European Agency for Development of Special Needs Education. This agency serves as a platform for sharing and disseminating ideas and best practices in the member countries.

Today, many international organizations concerned with education still tend to ignore the specific circumstances of children with disabilities in their mainstream programs. For example, OECD's Programme for International Student Assessment (PISA) excludes children with functional disabilities from testing if the child's capacity to engage in a paper-and-pencil test on reading, mathematics, or science literacy is limited. Development projects of national and international donor organizations tend to focus on single issues, for example, health, women, children, or community-based rehabilitation. Recently, however, different organizations have met to discuss disability issues in depth and have tried to develop an integrated strategy to address complex issues of poverty or social exclusion. UNESCO's action plan on Education for All (EFA) was a response to the pressures exerted by various interest groups in including a specific flagship program on inclusive education.

SELECTED CASES

Tracing the developments of special education is a dynamic process, because changes are rapid and the literature on the subject has grown at an exponential level. This entry, however, deals with only the development in Western European countries. The advances in other countries as well as the developing nations is worthy of equal attention. Attitudes, values, and beliefs in all countries are undergoing dramatic transformations and the advent of preventive measures and early detection of disabling conditions as well as a renewed commitment on the part of society to remove the stigmas associated with disability have helped improve the circumstances of children and adults with disabilities. Countries vary in population and other demographic factors that can influence the practicalities of providing educational services.

Finland, for example, occupies the fifth-largest mass in Europe, but has a sparse population of about 5.2 million inhabitants and boasts a literacy rate of 100 percent—with one of the lowest rates of migration in Europe. In the past, children with disabilities were served by a variety of agencies and only recently has compulsory education for children with disabilities been guaranteed by law. Today, Finland is justly proud of making excellent educational provision for all categories of disability. The local communes and authorities are required to provide suitable education for pupils with disabilities. Recently, the movement for including all children with disabilities in the regular school has been adopted by the education and government authorities. There is a high level of cooperation between parents, teachers, and education agencies. Similarly, Norway has undergone considerable changes in the manner it offers education for pupils with special needs. In the past, the Norwegian authorities had a range of special schools as well as facilities that enabled children with milder disorders to be instructed in the regular school system. The country seeks to offer its services at the local level and has established a wide network of resources for teachers and pupils. These centers offer advice and short courses on a variety of topics related to the education of pupils with disabilities. Parents play a very significant role in planning and placement decisions affecting their children. Education for children with disabilities in the Nordic countries reflects the wish for good provision and equal treatment for everyone, a value embedded deeply in the framework of a Western democratic welfare state.

Education for children with disabilities in England and Wales began around 1870 when universal elementary education was first introduced in Britain. Children suffering from malnutrition or physical or intellectual disability were first identified in ordinary classes. Increasingly, children with poor sight, hearing, physical, and other ailments were recognized as different as teachers felt inadequate in instructing them. From 1895 onward, schools for "defective" children sprang up and a number of categories, mainly based on medical diagnoses, were employed to select children for placement in a variety of special schools. Many of these were run by religious or charitable organizations. In 1899, Alfred Eichholz, an inspector of special education, drew up key recommendations, which left their mark on the historic 1994 Education Act legislation. The next milestone for England was the publication of the Warnock report in 1978, drafted by a committee chaired by Baroness Warnock, the philosopher at Oxford University. In this report, the term *special needs education* was first introduced and soon gained acceptance worldwide. A decade later, the Education Reform Act was passed by Parliament. Meanwhile parents and professionals urged that the use of categories served the welfare of children poorly and argued that the education designed for nonhandicapped pupils should be available for children with disabilities. However, the Warnock Committee was anxious to point out that while supporting the concept and practice of "integration," they cautioned that integration must be accompanied by full resource support.

These short accounts illustrate diverse approaches to changes in educational practice in different countries. While countries can never copy practices in other countries, they may serve as inspiration and as a mirror to better identify potential problems and downfalls a system may be prone toward.

—Judith Hollenweger

See also Children with Disabilities, Rights of; Education, Primary and Secondary; Francis Galton; Jean Marc Gaspard Itard; Maria Montessori; Jean-Jacques Rousseau; Special Education.

Further Readings

Barnes, Colin, Mike Oliver, and Len Barton, eds. 2002. *Disability Studies Today.* Oxford, UK, and Malden, MA: Blackwell.

Evans, Peter and Ved Varma, eds. 1990. *Special Education: Past, Present and Future.* London, New York, and Philadelphia: Falmer.

Goodlad, John I. and Thomas C. Lovitt, eds. 1993. *Integrating General and Special Education.* Toronto: Maxwell Macmillan International.

Mazurek, Kas and Margaret A. Winzer. 1994. *Comparative Studies in Special Education.* Washington, DC: Gallaudet University Press.

Meijer, Cor J., Sip J. Pijl, and Seamus Hegarty, eds. 1994. *New Perspectives in Special Education: A Six-Country Study of Integration.* London and New York: Routledge.

Winzer, Margaret A. 1993. *The History of Special Education: From Isolation to Integration.* Washington, DC: Gallaudet University Press.

EDUCATION, PRIMARY AND SECONDARY

HISTORICAL OVERVIEW

Long before education systems became aware of issues surrounding disability, individuals responsible for providing health-oriented institutions became interested in the education of children and youths with disabilities. Nineteenth-century pioneers such as Jean Marc Gaspard Itard in France and Maria Montessori in Italy demonstrated through their work that education did make a difference to children with disabilities. Their work arose from an understanding that while the care offered by large institutions was essential for survival of their wards, education could make a significant difference to the lives of these children. The realization that children with disabilities could be educated was interrupted by the philosophies promoted by the eugenics movement before and during World War II. After the war, however, several professorships related to the education of children and youths with disabilities were established, thus heralding a new understanding that children with disabilities were not simply to be cared for but also educated. The charity perspective of saving the souls and possibly lives of persons with disabilities had yielded to the notion that education could make a difference to the children's development and quality of life.

In many cases, the parent's initiatives led to the establishment of institutions and services that competed with the existing institutions based either on charity or medical services. These private services often served groups that did not receive adequate or appropriate services offered by the state or existing organizations. This led to a very diverse range of services with a variety of methods, curricula, and equipment. These parent organizations played an important role nationally and internationally in persuading governments to improve their services and acknowledge that the needs of their children had to be taken seriously.

With the advent of social welfare states in Western countries, educational services for children gradually increased and a recognition grew that education was an entitlement rather than a charitable offering. Usually, departments of social welfare or social security assumed this responsibility and only later were these responsibilities transferred to education authorities. While in most Western countries education authorities assumed responsibility for children with disabilities, the services offered were not part of the general education system. A segregated educational service under the umbrella of regular education was organized based on the major functional problems or impairments of the child. Eligibility to the special education services was generally dependent on the severity of a particular disability.

In recent years, a progression from an eligibility-based to a rights-based approach became apparent not just by activists but also in legislation changes in some countries. This coincided with a move away from category-based services to an integrated provision in general education. International conventions and other international documents emphasized the rights of people with disabilities enshrined in such documents as the United Nations Standard Rules that urge nations to adequately address the educational needs of children with disabilities. It pays extra attention to the rights of girls, very young children, and children in impoverished families or communities. UNESCO's Dakar Action Plan describes the policy as "Education for All," which includes all children potentially excluded from participating in education, work, and social life. Whether these ideals can be translated into practice will become evident over the next decade.

COMPULSORY EDUCATION

In most countries, education is compulsory for all children at the primary and lower secondary levels (International Standard Classification of Education [ISCED] Levels 1 and 2). Many countries extend educational provision for children and youths with disabilities beyond compulsory schooling up to the age of 18 or even 21 years and offer special educational services for very young children. At the primary level of education, the focus is on basic reading, writing, and calculating skills as well as a general understanding of the world. The secondary level has a more discipline-oriented approach and may have an element for vocational and work skills preparation. Some students with disabilities follow a similar curriculum as their nondisabled peers and are given special assistance

such as a sign language interpreter or information in Braille if needed. Others may follow a special curriculum that emphasizes the acquisition of life skills rather than academic skills.

The Organization for Economic Cooperation and Development (OECD) regularly compiles and publishes statistics and indicators in education. The OECD data on education reveal that depending on the country, the percentage of children in primary and lower secondary education who are identified as having a severe disability range from less than 1 percent to 5 percent of the school population. This variance is not primarily due to a difference in prevalence of disabilities, as more affluent countries tend to identify more children and youths as being "disabled" than poorer countries. The data reflect the manner in which countries allocate additional resources for the education of children. In some countries, the percentage of children receiving additional resources totals over one-third of the school population. This group includes not only children with disabilities but also children with learning or behavior difficulties as well as children and youths from disadvantaged backgrounds.

The diversity of student populations of today's schools has compelled education authorities to reconsider the traditional division between general and special education. With increasing numbers of children in need of special support, a reappraisal of the current policies is taking place in many countries with a view to ensuring effective and equitable uses of funds and resources.

Various countries and schools tend to offer diverse educational programs even to children with similar disabilities. These educational services could vary in terms of placement (i.e., integrated or segregated settings, day care or residential), function (preparation for an adult life in open society or a sheltered life in an institution), and content (regular or adapted curriculum, concentration on academic performance or life skills) as well as performance levels and range in intensity of support and training. A variety of professionals diagnosing the educational needs and the nature of therapy or special support may also be involved. These services may be school based or organized in centers that serve a particular region.

Education policies today are shifting from a content-oriented approach to a more standard-oriented one. The education authorities consider it more important to evaluate the competencies young people need to develop rather than insisting on the number of chemistry or geography lessons given. This coincides with a shift from judging education systems on input indicators to a general focus on outcomes. Thus, policy makers are more concerned with the abilities and achievements at the end of schooling rather than the amount of hours spent in school. This shift in perspectives has also led to a growing interest in the transition from school to work or employment. Young people seeking access to higher education, employment, and economic independence are perceived as important signs of the equity and effectiveness of compulsory education. The increased flexibility of school systems to respond to such changes could offer students with disabilities better opportunities for greater participation in education.

This development is reflected by the wide attention accorded to the OECD's Programme for International Student Assessment (PISA) in many countries. PISA claims to provide education systems better indication as to how well they have prepared their 15-year-old students for adult roles in their society and for lifelong learning. It measures the students' levels of reading literacy, mathematical literacy, and science literacy independent of a nation's curriculum or the specific contents of education in any given country. The results suggests that education systems with an integrative approach teaching all students together and focusing on their levels of competencies perform better than highly differentiated systems which direct students to different streams or programs.

CONCEPTUALIZING DISABILITY IN EDUCATION

The conceptualization of disability in education is reflected in the historical development of special educational services. Initially, an understanding as to what impact an impairment such as mental retardation or polio had on the development of a child was critical. Impairments were usually identified by a health professional in early life or following an injury or illness. Educational interventions were directed toward compensating or overcoming the impairment, generally

focusing on children with sensory impairments and to a less extent, physical disabilities such as cerebral palsy. The emphasis of the compensatory approach was to ease or reverse the effects of a disability of the child. Functional approaches adopt a similar approach insofar as they also stress the disability or dysfunction of the child. While compensatory methods were more concerned with the overall development and well-being of children, functional approaches were mainly focused on learning in school. A functional approach to disability concentrates on a child's functioning in educational settings and relates mainly to behavior, learning, and interaction with others. Although problems with learning and behavior are often the result of complex interactions, functional like compensatory approaches focus on the diagnosis and intervention of the individual child. Many of the categories of disability currently employed in educational settings are based on the functional model.

The campaign launched by the disability advocates for equal rights and antidiscrimination legislation has had a considerable impact on accessibility, employment, and social security. But the rights-based approach to disability has had less of an impact on conceptualization of disabilities within primary and secondary education. The underlying premise that people with disabilities are a minority group implies that without barriers and discrimination, full participation in public life would be accomplished. This premise is not easily applicable to education. Accessibility to the full range of the curriculum is more complex. A right to be physically placed in a regular classroom does not necessarily ensure an equitable education. The minority model or rights-based approach may influence the overall policy to include all children within a single education system, but it has insignificant influence on the educational practice itself. Yet another concept of disability related to education is the social constructivist approach, which views disabilities not as a reality but rather a social phenomenon. It regards the school system or the social interactions occurring in schools as leading to the exclusion of children. Disability therefore is viewed as something that is created or constructed through the social processes inherent in the education system itself. The social constructivist model is helpful in understanding processes of diagnosis and disparities in the provision of services to children, but it has yet to establish its relevance to educational interventions and school practices.

It might help to view disability as a complex phenomenon with biological, psychological, and social aspects. Any conceptualization of disability in educational settings should take account of the fact that children are identified only if a mismatch between the expectations of the educator and the performance of the child becomes apparent. Attitudes and other factors in the environment need to be viewed as contributing to a disabling condition and therefore also as part of the intervention process. A multilevel approach that might lead to equitable access to the curriculum is of paramount importance.

EDUCATIONAL SERVICES

The primary concerns of educational systems center around the difficulties children and young people experience in accessing the curriculum as well as the issues of providing equitable education for all students. This has encouraged educational service providers to reappraise their policies toward education and learning.

Historically, in most countries, educational services for children with disabilities were developed separately from regular education system. Health professionals, parents or volunteers, and charitable organizations offered specialized services in special centers and schools. The groups catered to included those with mental retardation, blindness, deafness, and polio. These centers attracted workers who developed increased expertise in their respective disciplines, which led to greater improvements in services. Undoubtedly, such institutions provided opportunities for children unavailable in regular schools.

In the 1960s, a wider view of the term *disability* occurred, which resulted in the inclusion of children with behavior, learning, or social difficulties. As compulsory education extended to children with disabilities, services were organized under the umbrella of the education system. This resulted in a dual regular and special education system. In many countries, educational services still cater to specific categories of disabilities

such as autism or dyslexia. They may also focus on associated aspects of disability categories such as communication, for example, through augmentative and alternative communication methods such as Bliss symbols or adapted computer technology.

A major shift in organizing educational services for children with disabilities was initiated in the late 1970s following the Warnock report. This resulted in the new conceptualization of special needs education. It assumed that while 2 percent of any given school population could be seen as disabled, about 20 percent constitute the larger group of children with special educational needs. Accordingly, special needs could be identified relative to communication, cognition and learning, behavior, emotional and social development, and sensory and/or physical functions. This change was confirmed internationally by the Salamanca Statement and Framework for Action on Special Needs Education, at the UNESCO's Conference held in Salamanca in 1994. Governments were urged to assume the responsibility for all children within the aegis of general education and abolish segregated settings. The integration of children into regular classrooms has been achieved to a greater or lesser extent in most Western countries, especially at the primary level of education. More recently, the trend has shifted from offering integrated services for individual children with special needs to the restructuring of education systems to better meet the needs of all children. This theoretical shift has been marked with the change of the term *integration* to *inclusion* or *inclusive education*. If and how this shift affects the everyday education of children with disabilities is yet to be seen.

In poorer countries where education is unavailable or not easily accessible for all, the issues are more basic. Children and youths with disabilities and especially girls and women with disabilities experience greater risk to being permanently excluded from learning and most aspects of adult life. Poverty is closely linked to disability and therefore increased exposure to social exclusion. UNESCO's initiative to ensure "Education for All" requires countries to increase the percentage of disadvantaged and disabled children and youth successfully participating in education. An effort is currently made by several international organizations to include issues of disability and education into their social development programs.

—Judith Hollenweger

See also Children with Disabilities, Rights of; Childhood, Youth, and Adolescence; Francis Galton; Jean Marc Gaspard Itard; Maria Montessori; Jean-Jacques Rousseau; Special Education.

Further Readings

Danforth, S. 2001. "A Pragmatic Evaluation of Three Models of Disability in Special Education." *Journal of Developmental and Physical Disabilities* 13(4): 343–359.

Hocutt, A. M. 1996. "Effectiveness of Special Education: Is Placement the Critical Factor?" *The Future of Children* 6(1): 77–102.

Kavale, K. A. and S. R. Forness. 2000. "History, Rhetoric and Reality: Analysis of the Inclusion Debate." *Remedial and Special Education* 21(5): 279–296.

Organization for Economic Cooperation and Development. 2000. *Special Needs Education: Statistics and Indicators*. Paris: Organization for Economic Cooperation and Development.

———. 2001. *Knowledge and Skills for Life: First Results from PISA 2000*. Paris: Organization for Economic Cooperation and Development.

United Nations Educational, Social, and Cultural Organization (UNESCO). 1994. *The Salamanca Statement and Framework for Action on Special Needs Education*. Paris: UNESCO.

———. 1997. *International Standard Classification of Education (ISCED-97)*. Paris: UNESCO.

———. 2002. *Education for All: An International Strategy to Put the Dakar Framework for Action into Operation*. Paris: UNESCO.

Wilson, J. 2000. "Doing Justice to Inclusion." *European Journal of Special Needs Education* 15(3): 297–304.

EDUCATION AND DISABILITY

EDUCATION AS A RIGHT OF ALL PERSONS

While public education is ideally a right of citizens in every society, universal access to schooling is only realized to varying degrees in countries around the world. In many countries, access to education is still denied or limited on the basis of gender, race, economic or social status, or disability. For individuals with disabilities, the right to education has been realized

only in recent decades, a fact primarily true for individuals living in developed countries. As has been the case for girls and poor children in developing countries, most children with disabilities share the experience of being denied access to education. For these groups of children, education remains what it was in earlier times, a responsibility of the family. In societies where the families themselves are uneducated, the cycle of illiteracy and failure to realize individual potential is perpetuated.

Recognition of the right to education of all persons is relatively recent with international and national laws and legislation emerging only in the latter half of the twentieth century. At the international level, the first version of the UN Convention on the Rights of the Child was approved in 1959. Among the major principles in the convention is the right of the child to education. This right is inclusive of children with disabilities as defined in paragraph 23 of the convention. The right to education also is declared for children in the preschool years in another UN document published in 1993, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In 1994, the Salamanca Statement and Framework for Action provided further elaboration of the right to education by defining special education for children with disabilities or learning difficulties. In this context, it was emphasized that the educational approach should be child centered and based on the principle of inclusion in which children with disabilities are served as much as possible in the same settings as their chronological age-peers. For young children with disabilities, goals for education in the preschool years should focus on fostering the child's development and readiness for school.

Collectively, 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 provide a summary of universal standards for equalization of educational opportunity for children and youths. As such, they represent a declaration not only of the child's protection from discrimination, abuse, neglect, denial of access, and illiteracy but also of the right to care, support, and education. These documents make the rights of children explicit, representing practices pertaining to the education of children with disabilities. While the scope of these declarations is universal, a review of policy and practice on an international level indicates substantial variability in regard to access to education for children with disabilities. In most developed countries, some level of commitment has been made to ensure the right of children with disabilities to education. However, in many, if not most developing countries, children with disabilities are denied access to education with groups of other underserved children.

In regard to access to education for children and youths with disabilities, policies and practices in the United States have often served as a model for other countries. In that context, this entry will describe the history and contemporary status of education for persons with disabilities in the United States recognizing that the situation in other countries may differ to varying degrees. In the United States, policies endorsing education for students with disabilities began in the early 1970s, with federal legislation to support free and appropriate education for persons with disabilities taking the form of Section 504 of the Rehabilitation Act of 1973. The intent of the act was to eliminate barriers that exclude persons with disabilities from educational institutions and other agencies in receipt of federal funds. The general focus of the Rehabilitation Act of 1973 was followed by the legislation directed to access to education for children with disabilities in the Education for all Handicapped Children Act (EHA) (P.L. 94–142) in 1975. This was a landmark law guaranteeing the right of all children with disabilities to education, specified under a zero-reject principle in which no child could be denied schooling. Eligibility for special education was based on meeting the criteria for defined disability categories. A comprehensive evaluation served as the basis for the development of the individualized education program (IEP), which provided the means and the goals for educational achievement of the child. An important element of the EHA was recognition of the central role of family participation in the education of their children with disabilities.

In 1994, a report was prepared for congress about effectiveness of the implementation of P.L. 94–142. The report concluded that special educational needs of America's (then 8 million) children with disabilities

were not being fully met. Specifically, three major findings reflected the lack of effectiveness:

1. Special education programs lacked full equality of opportunity.
2. One million children were excluded entirely from the public school system.
3. Disability was not identified in many children with the result that many children needing services were not served.

In response to these limitations of special education, the U.S. Congress passed a revision of the EHA, which was renamed the Individuals with Disabilities Education Act (IDEA) in 1990. IDEA was amended in 1997 and reauthorized again in 2004 as the Individuals with Disabilities Education Improvement Act reaffirming the underlying premise of a free and appropriate education with major guiding principles as follows:

- Free, appropriate public education (FAPE) for all children with disabilities
- Appropriate evaluation
- IEPs for each child with appropriate assessment techniques
- Least restrictive environment
- Parent/student participation in decision making with regard to child's education
- Procedural safeguards to protect rights of children with disabilities

Although each amendment of IDEA since its inception has included revisions, IDEA has continued to provide educators and parents with the tools necessary to promote quality educational experiences that will lead children toward a productive adult life. The intent of IDEA is remedial, requiring provisions of programs and services in addition to programs already provided to persons without disabilities. These provisions include education, technical assistance for families and children, assistive technology, parent and professional training, and an array of related services. The committee responsible for special education has the responsibilities and authority to determine what services and to what extent services are required for the child with a disability. Although the provision of services is decentralized giving authority to individual states, each state is required to establish performance goals and standards consistent with the goals and standards for all children established by that state. The federal government maintains ultimate oversight of each state and controls the funding to ensure states comply with the federal mandate.

A HISTORICAL PERSPECTIVE

1800–1850

Within a historical context, the provision of educational opportunities for children with disabilities in the early nineteenth century took the form of establishing special schools for children with sensory impairments. The first schools for children who were deaf and blind in the United States were established in 1817 and 1832, respectively. A similar pattern of establishing special schools for these two groups also was found in other countries. By the middle of the nineteenth century, children were taken out of almshouses and family settings to be sent to "specialized" schools developed specifically for children with auditory or vision impairments or mental retardation. Segregated settings excluded children with physical disabilities. While the goal of placement in these special schools was to assist the individual with a disability to become a productive citizen, the prevailing societal values and conditions resulted in the fact that these institutions often became custodial facilities with poor quality services.

1850–1900

While schools had been established for basic education of children and youths who were deaf, higher education did not become available until the National Deaf Mute College was established on February 16, 1857, as the first school for the advanced education of individuals who were the deaf and hard-of-hearing. Now known as Gallaudet University, it was named after Thomas Hopkins Gallaudet, a notable figure in the advancement of education for the deaf and hard-of-hearing. An interesting historical fact is that for more than a century, leadership of Gallaudet was provided by a hearing administrator. With the selection of a new

university president who was not a deaf individual, students expressed outrage, finding it patronizing, marginalizing, and inappropriate in the context of such an essential part of the Deaf community. Subsequent to the students' strike, the university was forced to hire a deaf president who could represent and relate to the deaf individuals enrolled in the university. This action represented a significant cultural and educational advance on behalf of the Deaf community.

Services for individuals with disabilities in the first half of the twentieth century continued to be largely institutional in nature with segregated schools and institutions providing all services on site. An important change, however, was emerging by the middle of the century with the growth of parent groups. The National Association for Retarded Children (NARC) in Minneapolis comprised of middle- and upper-class families was the first and most powerful parent-driven, human-services lobby in the nation to emerge in the early 1950s. The continued growth of parent advocacy for services for their family member with disabilities resulted in a climate of policy and legislative changes. In 1963, Congress enacted new legislation to ensure funding for a comprehensive program of research on mental retardation through National Institute on Child Health & Human Development. The premise of the legislation was to reframe mental retardation as a condition requiring services to promote health and development rather than a psychiatric problem to be treated.

Complementing the changing perspective on mental retardation was recognition of the link between disadvantage and developmental outcomes of cognitive and adaptive disabilities. The solution was to prevent developmental disability by the provision of increased educational opportunities for disadvantaged children in the preschool years. This approach was formalized with the passage of the Economic Opportunity Act in 1964 and the Elementary and Secondary Education Act (ESEA), commonly known as Project Head Start, in 1965.

A key indicator of the changing climate for persons with disabilities in the late 1960s and early 1970s was the abandonment of the concept of institutionalization. The President's Committee on Mental Retardation advanced a federal policy based on the principle of normalization contributing to the deinstitutionalization movement of institutions such as the Willowbrook State School in 1972. Paralleling deinstitutionalization was the need to establish a spectrum of community-based services to permit persons with developmental disabilities to reside in the community. For adults, this range included the development of halfway homes and intermediate care facilities (ICFs/MRs) to care for individuals with mental retardation outside of the institution. For children and youths with disabilities, there was an expansion of educational services culminating in 1975 with the passage of the Education for All Handicapped Children Act (P.L. 94–142) endorsing the right to a free and appropriate public education. A central element of FAPE was the design of an IEP plan based on the child's unique characteristics and needs. With preparation for independent living recognized as a right for the student with disabilities (*Board of Hendrick Hudson Central School District v. Rowley* [1982]), the provision of educational and community experiences to optimize the transition to the age of 21 years was included in the IEP (Clark and Lillie 2000).

CONTEMPORARY EDUCATION

Special education means specifically designed instruction to meet the unique needs of a child with a disability at no cost to the parent including instruction conducted in the classroom, home, hospital or institution, and other settings.

Early Intervention

The system of early intervention (EI) is primarily parent driven with case coordination provided through the county agency. For children 0 to 3 years of age identified as having a disability, an infant family/child education plan is developed, similar to an IEP, to ensure that children have access to appropriate community, educational, and related services. It is mandated that emphasis be placed on the natural, least restrictive, environment for provision and service coordination. Parents have the right to choose home- or center-based services. Typically, families prefer home-based services for younger children. The parent is usually the "coordinator" of home services, which may include related services of speech, physical,

occupational, special education, vision, and services for deaf and hard-of-hearing.

Local School Boards of Education

Each local school board has the responsibility to locate and identify all children with disabilities who reside in the district, whether they are of preschool or school age. A register must be maintained by the committee responsible for special education and revised annually. In addition, school boards must adapt a written policy to ensure that children with disabilities have the opportunity to participate in programs to which they are entitled.

Preschool Education

The local education agency (LEA) is responsible for the provision of services and procedural safeguards for eligible children 3 to 5 years of age. Procedural safeguards include notice, consent, and the right to an impartial hearing. An IEP is developed by the committee responsible for preschool education through the local school district. There is a continuum of service options for the least restrictive environment, and services need not be provided in conjunction with a program at a facility approved or licensed by a government agency. Least restrictive options include itinerant services, or related services at home; itinerant services in a day care placement; integrated, certified preschool with nondisabled peers; or segregated, approved preschool. The focus of instruction for children of preschool age is typically developmental with remedial treatment techniques supporting the transition to kindergarten. To be eligible for services, the child is given a general label of "preschooler with a disability." The more restrictive the environment the greater the intensity of services including one-to-one instructional support and a full array of related services including physical, occupational, and speech therapy; psychological counseling; audiological or other medical services; and transportation.

Elementary and Secondary Education

The LEA is responsible for the provision of services and procedural safeguards for children 5 to 18 years of age, and under certain circumstances until the child reaches 21 years of age. There are specific disability categories used to ensure eligibility for services under IDEA. These 13 categories are as follows: autism, deafblindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, speech or language impairment, traumatic brain injury, visual impairment, and other health impairment. There is a continuum of services for the least restrictive environment that includes full inclusion through a segregated, private setting.

The No Child Left Behind Act of 2001 (P.L. 107–110) aims to improve the performance of America's primary and secondary schools by increasing the standards of accountability for states, school districts, and schools, as well as providing parents more flexibility in choosing which schools their children will attend.

The state-mandated curriculum is typically modified to meet the child's individual needs as outlined in the IEP. Remedial techniques and adaptations to instructional material may be made based on cognitive, sensory, or physical impairments. All children, regardless of disability, are required to participate in mandatory state assessments or specifically designed alternative assessments. The state maintains ultimate oversight of the program implementation, and related services may be provided within the classroom setting or in a separate setting in a small group or individual format. Most related services are provided 1 to 5 times per week in half-hour units of time per session.

Parents are members of the committee responsible for special education program team, which is responsible for developing, reviewing, and revising the IEP. The committee members are required to meet on an annual basis to review progress, plan future goals, and make recommendations.

A functional curriculum may be implemented in conjunction with the mandated academic curriculum for students who require such educational training. Vocational skill development begins around the 10th grade, or when the child turns 15 years old. In some cases, as deemed appropriate by the committee responsible for special education, children with severe disabilities are eligible for school until the age of

21 years and also may be entitled to full-day, summer school (30 days) at no cost to the parent.

Vocational/Work

LEA/committee responsible for special education are required to develop transitional plans for children with disabilities at age 15 that address adult transition including employment and living options. It is expected that other state/federal agencies with responsibilities related to vocational education, rehabilitation, and work force development be contacted to be part of transition planning for the child. Parents maintain a key role in assisting the committee responsible for special education in ensuring their child is prepared for adult life. Community leaders and business managers also are important individuals that need to be closely linked to the LEA as most students with disabilities find employment in their hometown. The School-to-Work Opportunities Act (P.L. 103–239) was created to help states and local schools better prepare non-college-bound students for work. The provision of the law provides dollars for the state, local school district, and business partnerships to develop and implement a combination of vocational education and on-the-job training for work subsequent to graduation.

APPROACHES

Certified Special Schools

Certified special schools are schools regulated through the state, which are under the same state/federal mandates as the public school system. They are considered the most restrictive environment typically with self-contained classrooms and limited interaction with normal peers. Most children placed in these highly specialized, segregated settings are severely, multiply disabled with either medical or behavioral conditions that preclude them from attending public school. The curriculum must be responsive to the state standards, and all children must complete mandated assessments or state-approved alternative assessments to ensure progress and state compliance. Instruction is usually intense in terms of teacher/staff ratio and in some cases one-to-one instruction may be necessary to ensure educational benefit from the program. It is always preferred that a child be placed in state and as close to the parents' home as possible.

Special Classes

This option is available when a child cannot be taught within a regular class environment. Most children attending special classes and not being mainstreamed into the regular class present with moderate to severe disabilities that can be disruptive to others, or the child may be deemed incapable of participating in the curriculum in a regular classroom setting. The committee responsible for special education has the responsibility to determine the least restrictive environment and the ratio of teachers to students, which is generally lower than that of the regular class. Each child's placement should be reassessed on an annual basis. The curriculum implemented must be responsive to the state standards and all children must participate in the mandated state assessments to ensure progress in the learning environment.

Mainstreaming/Inclusion

Inclusion in the regular classroom setting with appropriate peers with special instruction and related services as needed is considered the least restrictive environment and most ideal for the majority of children with disabilities. Some children participate fully in the regular class with special instructional techniques/modifications to assist in the learning process, while others participate partially in a mainstreamed format. Special education teachers and/or related service providers assist regular education teachers in designing appropriate teaching techniques to assist a child in meeting IEP goals as designed by the committee responsible for special education. Each child's needs for continued services must be evaluated annually.

FUTURE DIRECTIONS

Access to education by persons with disabilities has a short history in the United States and industrialized countries and is only beginning to evolve in other, less developed countries in the world. The priority for the future is first and foremost to translate the right of all

persons with disabilities to a free and appropriate education into practice (UNESCO 1994). In the developing world, this right means creating legislation guaranteeing access for young children to early childhood intervention and special education for school-age students. An essential priority in this translation is education of parents regarding the rights of their child with disabilities to education. Associated priorities are teacher training and the development of curricula relevant to the academic and cultural standards of the country. The recent experience of India provides an encouraging example of the realization of the right to education. With the enactment of the Persons with Disabilities Act, India is committed to the provision of individualized education for children with disabilities through initiatives in teacher training, collaboration among government ministries, changing examination requirements, and involvement of nongovernmental organizations in implementation efforts (Sharma and Deppler 2005).

With fundamental building blocks for access to education in place in the United States and other industrialized countries, emerging directions focus on improvement of the effectiveness of instructional approaches and enhancing transition and continuity beyond the public school experience. While the IEP has been central to the concept of effective instruction for students with disabilities, the need to meet eligibility requirements as the basis for developing the IEP endorses a remedial rather than preventive approach and introduces a time lag in the initiation of services. While a categorical basis for special education eligibility has been challenged for some time (Hobbs 1973; Triano 2000), only limited alternatives have been explored at the level of individual states and assignment to one of 13 categories continues to be intrinsic to IDEA requirements. A priority for improving instruction is to identify means to initiate interventions earlier in the child's academic experience. To this end, the criteria for eligibility may need to be rethought for greater flexibility or consideration given to presumptive eligibility for young children. A second priority for improving effectiveness of instruction is to address the challenge of teaching children with severe and/or multiple disabilities. The unique and complex learning needs of this population require innovation in the nature and form of instructional approaches.

The transition from public school to the post-academic environment of work and independent living has been a significant concern in the field. Issues to be addressed include not only more individualized tailoring of instruction but also improving linkages with the community and the settings of work that the student with disabilities will enter. Fundamental to the transition to adult life is the process of the youth acquiring the rights under the IDEA and Section 504. Clarke and Lillie (2000) have identified steps in this process for transition planning and defined recommended actions for the student, family, the schools, and the community. In keeping with IDEA 2004, all transition planning needs to be consolidated by age 16 and requires a summary of the student's academic and functional performance at the receipt of a diploma or age 21. Finally, in the context of rapid societal changes, individuals with disabilities, like other persons, need continuing access to education across the lifetime. Such access could include existing methodologies of job coaching and on-site training, but also expand with new technologies using the computer for simulation and direct skill building. Education provides opportunities to learn and grow, essential to the quality of life of every individual.

—Theresa Hamlin and
Rune J. Simeonsson

See also Children with Disabilities, Rights of; Early Childhood Intervention; Individualized Education Program (IEP); Individuals with Disabilities Education Act of 1990 (United States); Race, Disability, and Special Education; Special Education.

Further Readings

Board of Hendrick Hudson Central School District v. Rowley, 458 U.S. 176, 201–02, n. 23 (1982).

Clark, S. G. and T. Lillie. 2000. "Growing Up with Disabilities: Education Law and the Transition to Adulthood." *Disability Statistics Quarterly* 20(4).

Dalton, M. A. 2002. "Education Rights and the Special Needs Child." *Child and Adolescent Psychiatric Clinics of North America* 11:859–868.

Hobbs, N. 1973. *The Futures of Children*. San Francisco: Jossey-Bass.

Individuals with Disabilities Education Act. 20 U.S.C. §1401–1485. (www.ed.gov).

Individuals with Disabilities Education Improvement Act (2004). (www.nectac.org/idea/Idea2004.asp).

Martin, Edwin W., Reed Martin, and Donna L. Terman. 1996. "The Legislative and Litigation History in Special Education." *The Future of Children* 6(1): 25–39.

New York State School Boards Association, Inc. 1994. *School Law*, 25th ed. Albany: New York State School Boards Association.

Sharma, U. and J. Deppler. 2005. "Integrated Education in India: Challenges and Prospects." *Disability Studies Quarterly* 25(1).

Triano, S. L. 2000. "Categorical Eligibility for Special Education: The Enshrinement of the Medical Model in Disability Policy." *Disability Studies Quarterly* 20(4): 496–514.

United Nations Convention on the Rights of the Child. 1989. A/Res/44/25. New York: United Nations.

United Nations Educational, Scientific, and Cultural Organization and the Ministry of Education and Science, Spain. 1994. *The Salamanca Statement and Framework for Action*. Geneva: UNESCO Special Education, Division of Basic Education. (http://unescodoc.unesco.org/images/0009/000984/098427eo.pdf).

United Nations General Assembly. 1983. *World Programme of Action Concerning Disabled Persons*. A/37/51. New York: United Nations.

———. 1993. *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. A/48/96. New York: United Nations.

———. 1996. "Monitoring Implementation of the Standard Rules." Note by the Secretary General. 52nd Session.

World Health Organization. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization. (www.who.int/classifications/icf/en/)

Websites

National Information Center for Children and Youth with Disabilities, www.nichy.org

EDUCATIONAL ASSISTIVE TECHNOLOGY

Educational assistive technology (AT) can serve to both augment and replace function for students with disabilities at all levels of education. These functions can include reading, writing, speaking, walking, remembering, and other activities of daily living, but many barriers to acquisition of AT exist, including lack of funding. The Assistive Technology Act (AT Act) of 1998 provides a definition of AT: "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 functional capabilities of individuals with disabilities."

The law includes in the definition of AT, those services that are necessary to implement AT solutions: "Any service that directly assists in the selection, acquisition, or use of an AT device including: evaluation and assessment; purchasing, leasing, or acquisition; selecting, designing, customizing, repairing; and training and technical assistance."

Although AT has the potential to enhance function for students with disabilities, 50 percent of all AT is abandoned within six months. To some extent, this is explained by developmental progress or changes in health or functional status (e.g., a student outgrows the wheelchair). However, it also appears that the failure to include active participation by the individual and family, individualize the process of matching the AT to the individual, include provisions for training the individual in use of the AT, and include a plan for maintaining and servicing the AT contribute to the high rate of abandonment. Most school-based AT specialists recommend a student-rather than technology-centered ecological approach to the evaluation of AT needs for students with disabilities where the interaction between the individual and the educational environment is stressed. AT evaluations are also best conducted by an interdisciplinary team, which must include the student and family representative and may include the teacher, speech pathologist, occupational and/or physical therapist, school psychologist, or other specialists. If the student is of an age where transition from school to work and the community should be considered, then representatives of the adult service system, such as a rehabilitation counselor, job coach, or even potential employers should be included to ensure that the AT considered can bridge the transition from school to work and life in the community.

CATEGORIES OF AT

AT can be described in terms of the function it serves. It is important to note that many AT devices can serve in more than one category.

Aids for activities of daily living. Enhancing independence with activities of daily living reduces the need for human educational aids in school and increases the student's autonomy. Aids for daily living include

devices to assist in eating, toileting, personal hygiene, and medical management, which may be useful for students with limitations in mobility, dexterity, endurance, cognition, and support, for example, daily medication requirements. Educators may also become involved in enhancing the independence of the student at home where bath lifts and home modifications may be useful.

Augmentative and alternative communication. Augmentative and alternative communications (AAC) include electronic and nonelectronic devices and strategies that enhance communication for students with severe communication impairment accompanied by limited or no speech. Included here are strategies such as alphabet and picture boards and other "light" tech devices that play a prerecorded digital message when a button is activated. In the midlevel of technology, AAC includes portable devices that can generate speech or text listened to or read by the communication partner as the student types. On the high end of technology solutions are very sophisticated devices that may or may not have dynamic displays that the user selects, depending on context, and that employ symbols or codes that can be sequenced to form communicative outputs. Commonly used communications/expressions, such as greetings, can be stored for ready access. These systems require an extensive assessment of the full range of skills and abilities and, to be successful, must consider issues such as the level of and acquisition of literacy, training availability, environmental access, and support.

Computer access. In this category are the devices that assist with gaining access to the computer. These include modified keyboards, using voice recognition software, or various switches including "sip and puff," to activate on screen keyboards or even the use of Morse or another coded system. Also included in this category of interfaces are alternative pointing devices to replace mouse function, which may be activated by other parts of the body such as the feet or head including the infrared pointing devices. Output may be made accessible through screen enlargement software that makes the screen easier to read for a student with low vision, text-to-speech software that reads text from the screen to the student, or hardware that allow students who are blind to read the screen from a refreshable Braille display. There are also a variety of software applications, including those built into some operating systems and office packages, that can increase accessibility for students when the user enables them.

Environmental control systems. Environmental control systems are primarily electronic and enable students with limited mobility to control various appliances (TV, radio); operate security systems; open doors; turn lights, heat, and air conditioning off and on; open doors; flush toilets; and other routine actions. For example, a student might have access to a remote control device mounted on a wheelchair that when activated opens the bathroom door.

Seating and positioning. Certain accommodations to a wheelchair, task chair, or other seating system can provide greater body stability, trunk-head support, and eye-hand coordination; reduce pressure on skin, spasticity, and pain; and enhance function.

Wheelchairs and mobility aids. Many students may require aided ambulation including canes, various crutches, and walkers. Others may be able to propel manual wheelchairs, which are less expensive, more durable, and easier to transport. Other individuals may require three-wheeled scooters, which can be easily stowed but cannot be used by students who do not have adequate leg function and trunk support. Electric-powered wheelchairs provide independence in mobility for the appropriate student. They can be configured to provide position changes to protect skin and to accommodate computers, cell phones, and other devices that may be powered from the chair battery. Power chairs require special consideration for initial training, transport, and a backup plan for repair, maintenance, and insurance.

Aids for hearing impairment. There have been significant advances in devices to aid hearing for students with significant hearing impairments including programmable digital hearing aids and cochlear implants (Some people in the Deaf community oppose cochlear implants contending that it is an invasive procedure that could be avoided if deafness were not viewed as a condition that should be cured.) There are a variety of systems available for use in the classroom or for

one-to-one conversation. These systems can either interact with the digital hearing aid or transmit to a set of headphones or earpiece worn by the user and may include infrared and FM loop systems. Other AT includes alarms that generate flashes or vibration to alert the student who is deaf to an emergency. Text pagers can allow transmission of emergency messages to deaf or hard-of-hearing students and text telephones (available in portable models) also enhance communication.

Learning disabilities. If students with writing disabilities are vocally fluent, voice recognition software may be useful. For other students with writing disabilities, word prediction software may allow them to identify and select the appropriate word from a list of possible choices. When the writing disability is mild, built-in spelling and grammar checkers may be helpful. For some students with reading disabilities, a plethora of software is available that combine text-to-speech output with colored highlighting of the text as it is read and a variety of other study aids. Here, it is necessary that the text be available in an electronic form. For students with memory difficulties, or deficits in executive functioning, prompts delivered as text pages to pagers or cell phones, calendars with alarms in personal digital assistants, watches with timers, and other readily available tools can help to reduce demand on memory or what is referred to as cognitive load.

Internet. The Internet itself can serve as AT. For students with limited mobility, or who are in fragile health, there may be times when access to the classroom is difficult. Because many elements of instruction, particularly in postsecondary education, are routinely available on the World Wide Web (WWW), students may be able to achieve an economy of energy by accessing an actual classroom, libraries, vast array of resources, discussion sections, peer reviews, and other academic programming from their homes. Also, the Internet renders communication barriers irrelevant and creates transparent bridges to the world of education and peers. Students who are blind can easily communicate with students who are deaf when web-based instruction is fully accessible. The potential for students with severe disabilities and concomitant health restrictions to fully participate in daily education regardless of medical status is limitless—we need only fulfill the promise of the technologies that are available to a digital society.

CONCLUSION

Educational AT can significantly enhance the performance of students with disabilities at all levels by augmenting or replacing function. Matching the AT with the student by incorporating an ongoing assessment of the student's changing needs and adapting to the resources and psychoeducational and psychosocial demands of the context with reference to other kinds of physical accommodations and learning styles is critical to maximizing successful AT use.

—Kurt L. Johnson and Carol Cohen

See also Accessible Internet; Aids for Activities of Daily Living; Assistive Technology; Augmentative Communication; Computer Software Accessibility; Computer Technology; Environmental Control; Mobility Aids; Wheelchair; Wheelchair, Electric.

Further Readings

Cook, A. M. and S. M. Hussey. 2002. *Assistive Technologies: Principles and Practice*. St. Louis, MO: C. V. Mosby.

Johnson, K. and D. Amtmann. 1998. "Increasing Access to Higher Education and Distance Learning through the Internet." *Technology and Disability* 8:133–139.

Phillips, B. and H. Zhao. 1993. "Predictors of Assistive Technology Abandonment." *Assistive Technology* 5:36–45.

Washington Assistive Technology Alliance. 2004. *Funding Manual: Paying for the Assistive Technology You Need.* (wata.org).

Websites

National Center on Accessible Information Technology in Education, "Accessible University" (instructional modules available at www.washington.edu/accessit) and "Surfing the Web with a Screen Reader" (order DVD or view streaming media at www.washington.edu/accessit)

EDWARD THE CONFESSOR
(ca. 1005–1066)

English king

King Edward "the Confessor" was the penultimate king of the Anglo-Saxons (reigned 1042–1066), succeeded briefly by Harold, and then by the Norman,

William the Conqueror. Edward's reign was distinguished by relative peace, concerns for succession of the childless king, and the early Normanization of the English church.

Edward's linkage with disability comes in two forms. The first, his reputed albinism, is dubiously supported by original sources. While later chroniclers of the twelfth and thirteenth centuries occasionally describe him as "white in his entire body," his only contemporary describer does not make such an observation. Even if he were an albino, the social consequences of such a pigmentary impairment would have been minimal in such an active and comparatively popular king.

Edward's more fixed association with disability is as the first of the European thaumaturgical kings. From Edward the Confessor through both the English and the French royalty came a tradition of the king's power to cure certain conditions by the touch of their hand—the royal touch. Cardinal among these was the "King's Evil," or scrofula/tuberculosis. King Edward, however, was also particularly well-known for healing blindness by touch.

King Edward was buried in Westminster Abbey and remains revered through accreted tradition as a "holy king." He was canonized in 1161 with a tradition of many healing miracles.

—Walton O. Schalick III

Further Readings

Barlow, Frank. 1997. *Edward the Confessor*. New Haven, CT: Yale University Press.

E-HEALTH CARE/ TELEMEDICINE

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. Use of these specialized technologies is considered to be a type of "online" intervention strategy. An online strategy involves the use of electronic technology usually in the form of a computer. Often a health care intervention uses a mixture of online and the more traditional offline approach as the methods for delivery of information directed either to the patient and increasingly to the health care consumer.

The *Internet* is a public, international network of linked, decentralized computers linked by fiber optics and other networks that allows users to communicate with each other no matter what the location or time. The Internet provides access 24 hours a day, seven days a week—24/7. The Internet is used to transmit electronic mail, find information, and engage in person-to-person exchange of text, graphic, audio, video, and other data. *Interactive TV* also known as polycom provides both audio and visual transfer of a variety of information between two or more individuals at two or more locations in real time. *Kiosk* is a free-standing device, usually a computer, that provides interactive information to the user. Most information is provided through a series of interactive prompts on a touch tone screen. Kiosks can also be used to collect data and information from users. *Personal digital assistants* (PDAs) also known as handhelds or palm pilots are personal organizers that store thousands of bits of data including phone numbers, addresses, notes, and customized software. PDAs exchange, or synchronize, information with a full-sized computer. *CD-ROM* also known as a compact disk is a device that stores a variety of nondigital data. Some CD-ROMs can be used repeatedly (read/write) while others can only be used once to store and retrieve data. *DVD-ROM* also known as a digital video disk is similar to a CD-ROM but stores data digitally.

Telemedicine, also known as telepresence medicine, is a field where telecommunications and medicine interact. Telemedicine can be viewed as a subset of E-health because it makes use of the wide variety of interactive technologies that comprise E-health and has the goal of health improvement, usually through clinical intervention.

Disabled individuals often lack some sensory ability (sight, hearing, touch, taste and smell) that prevents them from fully participating in society. E-health relies on environments that use a variety of technologies that can compensate for the lack of sensory ability. For example, technology can be applied to the movements of the hands, fingers, shoulders, or face so that communication can be established

between the individual, the computer system, and the person's environment. These adaptations have the potential to permit access for the disabled to the information society due to the less constraining environment of cyberspace compared to that imposed by the physical world. Likewise, telemedicine as an E-health strategy has the potential to improve patient–health care provider interaction and patient outcome through the increased ability to communicate on clinical and educational issues.

E-health and telemedicine have grown out of the need for health care systems and providers to document and track the health process and procedures performed on their patients, including the need for such documentation for reimbursement purposes by third parties such as insurance companies. Initially, providers kept paper records on the history and status of their patients. In the United States, during the 1970s and 1980s, spiraling health care costs led to the need for a systematic review of the number and types of procedures ordered for patients. This was known as utilization review. Often organizations external to the health care organization were responsible for utilization review. These organizations were known as management services organizations and they developed electronic tracking systems. This was the beginning of the transition from a paper-based system to an electronic-based system, which is known today as E-health. As E-health technologies continued to be developed, the field of telemedicine emerged. The field of medicine became interested in the application of telecommunications to improve the delivery and quality of patient care. Telemedicine first began in 1959 when X-ray images were transmitted across telephone lines.

CURRENT STATUS

E-health and telemedicine are designed to provide for effective exchange of health information among individuals and organizations within the community, usually in community-wide collaboratives known as electronic networks. Most E-health applications involve virtual environment technology, which is a system of technologies that allow the subject to explore and interact with computer-animated graphics. Other terms for virtual environment include *cyberspace*, *telepresence*, *mirror world*, *artificial reality*, *augmented reality*, *wrap-around compuvision*, and *synthetic environment*. In theory all five senses are involved in responding to an environment created by machine. The infrastructure needed to create the virtual environment includes computer networks, hardware, software, people, and management/quality assurance capacity.

Telemedicine can be used for remote consultation between physicians or between physician and patient regardless of geographic distance. Examples of telemedicine include remote diagnosis and surgery in which a specialist gives advice and assistance to a non-specialist during actual procedures such as in a remote location or an inaccessible environment. Some specialized uses of telemedicine include the following.

Teletriage—a specialized type of teleconsultation applied to military scenarios in which a military physician receives online health advice from a remote medical expert.

Telesurgery and telediagnostics—the local and remote physicians share the same virtual space with the patient and the normal and pathologic anatomy can be projected to the consulting physician while examining the patient.

Telecollaboration—the interactive exchange of audio-visual information or conferencing in real time between two or more participants. Several forms of telecollaboration exist including the telephone call, voice conferencing, video conferencing, pictoral information exchange, and data and/or document conferencing.

A major advantage of telemedicine is that it provides for a rapid linkage to remote "experts" who can help with patient care in underserved areas. Telemedicine facilitates the reality of providing a remote specialty consult from virtually any location within minutes. This provides greater expertise to the care of any individual patient. In addition, telemedicine is used to enhance the education of providers and patients through use of Internet-based interactives. Education is facilitated through the creation of telecommunication-linked classes providing interactive information on care and prevention to places

where such information and expertise is not currently available. For example, a number of international telemedicine efforts are currently taking place in Indonesia, Africa, Japan, Korea, China, Europe, and the United States. The Telehealth Africa project between African and European hospital centers is working to transmit health-related diagnostic images. A weekly teleconferencing link collaborative between an American hospital and a Budapest institution on issues related to diagnosis of pediatric movement disabilities is also taking place.

For the most part, E-health and telemedicine have been developed and studied as tools and strategies for use at the health care provider level to improve the quality and cost of care and to improve patient safety within the health care system. Viewed from this perspective, patients are the passive recipients of improved outcomes rather than active participants in the health care delivery process. Increasingly, however, consumers not only have become educated consumers due to the availability of E-health and telemedicine but also have become the primary intended audience for E-health-related information and technology. There are benefits and barriers to both provider and consumer use of E-health and telemedicine.

BENEFITS

Provider level. Beneficial impacts of computer-supported decision making on physician performance and patient outcomes have been documented. These include the use of computerized drug ordering systems for physicians that can reduce adverse drug events through decision support systems. Similarly, automated computerized reminders can increase orders for recommended prevention interventions such as yearly physicals, mammograms, and prostate examinations. In more extreme situations, E-health has been used by emergency medical personnel and first responders for consultation during natural disasters and in military battlefield situations. In rural and remote areas, this technology has been used by primary care providers to provide consultations and/or second opinions for patients through direct linkage to urban-based specialists. Increasingly, E-health is being used as a distance education strategy for primary and continuing education. International collaborative initiatives such as the Cochrane Collaboration, which produces a majority of the world's evidence-based medicine recommendations, have also benefited from advances in E-health and telemedicine by making information readily available to health care professionals and consumers.

Consumer level. Consumers have also benefited from advances in E-health. Pharmacy needs and prescriptions can now be ordered online and delivered directly to the buyer. Consumer-oriented health information is now a large market niche for a variety of medical and health-related organizations. A majority of hospitals and other acute care institutions host web pages that detail their expertise and services. For those with disabilities who reside in the community, a variety of E-health-based strategies exist. These include telerehabilitation systems for poststroke patients. These systems not only monitor vital signs of the patient (i.e., blood pressure, pulse, temperature) but also permit direct provider-patient communication through audio or video conferencing linkages to gauge home-based progress. Another consumer-oriented application is telelearning, which combines education with self-managed behavioral interventions designed to improve quality of life. Adaptations for consumers with disabilities who cannot use the standard computer are currently under development.

BARRIERS

Provider level. Barriers to wider use of E-health by health care providers include lack of financial incentives and reimbursement to support its use widely within and across organizations. As is true with adoption of any new innovation, the process is slow and has been characterized as a sequence that moves from innovator/risk takers, early adoptors, mainstream users, to latecomers. Incorporating a new technology will have effects on workflow with the initial start-up likely to slow established processes down due to the learning curve needed to implement the new technology, followed by a more streamlined and routinized system, which should increase efficiency and productivity.

Other barriers to E-health technology include cost (e.g., hardware/software purchases, maintenance/upgrades) and the current "lack of standards" concerning the format and content of E-health information, particularly private patient health-related information, which has legal and economic implications for providers with regard to liability and malpractice insurance.

Consumer level. One of the largest barriers to widespread consumer use of E-health is often referred to as the *digital divide*. The digital divide can be defined as a basic lack of knowledge about the availability and familiarity with technology in general. While access to electronic communications is steadily increasing both in the developed and developing worlds, these increases are not uniform and disparities in availability and skill level in using these technologies are growing wider. Issues such as cost, literacy level, cultural appropriateness, and compliance with standards for those with disabilities (i.e., Americans with Disabilities Act) continue to be barriers in the use of E-health. For patients and consumers, issues such as protection of privacy and confidentiality and informed consent should be considered. Finally, related to the disabled in particular is the need to determine the ease of use and ergonomic issues related to the use of E-health.

In response to many of the issues raised by the exponential growth in E-health, the Institute of Medicine (IOM) issued a report in 2001 titled "Crossing the Quality Chasm." The report recommended that an information infrastructure be built that will support the following: health care delivery, consumer health, quality measurement and improvement, public accountability, clinical and health services research, and clinical education. Implementation of the recommendations of the IOM report will provide greater assurance that high quality standards are in place that will help to improve the health of many communities, including those with disabilities, that can benefit from new technology such as E-health and telemedicine.

—Karen E. Peters and Michael L. Glasser

See also Accessible Internet; Health Care and Disability; Telerehabilitation.

Further Readings

Akay, Metin and Andy Marsh, eds. 2001. *Information Technologies in Medicine: Vol. I. Medical Stimulation and Education*. New York: John Wiley.

Blasiotti, Ellen L., John D. Westbrook, and Iwao Kobayashi. 2001. "Disability Studies and Electronic Networking." Pp. 327–347 in *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury. Thousand Oaks, CA: Sage.

Darkins, Adam W. and Margaret Ann Cary. 2000. *Telemedicine and Telehealth: Principles, Policies, Performance and Pitfalls*. New York: Springer.

Kovacs, Diane K and Ann Carlson. 1998. *How to Find Medical Information on the Internet: A Print and Online Tutorial for the Healthcare Professional and Consumer.* New York: Library Solutions.

U.S. Department of Health and Human Services, National Institutes of Health. 2003. "Research Based Web Design and Usability Guidelines." Washington, DC: DHHS National Institutes of Health. Retrieved March 15, 2004 (http://www.usability.gov/pdfs/guidelines.html).

Websites

Global Applied Disability Research and Information Network (GLADNET), http://www.icdri.org/Employment/gladnet.htm

Institute of Medicine, "Focus on Crossing the Quality Chasm: The IOM Health Care Quality Initiative," http://www.iom.edu/focuson.asp?id=8089m

Journal of Medical Internet Research, http://www.jmir.org/ehealth_books_literature.htm

National Rehabilitation Information Center of the National Institute on Disability and Rehabilitation Research (NIDRR), www.naric.com

ELDERLY

See Aging; Aging, International; End-of-Life Care; Frailty; Hip Fracture; Osteoporosis

ELKIN, STANLEY (1930–1995)

American writer

One of America's most acclaimed twentieth-century writers, novelist Stanley Elkin lived and wrote with multiple sclerosis for 30 years. In 17 award-winning books, he developed a virtuoso prose style and a hilarious, provocative, humane "comedy of affliction" in

American life that reflected his adage: "The Book of Job is the only book."

An early work, *The Franchiser*, published in 1976, employs paralysis as an ironic metaphor. Business visionary Ben Flesh hopes to "democratize" American wealth by spreading bright, identical franchises—Dunkin Donuts, KFC, Mister Softee—to the country's underdeveloped corners. But "Flesh fails"—the entrepreneur is diagnosed with multiple sclerosis, his limbs grow dully indistinguishable (like franchises), and so MS turns Flesh into "Mister Softee"—a living parody of his plan to enrich America by homogenizing it.

In a 1993 novella, "Her Sense of Timing," Elkin makes provocative dark comedy from the frustrations of dependent illness: A wheelchair-bound college professor's wife leaves him suddenly, just before guests are to arrive for their annual faculty party. The plot pays ironic tribute to Elkin's wife, who faithfully assisted him throughout his illness.

In *The Magic Kingdom*, from 1985, seven terminally ill children go on a last hurrah "dream holiday" to Disney World. The compelling, messy reality of sick children's lives collides with the clean, efficient unreality of the Disney cartoon world. By turns hyperrealistic, fantastic, comic, and serious, the novel celebrates the shabby-but-wondrous condition of all embodied lives.

Elkin also wrote numerous Faulkner-styled essays about how art helps us prevail in the face of life's—and the body's—injustices: "As the old saying should go, as long as you've got your health you've got your naivete. I lost the one, I lost the other, and maybe that's what led me toward revenge—a writer's revenge, anyway, the revenge, I mean, of style."

William Gass, novelist and critic, wrote that among Elkin's achievements was "to disable disabilities by finding their use."

—Tom Feigelson

See also Novel, The.

Further Readings

Dougherty, David C. 1991. *Stanley Elkin.* Boston: Twayne.

Websites

Center for Book Culture.org, "Stanley Elkin," http://www.centerforbookculture.org/dalkey/backlist/elkin.html

EMERGING DISABILITIES

Our perspectives on disability are often framed by an implicit assumption that disability is an entity fixed in form and static in size. The term *emerging disabilities* was coined in the 1990s to focus attention on the changing nature of health risks in the United States and the possibility that these changes were affecting the composition of the disability population. Examples include the epidemic of drug-related gang violence, emergence of high-profile illnesses such as HIV infection, and growing awareness of the potential impact on disability of large-scale demographic transitions such as aging. The emerging disability concept can be seen as a working hypothesis about the impact of these trends on the size and character of the disability population.

Emerging disability is neither a discrete condition nor a group of diagnosable conditions. Rather, the term attempts to conceptually summarize different dynamics affecting the composition of the disability population: (1) changes in the economic or social environment that affect risk for disablement, (2) emergence of newly recognized conditions or sudden growth in the numbers of established disability conditions, and (3) changes in definitions that lead to the incorporation of conditions not traditionally thought of as part of the disability "universe."

CHANGES ASSOCIATED WITH SHIFTING PATTERNS OF RISK

Understanding the impact of shifting cultural, demographic, or economic forces on disability populations is a major theme in emerging disability. The decade-long epidemic of firearm-related injury associated with gang violence and urban drug trafficking is a striking example of a disability shift embedded in the changing cultural circumstances of the 1980s. Data from spinal cord injury data systems reported violence-related injuries more than doubling from the 1970s to the early 1990s. Aging is an important example of change in disability populations caused by demographic forces since rates of severe disability are disproportionately represented among the elderly. With the anticipated rapid growth of the oldest population cohort—those age 85+ years—disability due to

onset of later-life illnesses and impairments will become an increasingly important part of disability demographics. The shift in age distribution and its role as a risk factor for disability represents an unprecedented challenge to long-term care services, social welfare, and other health and support systems.

The role of economic forces is a central feature of emerging disability conceptions given the inextricable linkage of disability and poverty. Although the relationship is affected by age, education, and other demographic characteristics, two essential observations of disability and economic status are well established: first, that persons with disabilities are more likely to be economically marginalized, and second, that the poor are far more likely to be exposed to risks associated with disablement. The emerging disability framework considers this connection from the perspective of change, specifically, any changes in the structure of poverty. For example, the steady increase in income inequality since the 1960s signals a long-term change in the distribution of wealth in the United States—an expanding gap between rich and the poor, and greater concentration of poverty among families with young children. To the extent that impediments to childhood development are embedded in the conditions of poverty—lack of maternal and postnatal health care, malnutrition, and developmental deprivation, among other risks—emerging disability frames the trends in terms of the impact on the disability population.

CHANGES ASSOCIATED WITH NEW CONDITIONS/CHANGING ETIOLOGIES

A second form of change represented in the emerging disabilities concept is the recognition of new forms of impairments or unexpected increases in the incidence or prevalence of existing conditions. Examples of newly recognized conditions include chronic fatigue syndrome (CFS), multiple chemical sensitivity, and carpal tunnel syndrome. Conditions tend to be controversial because of an absence of standardized case definitions; consequently, estimates of the affected population tend to vary widely. Emerging disability also refers to familiar conditions or causes of disabilities that are undergoing a transformation in character or magnitude. Autism and attention deficit hyperactivity disorder (ADHD) are prototypical of the established condition becoming more prominent. Clinical service registries and school systems reported dramatic increases in the numbers of diagnosed children throughout the 1990s. However, the results of prevalence studies are contradictory and analysts fail to agree on whether the increases are real or merely an artifact of increased awareness and access to improved treatment options. Less contentious examples of increased prevalence among established conditions are spinal and brain cord injuries. With recent improvement in trauma care, survival rates for spinal cord and severe brain injury improved dramatically in recent decades. The form of injury is not new, but the increased likelihood of survival as well as the extension of lifespan because of improved posttrauma care creates new challenges for the systems of rehabilitation and support.

CHANGES ASSOCIATED WITH EXPANSION OF DISABILITY BOUNDARIES

A third emerging disability theme is the effect of conceptually broadening the disability universe by incorporating groups not traditionally served by the disability and rehabilitation field, such as persons with HIV infection, obesity, cancer, or other chronic illnesses. Expansion of the disability universe was first formalized in the 1990 Americans with Disabilities Act (ADA) in which *disability* was defined as a physical or mental impairment that substantially limits one or more major life activities, or as being regarded as having such an impairment. The qualifying phrase, "regarded as having an impairment," extended antidiscrimination provisions to those with conditions that did not directly affect performance, for example, the presence of disfigurement or obesity. Emerging disability extends the logic of expanded legal protections to encompass the potential role of traditional disability and rehabilitation service providers in addressing the needs of persons with conditions not typically associated with "disability" status. But expansion is problematic in that the linkage of label to disability is under increasing challenge in both our diagnostic theories and legal frameworks. In the new paradigms of disablement, disability is not

an attribute of the person but rather a complex interaction of personal, environmental, political, and cultural considerations. The presence of impairment should not automatically be equated to disability status. Recent legal challenges seeking to restrict the scope of the ADA have also served to weaken the link between impairment and disability. In 1999, the U.S. Supreme Court ruled that impairments that can be corrected or do not substantially limit activities are not considered disabilities. Emerging disability is anchored in older, more medicalized paradigms of disability in its emphasis on reclassification of chronic conditions as disabilities and its focus on the causes and prevention of impairment. The effort to include these and similar groups of conditions highlight the ambiguities of defining a class of citizens as "disabled."

SUMMARY

Emerging disability is a conceptual amalgam of different dynamics affecting population change: changing demographics and etiologies, newly recognized impairments, and shifting boundaries for disability definition. Emerging disabilities is a useful conceptual tool for drawing attention to the dynamics of change in populations that may be the consequence of socioeconomic and cultural trends. It also serves to make more prominent public health concerns within the disability and rehabilitation fields by focusing on the epidemiology of impairment. The concept, however, has yet to gain widespread acceptance except as a broad and inconsistently applied umbrella term for unusual impairments. Perhaps a more fundamental challenge to the conceptual integrity of emerging disability comes from the new paradigms of disability that directly challenge disability definition based primarily on diagnostic categories. Contemporary disability definitions are increasingly nuanced. Until clear definitions and boundaries of impairment and disability are forthcoming (and there is debate whether that is achievable), the central utility of the emerging disability idea is to draw our attention to the reality of change and the fact that disability, however defined, is dynamic rather than static.

—Glenn T. Fujiura

See also Epidemiology; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Obesity.

Further Readings

Albrecht, Gary L., Katherine D. Seelman, and Michael Bury, eds. 2001. *Handbook of Disability Studies.* Thousand Oaks, CA: Sage.

Fujiura, G. T. and K. Yamaki. 2000. "Trends in Demography of Childhood Poverty and Disability." *Exceptional Children* 66:187–199.

Seelman, K. and S. Sweeney. 1995. "The Changing Universe of Disability." *American Rehabilitation* 21:2–13.

World Health Organization. 2001. *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization.

EMPLOYABILITY

Employability means the degree of possibility of finding or regaining employment. It can also denote an objective situation or a characteristic specific to an individual. In Europe, it was in the context of the great rise in unemployment at the end of the 1980s that the term took on its present meaning. This was accompanied by a shift in theoretical explanations of unemployment and in the measures taken to address it.

Until that time, employability had been a statistical concept, based on the average period of unemployment. It was an instrument to measure the workings of the labor market, which eliminated groups with objective characteristics such as age, sex, or qualifications. One could state from statistics, for example, that a given age cohort or that women, the disabled, or people with a certain level of education remained unemployed longer. For each of these categories, the chances of finding employment could be evaluated. Such tracking made it possible to better administer the flux of the unemployed, particularly by retraining them. This is employability in the "probabilistic" sense.

By the end of the 1980s, employability also denoted the medical and sociocultural obstacles encountered by job seekers. In other words, unemployment was no longer simply a question of vocational training; it was seen as linked, as cause or effect, to a desocialization, a destructuring of individuals. The solution to unemployment was sought in social qualifications, which could include such details as dressing correctly and

arriving at work on time as well as having the necessary vocational credentials and references. From an objective, collective term, employability now designated an attribute of job seekers themselves, in fact, their only attribute, as the term "disabled" tends to do. Logically, then, attention to unemployment shifted toward attention to people, on whose behalf all sorts of social interventions, well beyond the vocational training of adults, had to be provided.

It was at this same turning point at the beginning of the 1990s that a new paradigm was introduced in Europe, along with a new term: the excluded. This term denotes the capability of maintaining oneself in the social fabric more than a capability for work. The job seeker is no longer simply one of the inactive; he or she becomes socially maladjusted, vocationally unfit, and, once again, one of the excluded.

Conceptual contours were becoming blurred from several perspectives. An individual's trajectory could move him or her from one status to another, according to which criteria were employed and to the interest of the stakeholders. Thus, we see the unemployed beginning to sign up for benefits previously reserved for disabled people or, inversely, disabled people finding, at least provisionally, greater satisfaction in being paid minimum wages that were primarily intended for job seekers. A second instance of blurred contours was on the level of interventions by social workers and counselors seeking to remedy unemployment.

Employability often becomes unemployability, as the lack becomes the focal point, thereby creating the category of the unemployable. The latter term is rather like a return to the old category of the able-bodied poor, that is, people who begged for lack of work but by virtue of their ablebodiedness were reproached, even condemned, as useless, lazy, or superfluous. But there is a growing confusion between the able-bodied without work and the disabled, whether the latter are themselves also without work or are prevented from working by their impairment. One confusion leads to another: Where does the distinction lie between the right to work and the duty to work? In countries with a welfare state, primarily in Europe, a distinction was established, on the one hand, between policies related to insurance, organized around the notion of salaried workers (social security), which covered the unemployed, and, on the other, policies of social assistance aimed at those who had difficulties in finding and retaining salaried work because of their individual characteristics(e.g., severely disabled people).

Even though things have never been so cut-and-dried—disabled workers are for the most part capable of work and there are many social assistance options available within the social security system—the fact remains that the expanded notion of employability, which includes notions of unemployable and of maladjusted, blurs employment policy. Indeed, new population groups that find themselves without work cannot be clearly identified as the able-bodied unemployed or as the disabled. The term employability leaves them between the two camps, sharing some of the characteristics of each. As a consequence, policy options drafted for their situation display neither a universalist vision, which would be that of integration policies focused on employment, nor an individualist vision, which would spring from social policy. It is into this interstice that the so-called insertion policies slip, producing a thick stratum of citizens who occupy a social substatus, always being inserted and disinserted.

In other words, the categories of employable and unemployable mask a variety of difficulties, for which there is now only a single remedy: minimal integration (some work, provisional and discontinuous, and some social networking effected by assistance and support measures). Such a minimum is self-perpetuating and creates a segment of the population whose stake is enduringly precarious.

—Henri-Jacques Stiker

See also Affirmative Businesses; Consumer-Run Businesses; Disability and Career Development; Employment; Job Retention.

Further Readings

Bloch, F. S. and R. Prins. 2001. *Who Returns to Work & Why? A Six-County Study on Work Incapacity and Reintegration.* New Brunswick, NJ: Transaction Publishers.

Bosco, A. and Y. Chassang. 1998. "L'émergence du concept d'employabilité." *Droit social* 11:903–911.

Castel, R. 1995. *Les métamorphoses de la question social, une chronique du salariat.* Paris: Fayard.

Ebersold, S. 2001. *La naissance de l'inemployable ou l'insertion au risque de l'exclusion.* Rennes, France: Presses Universitaires de Rennes.

EMPLOYMENT

Employment and disability; these two areas appear to be antithetical. Employment portrays gainful productive activity, while disability depicts inability to work or be employed due to impairment or limitations. With or without disability, work is an important aspect of life, a major role in adulthood. Sigmund Freud saw work as one of the basic requirements of human existence, and Erik Erikson indicated that work brings people a sense of selfhood. Inability to work not only hampers one's development in the life cycle but also brings damage to an individual's self-identity and worthiness.

Vocational psychologists suggest that employment has six functions. It provides income for daily living necessities such as food, clothing, and shelter. It regulates daily activities, allows for social interaction with others, and is a major determinant of one's social status. For the most part, one's social standing is determined by the perceived prestige of one's occupation and accomplishment at work. It gives a person an identity and provides content and meaning to life. In sum, work determines a person's worth and place in society, and it influences one's psychological identity and sense of well-being. Employment, however, is not readily available to all people, especially to those who have disabilities. Environmental barriers, societal prejudice, and functional limitations caused by disabilities often exclude people with disabilities from the world of work.

In the United States, attention to the employment of people with disabilities was heightened after World War I, responding to the postwar employment challenges faced by veterans. Subsequent development of vocational rehabilitation legislation and the state-federal vocational rehabilitation program extended services to all citizens with disabilities. Recent legislation, such as the Americans with Disabilities Act (ADA), is intended to ensure equal opportunity and nondiscriminatory practice in employment for people with disabilities. Despite passage of such legislation, obtaining and maintaining employment for people with disabilities remains a big challenge.

Employment Statistics of Persons with Disabilities

Employment rates among persons with disabilities vary depending on the measure of disability that is used. In a 1996 U.S. Census Bureau survey, about 11 percent of working-age Americans reported a "work disability" defined as having a health condition that limits the kind of work they can do. Among those reporting a work disability, about 20 percent are employed in a given week, compared to 75 percent of those not reporting a work disability.

If one uses the ADA's broader definition of disability involving major life activity limitations and functional impairments, it is estimated that there are 54 million Americans with disabilities. Of these, 29.5 million are of working age constituting 20 percent of the total working-age population. Under this broader definition, approximately 50 percent are employed in a given month, compared to 80 percent of working-age people without disabilities. The figure is much lower among those with severe disabilities, of whom only 25 percent are employed in a given month. More recent data from the U.S. Census Bureau (2002) show that 22.3 percent of people with disabilities between age 16 and 74 were employed, of which only 14.4 percent worked full-time. As expected, 25- to 34-year-olds have the highest employment rate (36.9 percent); the next group is 35- to 44-year-olds (30.2 percent) followed by those ages 45 to 54 (28.8 percent) and 16 to 24 (28.5 percent). Employment rate decreases as the person's age increases after age 55. There are similar employment patterns between workers with disabilities and those without disabilities. In general, women with disabilities are less likely than men with disabilities to be employed, and employment rates are especially lower among people with disabilities who are African American, older than 45, or who have never been to college.

The above data clearly indicate that persons with disabilities have difficulties in obtaining and retaining employment. When asked whether they are willing to work, most persons with disabilities would indicate so, but in fact only about 25 percent do actually work and most are on a part-time basis. Thus, the question is not, and never has been, whether people with disabilities are interested in working, but rather what is prohibiting their participation in the work force and what corrective action is required.

Earnings of Persons with Disabilities

Workers with disabilities earn lower wages than do nondisabled workers. It is estimated that people with

disabilities earn 10–25 percent less on average than do comparable people without disabilities. A recent survey on earnings of recipients of state-federal vocational rehabilitation services show that the average hourly wage was $7.33 per hour (median $6), which increased to $9.62 (median $7.65) per hour three years after exiting from the vocational rehabilitation system. The lower employment rates and earnings of people with disabilities contribute to lower economic well-being. Including all sources of income, the median personal income of working-age people with disabilities is only 60 percent that of people without disabilities, suggesting that the various sources of disability income do not come close to making up for the loss of earned income. More important, about 19 percent of all people with disabilities live in poverty households, twice the estimated rate for people without disabilities (8.9 percent). While employment provides the means for a better standard of living, the lower earnings of workers with disabilities causes them to be more likely to live in poverty than employed workers without disabilities. Health insurance coverage, though, is very similar between people with and without disabilities, since greater Medicaid and Medicare coverage among people with disabilities mostly makes up for the lower levels of employer-provided health insurance. It is evident that employment is critical to the economic well-being of people with disabilities. However, many people with disabilities continue to suffer financially due to higher unemployment rates.

Barriers to Employment

While many speculate that the disability itself would be the main barrier to employment, the literature in disability and employment suggests otherwise. In most studies, disability accounts for only a small amount of the variance in employment. Barriers due to accessibility and discrimination appear to be the main and surmountable hurdles for employment among persons with disabilities. In general, there are three major types of barriers: environmental, societal, and personal.

Environmental barriers. Buildings with stairs at entrances and doors that are too narrow are obvious examples of architectural barriers to persons with physical disabilities. These barriers can be viewed as arbitrary limitations on equal opportunity when a person with a disability is qualified for a job but cannot take the job due to inaccessibility. The building itself is, in effect, an agent of discrimination. Other environmental barriers include limited access to public transportation and communication. The federal government has passed legislation to create barrier-free environments for people with disabilities. Under Section 502 of the Rehabilitation Act of 1973, the Architectural and Transportation Barriers Compliance Board was established to enforce the accessibility standards. The subsequent passage of the ADA further enforces equal opportunity and accessibility to employment. The ADA has been called the "Emancipation Proclamation" for people with disabilities. It prohibits discrimination in employment, public accommodations, government services, and telecommunications. It requires employers to make reasonable accommodations in the work environment so that a qualified worker with a disability can be employed. Incentives have been proposed for removal of barriers to encourage both public and private companies to become more accessible. Businesses that incur expenses in removing barriers, as is required under the ADA, may receive up to a $35,000 deduction for expenditures to remove architectural and transportation barriers to people with disabilities.

Societal barriers. A hidden but pervasive barrier to employment of people with disabilities is prejudice and discrimination. Society has certain beliefs or stereotypes of people who are different. Commonly expressed stereotypes about people with disabilities include pity, dependence, incompetence, and character weakness. Just because most people have knowledge of a set of stereotypes does not imply that they agree with them. In fact, many persons can recall stereotypes about different racial groups but do not agree that the stereotypes are valid. People who are prejudiced, on the other hand, concur with these negative stereotypes and generate negative emotional reactions as a result. A behavioral reaction of prejudice is discrimination. Discrimination toward people with disabilities includes outright intentional exclusion or relegation to lesser services, jobs, or other opportunities.

Formation of stereotypes and subsequent prejudice toward people with disabilities are often caused by misinformation or misconception. Misconception about specific disabilities, including presumptions about the cause of disability, often affect hiring recommendations. These unfounded myths and false assumptions are deeply, often subconsciously, rooted in many of us. Some of the myths about people with disabilities include the following:

- Increased insurance costs due to workers' compensation and higher accident rates
- Limited dependability and poor attendance records
- Low productivity
- Need for special accommodations and work arrangements
- Lack of acceptance by coworkers

Many of these myths can be disputed by facts. For instance, workers' compensation insurance rates are based on the hazardous nature of the work itself, the previous accident rate of the company, and the amount of resulting compensation and medical costs charged to the insurance carrier. Research evidence shows that employees with disabilities in general do not have higher accident rates than employees without disabilities. Also a long history of research findings rejects the assumptions that workers with disabilities have more problems than workers without disabilities in regard to absenteeism, productivity, and ability to perform the job. In addition, most work site accommodations cost nothing or less than $500, not the thousands of dollars most people believe. Specifically, about 50 percent of the reasonable accommodations cost nothing, 30 percent cost less than $500, 10 percent cost between $500 and $2,000 and 10 percent cost in excess of $2,000.

Personal barriers. Research evidence indicates that there is a correlation with certain personal characteristics and employment opportunities. In general, those who are employed tend to be younger, male, Caucasians, have more education, have previous work experience, and a physical disability. To understand the extent to which disability affects employment, one has to consider the disability in relation to the individual's physical, psychological, and vocational functioning. Questionable physical capacity becomes a significant concern in the consideration of types of employment for which the individual is otherwise psychologically and vocationally suited. The literature suggests that it would be a mistake to ignore the fairly consistent limitations associated with particular disabling conditions in relation to employment choices. Obvious examples are people who have ambulatory difficulties need accessible facilities (e.g., barrier-free buildings), those who have cognitive process problems need to consider jobs with less complexity, and people with disabling conditions exacerbated by stress should be aware of the stress levels associated with the job.

Psychological functioning, a significant employability factor, can either restrict or enhance the chance of employment. Maladaptive adjustment to disability such as denial or oversensitivity to one's disability could reduce employability. There is research evidence that suggests self-stigma could be one of the psychological barriers that people with disability need to overcome to be gainfully employed. Living in a culture that endorses prejudices about disabilities (e.g., people with disabilities are incompetent to hold anything but substandard jobs), people with disabilities may apply the prejudice to themselves (I am disabled so I must be unable to hold a regular job), resulting from diminished self-esteem (I am less of a respected person because of my disability) and subsequently report lowered self-efficacy (why try to get a job; someone like me is incapable of doing regular work). Turning this negative psychological force into a positive power would be beneficial to persons with disabilities in terms of adjustment to disability and enhancement of self-efficacy and self-esteem. Current emphasis on empowerment of persons with disabilities is a positive strategy to assist people with disabilities to address self-stigma issues.

For an individual to be employable, one has to possess necessary vocational skills and demonstrate appropriate behaviors. Due to limited work opportunities and consequent work history, persons with disabilities may not possess these necessary work behaviors and skills. Work adjustment training, a service provided through the state-federal vocational rehabilitation system, is designed to teach people the behaviors

needed to fulfill employment requirements. Work adjustment training covers three major areas: job responsibility, task production, and social-vocational competence with strategies to enhance physical capacities, psychomotor skills, appropriate dress and grooming abilities, interpersonal and communicative skills, orientation to work practices, work habits, response to supervision, and getting along with coworkers.

It is obvious that persons with disabilities possess certain limitations that handicap their employability. The extent of handicap does, however, depend in large part on the complex interaction of the individual, the disability, environment, society, and culture. Rehabilitation psychologists have extensively studied this complex phenomenon and offer the following observations to help explain the effects of disability on employment.

- It is more important to focus on the functional limitations resulting from a disability and the individual's psychological reactions to those limitations than on diagnosis such as schizophrenia, mental retardation, or learning disabilities.
- It is easier to predict the source of disability to a tangible functioning and behavior (such as spinal injury to ambulatory problems) than intangible behaviors (such as learning potential, employability).
- There is a weak association between disability and personality. That is, there is no such thing as a "blind" personality or a "spinal cord" personality. Stereotypes or overgeneralization of disability results in prejudice and discrimination toward people with disabilities.
- Psychological factors are only a part of the equation in determining how one responds to disability. The importance of social or sociological factors must not be underestimated and negative societal attitudes serve to mask the rehabilitation and vocational potential of persons with disabilities.
- Persons with disabilities have the abilities to perform successfully in a large variety of employment functions and have demonstrated dependability and good performance on jobs.
- Employers' attitudes in hiring persons with disabilities are mixed. Among employers there is a discrepancy between reported intention to hire and actual hiring of persons with disabilities.

Strategies and Practice to Secure Employment

To compete with nondisabled workers, workers with disabilities need to have adequate job-seeking skills and abilities to secure employment. While some individuals with disabilities have sufficient job-seeking skills, many do not have preparation in the area. Studies show that a high percentage of persons with disabilities do not look for jobs frequently enough, most are unaware of techniques for securing and following up on job leads, most of them could not explain skills to employers, some have poor personal appearance or inappropriate mannerisms, and nearly all could not explain their handicapping condition. Inadequate job-seeking skills often limit persons with disabilities to entry-level, secondary labor market positions, which are commonly the last hired and first fired. Only with sufficient job-seeking skills can they reenter the workforce on their own initiative.

Some job seekers with disabilities may be unclear as to how their abilities and interests can best meet the needs of employers or be unable to conduct an extensive job search. Rehabilitation service intervention, such as job placement service, is necessary in assisting individuals with disabilities to secure employment by acting as information intermediary or broker between buyers and sellers of labor.

Job-seeking skill training. The goal of the training is to prepare persons with disabilities in job-seeking skills so that they can seek and secure employment. Common activities in the training include the following:

- How to find job leads
- Preparing personal resumes
- Filling out applications
- Role-playing job interviews
- Understanding hiring practices
- How to disclose disabilities

The Job Club strategy developed by Nathan Azrin and his colleagues is an effective approach in job-seeking skill training. Based on behavior theory, the Job Club uses multiple proven techniques to increase the individual's job-seeking capabilities, such as the buddy system, family support, role models, intense role-play practice of job interview, and practice in completing

job applications. Club members meet daily in a small group format and follow up on job leads they have obtained from family, friends, other Job Club members, the phone directory, and previous employers. Members have a standardized script to use in making phone calls to employers, after which they receive reinforcement and feedback from their counselors and other club members as they complete calls and job interviews. Studies have demonstrated the positive results of job-seeking skill training and the Job Club.

Job placement. People with severe disabilities may require direct placement intervention and support to secure and maintain employment. Acquisition of employment for these individuals often requires the help of rehabilitation professionals such as rehabilitation counselors or job placement specialists who can both sell employers on hiring them and supply the necessary on-the-job support. Strategies that match the person to job requirements are used frequently to place persons with disabilities. Job matching considers the person's skills, abilities, interests, and needs. To facilitate a good job match, job analysis often is performed by studying the job demands such as physical demands, mental demands, job-related stress factors, characteristics of work environment, and existing and potential hazards. Job tenure occurs when the job meets the needs of the person and the person meets the demands of the job.

Another approach to job placement is partnership with employers, also known as demand-side job development. As proposed by job development professionals, demand-side job development provides services directly to employers that make the workplace more user friendly for people with disabilities and assists employers in meeting their personnel needs by hiring persons with disabilities. The demand-side model extends marketing away from sales and into consulting. To make job placement successful, rehabilitation professionals must provide counseling and consulting assistance to both individuals with disabilities and employers. This would prepare employers to be better able to make accommodations and train employees in accepting diversity through increasing demand for applicants with disabilities. Rehabilitation professionals enhance persons with disabilities' employment outcomes by functioning as consultants to employers in providing services such as human resources planning and filling "hard to fill" positions. In addition, they provide postemployment counseling and consulting to employees with disabilities and their supervisors to improve work performance, maintain employment, and enhance career advancement. Several national chains and franchises have been involved in providing employment opportunities to persons with disabilities through this partnership approach.

Assistive technology and accommodation in the workplace. In addition to the job placement strategies described above, assistive technology is used in the workplace. Assistive technology is an effective means to replace or extend a person's capacities to cope with different types of vocational and daily living demands. Technology can contribute to employment and social integration of individuals with disabilities through enhanced mobility, manipulative capabilities, and communication. A specific use of assistive technology in the workplace is job accommodations. Reasonable accommodation is a logical adjustment to a job and/or the work environment that enables a qualified person with a disability to perform the duties of that position. Accommodations in the workplace could include making existing facilities used by employees readily accessible to and usable by individuals with disabilities, job restructuring, use of part-time or modified schedules, reassignment to vacant positions, and acquisition or modification of equipment or devices. Examples of physical access job accommodation can be putting the job on the first floor, near the employee parking lot, or near the bathroom. Resource accessibility accommodation for a person with hearing impairment can be providing a notetaker or sign language interpreter; for a person with visual impairment, accommodation can be providing a reader or notetaker. Adaptive equipment accommodation includes "low tech" and "high tech" assistive devices. Examples for the person with arthritis or carpal tunnel syndrome can be providing a special pen/pencil holder; for those who have orthopedic problems by providing desk or chair modifications, speaker, and earphone on telephones. Accommodations

for persons with visual impairment can be by providing a talking calculator or talking computer.

Job modification for persons with disabilities is based on the principle that modifications are made only to the job performance while maintaining the same job duties. A modification for a salesperson with energy or ambulation problems may be to do more telephone sales with fewer field appointments. A parking lot attendant with orthopedic problems perhaps could use a chair for sitting instead of standing throughout the day.

The Job Accommodation Network (JAN; 1–800–526–7234) is a resource available for information on employer accommodations. Before contacting JAN for information, it is necessary to have specific medical restrictions regarding the worker with disabilities, job duties that are precluded as results of the restrictions, and general information about the industry in which the job is located.

Future Employment Trend and Its Impact on Persons with Disabilities

The U.S. Department of Labor (DOL) unveiled its 10-year long-term forecast in 1998. In its forecast for the 10 years from 1996 to 2006, total employment will grow by 1.3 percent per year through 2006. After the September 11, 2001, terrorist attacks and subsequent two foreign wars, the U.S. economy suffered from a high unemployment rate and huge federal deficits. One could question the accuracy of DOL's long-term forecast considering the aftermath of 9/11. Nevertheless, trends and characteristics of future work force and job markets identified in the long-term forecast remain relevant and can affect future employment opportunities for persons with disabilities. While manufacturing employment is forecasted to continue its modest decline, employment in service-producing industries is expected to grow 2.9 percent per year, with employment in personnel supply services expanding by 4.3 percent per year and employment in computer and data processing services increasing at 7.6 percent per year. In terms of supply and demand in the workforce, DOL predicts that the supply of workers will increase by 1.1 percent annually, short of the 1.3 percent annual increase of employment. In translating the percentages to numbers, it is forecasted that through 2006, employers will increase their payrolls by 18.6 million workers, while the labor force is expected to grow by 14.9 million workers, creating a shortfall of 3.7 million workers. In short, labor markets are expected to remain tight in the next few years. Research evidence suggests that lower unemployment rates benefit low-wage earners more than high-wage earners. In general, low-wage earners usually are individuals with low skills and they tend to benefit from greater employment opportunities and higher wages when unemployment rates are low. Similarly, people with disabilities benefit from low unemployment rates.

The DOL's long-term forecast shows a variation in growth rates among industries. The fastest growing employment sector is personnel supply services, including temporary employment agencies. The food and beverage industry is the second fastest growing sector. State and local governments, including education, is the third fastest growing sector. Computer and data processing, health practitioner, and retail trade services make up the fourth, fifth, and sixth fastest growing sectors, respectively. Variations in job growth predictions underscore a growing dichotomy in labor demand between high-skilled, high-wage jobs and low-skilled, low-wage jobs. The dichotomy becomes clearer when the top 10 fastest growing occupations are compared. The top 10 fastest growing occupations through 2006 as reported by DOL are (1) cashiers; (2) system analysts; (3) general manager and top executives; (4) registered nurses; (5) salespersons; (6) truck drivers; (7) home health aides; (8) teacher's aides and assistants; (9) nursing aides, orderlies, and attendants; and (10) receptionists and information clerks. Low- and modest-skilled occupations such as cashiers, salespersons, and aides and attendants are usually low-paying jobs as compared to high-skilled and high-wage occupations such as system analysts, managers and CEOs, and registered nurses. As suggested by the literature, people with disabilities, especially those with severe and multiple disabilities, will fill many of the low-skilled and low-wage occupations such as retail salespersons, waitpersons, hotel workers, janitors, cashiers, hospital attendants and orderlies, nurse's aides, and security guards due to limited training or education. In addition, high-paid employment requires technical and professional education beyond high school, and high

school graduates face a much harsher employment outlook today than 20 years ago. Lack of career advancement opportunities for people with disabilities is an expressed concern of vocational rehabilitation workers. For persons with disabilities to compete in the future job market, they need post-high school education and specialized vocational training.

Economists point out that as technology develops, especially in the area of information technology, globalization becomes the norm of modern society. Development of a global economy causes changes to the U.S. work force. The traditional ways of performing work no longer hold true. Future workers will require greater use of communication technologies and computer skills. They will be expected to make choices and decisions on their own and have abilities to handle multiple tasks and skills, and work as part of a team. It is likely that the future employment opportunities will be temporary and part-time, rather than permanent and full-time employment. Flexible work hours and job sharing will become more common. While most people with disabilities benefit from these new employment structures, some may find these changes challenging. For instance, persons with a psychiatric disability may find flexible hours difficult to handle.

In sum, while some people with disabilities have made gains in employment, they still remain at a disadvantage in many facets of the labor market. A range of employment opportunities will continue; however, the best jobs go to persons who are literate, can adapt to change, and continue to learn new skills.

—Chow S. Lam

See also Americans with Disabilities Act of 1990 (United States); Assistive Technology; Disability and Career Development; Employment, International; Employability; Job Retention; Vocational Rehabilitation.

Further Readings

Brodwin, Martin, Randall Parker, and Denise DeLaGarza. 1996. "Disability and Accommodation." Pp. 166–203 in *Work and Disability: Issues and Strategies in Career Development and Job Placement,* edited by E. M. Szymanski and R. M. Parker. Austin, TX: Pro-Ed.

Glibride, Dennis D. and Robert Stensrud. 1999. "Demand-Side Job Development and System Change." *Rehabilitation Counseling Bulletin* 42:329–342.

Glibride, Dennis D., Robert Stensrud, and Mikel Johnson. 1994. "Current Models of Job Placement and Employer Development: Research, Competencies and Education Considerations." *Rehabilitation Education* 7:215–239.

Kruse, Douglas L. 1998a. *Disability and Employment: Characteristics of Employed and Non-employed People with Disabilities.* Report to the Office of Policy. Washington, DC: U.S. Department of Labor.

———. 1998b. "Persons with Disabilities: Demographic, Income, and Health Care Characteristics." *Monthly Labor Review* 121(9): 8–15.

Louis Harris and Associates. 1998. "1998 N.O.D./Harris Survey of Americans with Disabilities." New York: Louis Harris and Associates.

Rubin, Stanford E. and Richard T. Roessler, eds. 1995. *Foundations of the Vocational Rehabilitation Process,* 4th ed. Austin, TX: Pro-Ed.

Szymanski, Edna M., Carole Ryan, Mary A. Merz, Beatriz Trevino, and Sarah Johnson-Rodriguez. 1996. "Psychosocial and Economic Aspects of Work: Implications for People with Disabilities." Pp. 9–38 in *Work and Disability: Issues and Strategies in Career Development and Job Placement,* edited by E. M. Szymanski and R. M. Parker. Austin, TX: Pro-Ed.

Szymanski, Edna M. and Randall M. Parker, eds. 2003. *Work and Disability: Issues and Strategies in Career Development and Job Placement,* 2d ed. Austin, TX: Pro-Ed.

Twenty-Fifth Institute on Rehabilitation Issues. 1999. *Meeting Future Workforce Needs*. Menomonie: University of Wisconsin–Stout, Continuing Education Center.

U.S. Census Bureau. 2002. *Statistical Abstract of the United States: Labor Force, Employment, and Earnings.* Washington, DC: U.S. Census Bureau.

U.S. Department of Labor. 1998. *Employment Outlook, 1996–2006: A Summary of BLS Projections.* Bulletin 2502. Washington, DC: U.S. Department of Labor.

EMPLOYMENT, INTERNATIONAL

Employment is often considered to be work for which a person is paid. However, in many countries, work that provides sustenance does not also always provide a wage. Definitions of disability drawn from urban, industrialized settings that see disability primarily as an inability to work at a wage-paying job are problematic in the rural, nonindustrialized, and primarily agricultural economies found in developing countries. Nonwage work is an important source of sustenance for many people, both with and without impairments, in developing countries.

In developed countries, there is a large amount of research about people who have a "work disability"—that is, who have an impairment that limits the kind or amount of work they can do. However, that research—by definition—does not consider people who do not perceive themselves to have a work limitation, although they may actually have an impairment, and who are in fact working. Thus, results from this research do not apply to all workers with impairments. Although "objective" measures of disability are used as the basis for policies such as workers' compensation in the United States, they do not tell us about disability and work. For example, partial loss of a limb or a hearing impairment will qualify people for payments under workers' compensation, even if they can continue to work at their old jobs. One person with a severe impairment may be working, while another with a similar impairment may not—partially because of the types of training, skills, and job expectations they have.

When we put these two ideas together, we can see that there are four possible relationships between disability and work. These are shown in Table 1. These cells provide the organizing principle around which this entry is built.

Table 1

	Perceived impairment	
Type of work	*Work limiting*	*Not work limiting*
Wage	1	2
Nonwage	3	4

Cell 1: People who work in paid work and have an impairment that limits the kind or amount of work they can do.

This category of people has been extensively researched in the United States, Canada, and Western Europe, and the results tend to be fairly similar. People who are working despite having a work-limiting impairment, not surprisingly, earn less than workers without such an impairment, and they often feel that they are underemployed. In addition, they are more likely to be unemployed. (*Unemployed* means a person is actively looking for a job, but it does not refer to people who have given up looking or who have not yet started looking.) Because of this, one report on disability and employment in Canada states that "over 80% of disabled persons in Canada suffer from the 3 U's: unemployment, underemployment, and underutilization." In the United States, only about 30 percent of people of working age (ages 16–64) who have a work disability are even counted as being in the labor force (i.e., are either working or looking for work). In the United Kingdom, about one-third of disabled people of working age were at work in 1998.

In the United States in 1994–1995, men with nonsevere disabilities earned about 85 percent of the median salary of men without impairments; for women, the comparable percentage was about 82 percent. For persons with severe disabilities, the comparable percentages were 58 percent and 68 percent, respectively. (That women with and without impairments are more similar than men has been found in many different types of studies in the United States and is likely explained by the effects of occupational segregation by sex, which is strong and pervasive in the United States.)

Economic policies in many developed countries include support for segregated employment (Britain, Sweden, and the Netherlands) as well as incentives for employers to hire people with impairments. In addition, policies in all developed countries include some sort of social insurance system for workers with disabilities, which most have recently expanded to include nonworking people. Policies range from income assistance, as in the United States, to tax exemptions, as in Japan. These policies often offer disincentives to work, because the side benefits they offer, such as health insurance, cannot be duplicated in the lower-wage jobs that many people with impairments might be most likely to get. They are also sometimes seen by people with impairments as being given in exchange for exemption from benefits and obligations of citizenship.

Cell 2: People who work in paid work but do not have a perceived impairment that they perceive to limit the kind or amount of work they can do.

These people may have less severe impairments, or they may not, but in either case, they perceive their impairment as not limiting their work. Some research

done on such people in the United States shows startlingly different results than does research related to people in Cell 1. For example, one study showed that workers with hearing or visual impairments earned higher wages than did workers of the same sex in the general population or with mobility or multiple impairments. These results showed that males had greater income than did females, while having an impairment, net of other differences, decreased income, and they showed that variables that have been strong predictors of incomes in many other studies are not consistently strong predictors of the wages of workers with impairments.

These results, which are so at odds with the preponderance of research results regarding people with work disabilities, support the notion that when the question is asked differently, the answers are also different. Thus, asking people who work *about* impairments they might have gives different results than asking people *if* they have a disability that limits their work. The latter group may be comprised of very different types of people, with very different types of jobs, than the former group. Workers with impairments are likely to be older (since the rate of impairment increases with age) and so more likely to have an established work history. As such, they are also more likely to be in a position to demand disability accommodations from their employer, since their expertise may have more value than the cost of the accommodations. Alternatively, some of these workers may be people who have earlier onset impairments but who overcame potentially disabling obstacles through the use of technology and or education. This is not to say that having an impairment has no effect on their work. Having an impairment *does* limit a person's occupational choices—although in the United States it is clear that gender is more limiting than is impairment.

This section has discussed research that comes from the United States only. But it is clear that similar research, which focuses on workers and only incidentally asks about impairments, needs to be done in other countries.

Cell 3: People who do not have a paid job and who have an impairment that limits the kind or amount of work they can do.

This situation may be more likely to occur in developing countries. However, in those countries, the percentage of people who actually hold wage-paying jobs is low and up to 80 percent of the population lives in rural areas. Unemployment rates as a proportion of people who *are in the work force* tend to be low. This is because people who cannot get wage-paying jobs do not spend huge amounts of time looking for work (nor do they spend that time drawing support payments such as unemployment, workers', or disability compensation, because most such countries do not provide such "social insurance").

Rather, people who cannot find wage work in developing countries have two choices: One is to work either in informal self-employment or informal paid employment, usually in cities; the other is to live in rural areas. Traditional examples of informal self-employment include selling cigarettes, souvenirs, toothbrushes, combs, toothpicks, or towels on the street. Begging, also an example, may entail walking around, sitting in a specific place, or visiting stores and asking for help. It could also include opening doors of cars in front of hotels or theaters, carrying baggage, or washing car windows, and requesting a small gratuity.

While people in Westernized countries tend to find the notion of begging or selling souvenirs to be morally or otherwise repugnant, the same reaction is not always true for people in other countries. For example, while the Hindu or Shinto religions may not explicitly view begging positively, helping beggars by giving money or food is seen as a charitable action which aids one's chances of a better life in the next world. (And, conversely, it is the duty of a disabled person to beg, to provide that opportunity for the person who is helping.) There is some indication that disabled people in developing countries are in fact beginning to object to the ways in which begging reinforces stereotypes and denies them the possibility of other types of employment.

Examples of informal paid employment could include working as a housekeeper, cook, gardener, or guard for a family. However, a person with an impairment may have difficulty finding work in this sector of the economy in developing countries. Such work is more likely either to involve physical labor (construction worker, gardener) or a certain level of education

(housekeeper, ayah [nanny], or cook). This work is likely to be for people such as diplomats or employees of aid agencies who will need their employees to speak and possibly read some of their own language (often English, French, or Spanish). Since education is often not available to children with impairments in such countries, adults with early-onset impairments are quite unlikely to have these skills.

The picture of employment of persons with disabilities is quite different in rural villages in developing countries than in cities. In villages, people with impairments may be able to work within their family's farming or herding enterprises. While this will not provide a wage, it is likely to provide at least a minimum amount of food, clothing, and shelter. Physical, cognitive, or mental impairments *may* not prevent a person from fulfilling an economically productive role. (In fact, some scholars have suggested that industrialization had an important role in creating the notion of cognitive impairment.) For example, a person with a developmental impairment may be able to herd animals or carry water. Deafness might not prevent a person from working in fields or caring for animals. A blind person might be able to take care of children or grind spices. A person missing a leg might still be able to weave or stir porridge. (The diet in most African countries is based heavily on one type of starchy food. For example, in Zimbabwe, ground corn is made into *sadza*, while in Ghana, the staple food is *fufu*. Vegetables and/or meat and spices are cooked into sauces that can accompany these staple foods, which are often called porridge. Large parts of every day are spent in the preparation of staple foods as well as the accompanying foods.) In all of these examples, if nothing else, the person with a disability would be freeing another person to do other types of work.

There is a caveat to this discussion, however, related to gender role expectations. All societies have expectations about which sex does what type of work. Thus, if carrying water is expected to be done by women (which it frequently is), a deaf male either will not be expected to do that or he will be looked down upon (as being deviant) because he is doing "women's work." It is likely that many of the tasks that could be done by a person with a mobility impairment are usually done by females, since female gender roles tend to keep them closer to home than do male gender roles. This suggests that males in developing countries who have physical impairments may be at a greater disadvantage than are females.

In rural areas or small villages, it is likely that there is less difference between people with and without impairments than there is in developed countries. In developing countries, a larger proportion of the population exists at a subsistence level, whether or not they have impairments. People grow or produce much of what is needed for survival, and their village economy may not be based on cash but on informal exchange or reciprocity. They are most at a disadvantage in those parts of their society's economy that require cash, such as utilities (the provisions of gas, electricity, or telephone service), education, medical care, and transportation; in food, clothing, or housing, they may not be at a disadvantage if weather conditions are good for farming or herding. In such economies, people with impairments are frequently not worse off than people without impairments. They will not have cash, but they are likely to be supported by their families to the same extent that the families support themselves.

However, in developing countries, the impairment may interfere with noneconomic roles and thus may indirectly reduce economic status. Disability reduces the marriageability of women in many developing countries—and may even affect the marriageability of their siblings. This clearly affects their *economic status* in those societies, even though their *economic abilities* as such are not necessarily diminished.

Some of the initiatives that attempt to help people with impairments in developing countries focus on improving the possibilities for self-employment. These initiatives may include craft work done at home or sometimes in sheltered workshops. Zimbabwe had a very early example of this in the workshops set up by the Jairos Jiri organization.

Cell 4: People who do not have a paid job and who do not have an impairment that they perceive to limit the kind or amount of work they can do—although they do have an impairment.

People who have impairments that they do not define as work limiting in developed countries tend to be people for whom technology solves some problems posed by the impairment, who have enough education that they can find a job in an area in which the presence

of a physical impairment is not in fact limiting, or who have a skill or talent that is so significant that it can overcome limitations posed by the impairment. Examples of these types of people include a person who has severe motor and speech impairments but who also has a computer that is programmed so that she can indicate words and the computer can "speak," a person who is deaf but who earns a Ph.D. and so can work as a college professor, and an opera singer who is blind but whose talent is recognized and nurtured despite her impairment.

One group of people quite likely to show up in this category in developed countries is women with impairments. Many women who believe that their impairments should not limit their work are, in fact, not working for wages. Rather, they are working as housewives. However, their work is not valued—it is not counted in economic statistics about national economies; it does not qualify them for pensions, disability support, or retirement income other than that derived from their husbands' work; and it does not qualify a woman for unemployment compensation if she should lose her "job" as a result of divorce.

In developing countries, however, people who have an impairment that they do not perceive to be work limiting and who do not have wage work are very similar to those people discussed with reference to Cell 3. They are people who are not part of the formal economy but who may be able to find many niches through which to support themselves. However, it is likely that this category of people is only beginning to exist in developing countries, since none of the developed country scenarios described above seems likely to occur in a developing country unless the person has a family with enormous wealth. Another reason why such scenarios are unlikely to occur in developing countries is that attitudes toward impairments are more negative and less accepting. Despite slogans such as "disability does not mean inability," which have appeared in several African countries, traditional cultures that equate disability with religious punishments still hold sway in many places. In addition, less developed countries are just beginning to adopt antidiscrimination legislation for people with impairments—even many developed countries are only beginning to make strides in this area. Thus, it would require an extremely unusual person in a developing country to have an impairment, not define it as work limiting, and be able to work.

This entry has shown that the relationships between employment and disability are not simple and are not universal. Rather, it has shown that more research needs to be done about these relationships in different types of economies.

—Sharon Barnartt

See also Begging; Charity; Developing World; Disability in Contemporary Africa; Disability in Contemporary China; Disability in Contemporary India; Employment; Employability; Family, International; Jiri, Jairos.

Further Readings

Barnartt, S. 1992. "Policy Issues in Disability and Rehabilitation in Developing Countries." *Journal of Disability Policy Studies* 3(1): 45–65.

———. 1997. "Gender Differences in Changes over Time: Educations and Occupations of Adults with Hearing Losses 1972-1991." *Journal of Disability Policy Studies* 8(1): 7–24.

Barnartt, S. and B. Altman. 1997. "Predictors of Employment Income: Comparisons by Gender and Type of Impairment." *Journal of Disability Policy Studies* 8(1): 51–74.

Barnes, C. 1991. *Disabled People in Britain and Discrimination.* London: Hurst.

Daniel, C. 1998. "Radical, Angry, and Willing to Work." *The New Statesman,* March 6.

Leonard, M. 2000. "Coping Strategies in Developed and Developing Societies: The Workings of the Informal Economy." *Journal of International Development* 12(8): 1069–1085.

Majid, N. 2001. "The Working Poor in Developing Countries." *International Labor Review* 140(3): 271–291.

Raskin, C. 1994. "Employment Equity for the Disabled in Canada." *International Labor Review* 133(1): 75–89.

———. 1998. *Chartbook on Work and Disability in the United States.* San Francisco: InfoUse.

Websites

Independent Living Institute, http://www.independentliving.org

Mennonite Central Committee, "Current Status of Disabled People," http://www.mcc.org/respub/occasional/92.html

EMPOWERMENT AND EMANCIPATION

Empowerment has become a key concept for disabled people and the disabled people's movement because of its associations with liberation and emancipation.

Disabled people's understandings of the idea highlight the essentially political nature of the concept and its focus on power and the redistribution of power. The idea of empowerment has also come to much wider prominence in recent years. This reflects broader interest in a concept that transcends conventional politics and ideology, addresses both the "personal" and the "political," and seeks to unite the two. Empowerment has become an important concept in public policy as well as personal living. It has become central in political, public, and social policy and educational, cultural, sexual, personal, and managerial discourses, as well as entering popular usage. This has been an international development. At the same time, there have also been growing concerns that the term has been reduced to jargon through overuse and lack of clarity.

The term *empowerment* can be used to refer to a process, a goal, or a combination of the two. While disabled people's definition of the term is closely connected with emancipation, this is not true of all interpretations placed upon it. There is little agreement about the definition of the term. Widespread concerns have been expressed about its meaning being diluted and distorted. But the contradictory and diverse meanings attached to empowerment say more about the complex origins of the idea than its practical or philosophical limitations. Inherent tensions in the concept are highlighted by its traditional dictionary definition, which is framed in terms of "licensing," "authorizing," or "giving power" to someone. The organization or individual "empowered" in this way is only an intermediary in the process, and the nature, extent, and goals of empowerment continue to be determined and circumscribed by the original powerholder.

Such a definition is far removed from the emancipatory interpretation of empowerment that has been placed on it by the disabled people's and other liberational and new social movements. It is helpful to remember that disabled people's discourse about empowerment is only one of a number of such discourses. In conventional terms, it is far from being the dominant one. The idea and practice of empowerment in relation to disability and disabled people can only be understood adequately in this broader context. The predominant discussions about empowerment in recent times have been consumerist and professional ones.

Many different strands can be identified in the development of the idea and usage of empowerment. There are self-help, liberational, professional, managerialist, and market models of empowerment. They are in complex relationship with each other. While there are overlaps between them, there are also important differences. Empowerment has become the site of key struggles over the nature and purpose of politics, policy, services, identity, and professional intervention. That is why its meanings are heavily contested and it is important to recognize its regulatory as well as liberatory potential.

The origins of modern discussions about empowerment are generally traced to the U.S. black civil rights movement of the 1950s and 1960s. They are also associated with theories and practices relating to feminist, (international) black liberation and radical politics of the 1960s and 1970s. Disabled people's discussions of empowerment are linked with these. Other key understandings of empowerment have subsequently developed, and disabled people's interest in empowerment needs to be considered in relation to these to avoid confusion. These approaches to empowerment—the popular, consumerist, and professional—all have had a bearing on the activities and debates of disabled people, but all have also been distinct from disabled people's own conceptualization of empowerment.

The most visible modern expression of the idea of empowerment is its adoption in popular culture. The word has now entered common usage. This is probably also the area where its use is most superficial. It has mainly been used to convey a sense of feeling good and powerful. It has increasingly been offered in this way in advertising, particularly to sell cosmetic, relaxation, and leisure products. Its lack of clear meaning has encouraged its being put to questionable uses. In the early 2000s, for example, an international pyramid selling scheme, called "Women Empowering Women," made headlines when many women lost their savings.

EMPOWERMENT, THE NEW RIGHT, AND PUBLIC PROVISION

Wider interest in the idea of empowerment toward the end of the twentieth century was associated with a

political move to the right. This was characterized by a new enthusiasm for the private market in public policy and an increasing philosophical rejection of state intervention and provision. This shift in ideology extended to countries such as the United Kingdom, where there had been a strong tradition of large-scale state intervention and of collectivist state welfare.

The emergent political New Right highlighted the idea of empowerment. Its approach to empowerment was based on an individualistic consumerist model, which prioritized the market. The political New Right based its use of the term on its view of the state's capacity to meet individual needs as problematic and inferior to that of the market. It saw state services as inherently worse than market provision. Yet it also acknowledged that there might some policy areas where state services would continue to be needed, for example, for disadvantaged and impoverished groups. The New Right's understanding of empowerment was based on developing consumer rights, which would give citizens real and measurable powers over state services. "Customers" would have powers to make public services deliver the level and quality of services that the public felt were required. In this way, empowerment in public provision was offered as a parallel and complementary strategy to privatization. Arrangements for guarantees, regulation, and inspection were proposed to help ensure that "quality" standards were achieved. The political New Right conceived of empowerment in terms of equalizing the citizen's relationship with state provision. In the United Kingdom, for example, where this approach was particularly developed, it defined empowerment as increasing people's control over public services through "citizen's charters," "chartermarks," and government hotlines.

The political New Right's commitment to the market had long-term consequences for public services internationally, particularly health and welfare services. It gave direction to broader economic, social, and political pressures toward more consumerist and market-led approaches to public provision, particularly welfare provision. Traditional state welfare came in for criticism from both the political Left and Right for it paternalism, bureaucracy, centralization, inflexibility, and lack of responsiveness. A new welfare pluralist approach was pioneered in the United Kingdom with the advent of Thatcherism. This has had continuing effects on public service and welfare policies in Europe and beyond. It has been reinforced internationally by restrictions on public expenditure imposed by conventional approaches to and understandings of globalization. In the United Kingdom, this consumerist approach to policy was most coherently developed first in the field of social or "community care"—a key policy for disabled people.

Such community care reforms were explicitly concerned with changes in how and where disabled people and other service users received support, with an accent on them being able to live in their own homes and neighborhoods. However, they also actually heralded ideological changes that have had international significance. They entailed both a greater role for the market in the financing and supply of services and also the reframing of public provision to create "quasi-markets," where state and nonstate service providers operate in competition with each other. They highlighted a distinction between (public) purchasers and (private) providers. The rationale for this move was that the individual citizen/consumer would now have greater choice in health and welfare. This clearly had major ramifications for disabled people as a group historically denied choice and opportunities.

Empowerment became a core concept in such development. It was mainly understood in individual consumerist terms of the individual having voice, choice, and exit, that is to say, gaining opportunities to express their preferences, to choose from different services and service providers, and to go somewhere else if they don't like the service they receive. In practice, opportunities for choice and exit tend to be limited, particularly where people receive services on an involuntary basis, as is often the case for mental health service users, people with learning difficulties, and frail older people. Such arrangements have tended to be associated with charging, means testing, and with increasing restrictions on public expenditure, a tendency to increasingly restricted eligibility criteria. With an increasingly globalized sector of large multinational corporations as "care" suppliers and use of bulk contracts, it has also encouraged standardization of service, rather than customized provision.

Political interest in empowerment did not diminish with the waning of interest in the New Right. The realignment of left-of-center politics resulted in an increasing interest in reassessing relationships between state and market. One expression of this, which has had an international influence, extending to Europe, the United Kingdom, and United States, has been the development of ideas such as "the third way." Such remixes of market and state involvement have encouraged the development of ideas of empowerment that combine managerialist and consumerist elements.

THE PROFESSIONALIZATION OF EMPOWERMENT

Empowerment has become a key concept in public service professions particularly in health and social welfare. The concept has its longest history and has become most developed in social work and social care. The professional definition of empowerment sees professional intervention as the route to service users' empowerment. This is a strongly contested view. The concept of empowerment is now deeply ingrained in professional vocabulary, discussion, and practice. The most significant early developments in thinking about social work as empowerment came from the United States, highlighted by the writing of Barbara Solomon in the field of black empowerment. Professional interest in the concept has developed in European countries, such as the United Kingdom, in response to the new demands of the consumerist care market.

Empowerment has offered social care professions facing uncertainty and insecurity, new arguments for their own autonomy and consolidation, by emphasizing the prior need for their empowerment if they are to empower service users. Professionals, the argument goes, must be empowered if they are to empower service users. The concept of empowerment is also embraced enthusiastically as providing a new paradigm for practice, giving it fresh vitality, legitimacy, and credibility. Commentators such as Clare Evans and Mike Fisher argue that empowerment in social work and social care has largely been defined by professionals.

A liberatory and emancipatory rhetoric has been associated with such professional discourses on empowerment, as though the professional can play a key role in transformation for disabled people. Such workers are seen as having the potential to empower both individuals and groups. Some outside commentators, however, have also pointed to the regulatory as well as liberatory potential of such professional approaches to empowerment. Bearing in mind the social control role of professional social work, it is difficult to ignore this argument.

Professional approaches to empowerment have been particularly concerned with *personal* empowerment. Personal empowerment is concerned with people being able to develop new and different understandings of themselves and their world, so they are better equipped to respond to opportunities to take power. However, in professional welfare relationships, this can also mean working for change in people's attitudes and behavior consistent with the agendas, imperatives, and requirements of state agencies. Thus, empowerment becomes particularly concerned with people taking increased responsibility for managing their lives, relationships, and circumstances; to live in conformity with prevailing values and expectations; and to change in accordance with professionally set goals and norms. While this may be consistent with individual aspirations and self-determination, it cannot be assumed that the two are necessarily synonymous.

EMPOWERMENT AND DISABLED PEOPLE

Disability activists, however, have generally been suspicious of the idea that professionals can "empower" them. This is not least because such workers have historically been more often associated with structures, attitudes, and services that disabled people have seen as reinforcing their disempowerment. Disabled people have argued that professionals and service providers must learn to work in different ways and *stop* disempowering them. Many disabled people reject the idea that power can be "given" and see it as something that can only be *taken.* Two understandings of the role of professionals in relation to empowerment can thus be identified: first, the contested view that they can empower disabled people, and second, the idea that they can support disabled people to empower themselves, through the skills, resources, networks, and legitimacy

that they can command. This latter view is consistent with the dominant view among disabled people that disabled people can only truly empower themselves.

Among disabled people, empowerment has tended to be understood through their understanding of *disempowerment*. The search for empowerment starts with the experience of disempowerment. This helps explain the significance that the idea of empowerment has among disabled people. They have wide experience of disempowerment through segregation, institutionalization, isolation, inferior educational opportunities, poverty, low income, and restrictions on opportunities and choice. For disability activists, empowerment means challenging their disempowerment, having more say in and control over their lives, being able to influence others and bring about change. The goal is greater autonomy and self-determination.

Empowerment is an inherently political concept and this is explicit in disabled people's understandings of the idea. These have focused on both personal and political empowerment. While professional interest in personal empowerment has tended to be concerned with encouraging change in individuals in conformity with state and service values and requirements, significantly different meanings have been placed on personal empowerment by disabled commentators. Here the aim is to alter disabled people's understandings of themselves and their situation as a basis for challenging and transforming both. Key elements toward achieving this are gaining new skills and knowledge and raising expectations, confidence, and self-esteem.

If the professional approach to personal empowerment is concerned with people accepting from outside the need to make change in themselves, disabled people's liberatory understanding of personal empowerment means having the chance to change your understandings of yourself and your situation.

A range of components are associated with empowerment. These include equal opportunities and access; access to advocacy and self-advocacy, to enable disabled people to speak and act for themselves; opportunities for personal development and to acquire new skills; participation, as fully as possible, in the range of activities in society available to nondisabled people and inclusion in the mainstream, rather than segregation in special institutions and services.

A key concept in achieving personal empowerment in the disabled people's and other liberatory and new social movements is consciousness-raising.

CONSCIOUSNESS-RAISING

Ideas of consciousness-raising are notably embodied in the writings and activities of Steve Biko in South Africa and Paulo Freire in South America. Freire has been described as the starting point for many liberationist and participatory approaches to empowerment, especially in the area of community work. Freire coined the term *conscientization*, the process by which oppressed people come to understand the causes of their oppression and to do something about it. Such approaches have been developed in many parts of the majority world by indigenous populations, communities, and their supporters.

There is a tension between these approaches to consciousness-raising and related professionalized, sometimes managerialist and top-down models adopted in community and international development. These tend to employ people without shared experience, often outsiders working for both government and nongovernmental organizations, who seek to involve and empower local disadvantaged groups and communities. They have raised concerns about the tyrannizing effects of supposedly participatory and empowering approaches to development. One initiative that has been associated with this approach has been the development of community-based rehabilitation (CBR) programs for disabled people in the majority world.

Raised consciousness involves an altered understanding of yourself (and others), based on a reinterpretation of your experience and identity. It entails a change in consciousness so that negative understandings of disability as an individualized, tragic (and blameworthy) medicalized condition are replaced by an awareness and understanding of disability as a social condition. Individuals are no longer the cause of "the problem." They are able to see what they have in common with other disabled people as well as how they are may be different from (as well as the same as) nondisabled people. They are able to see the social relations of their situation. They are able to question the legitimacy of their inferior treatment and status

because they are disabled. They can resist external judgments that are discriminatory, as well as recognizing and questioning their own internalization of such judgments. Such altered understandings are liberating and provide a basis for taking collective action and seeking political change.

Consciousness-raising thus makes it possible to exert power. This connects closely with modern discussions about the meaning and nature of power. These have developed understandings of a view of power as relational, that is to say, based on the nature of relationships between people and organizations rather than a zero sum game where if one actor gains more power then it is because another loses it. In his influential discussion, Steven Lukes developed a "three dimensional" view of power that offered an analysis of why some people did not challenge their powerlessness, because of their inability to recognize or articulate their own interests. Thus, it is not enough for people to be offered power; they also have to be in a position to make use of it. This has traditionally been the situation of many disabled people, whose segregation and extreme powerlessness have frequently denied them the resources and opportunities to explore, reinterpret, and effectively challenge their disempowerment.

Three developments have supported and encouraged the self-empowerment of disabled people internationally: (1) the move to managerialist/consumerist models of public and social policy, (2) the development of the social model of disability, and (3) the development of new approaches to self-organization by disabled people.

CONSUMERIST/ MANAGERIALIST MODELS OF PUBLIC AND SOCIAL POLICY

The managerialist/consumerist approaches to public policy and services that developed toward the end of the twentieth century brought with them very different understandings of empowerment and participation to those of the disabled people's movement. However, with their rhetoric of consumer choice and involvement, they provided a window of opportunity for the disabled people's movement and its related goals. The same was also true of the shift in public policy away from traditional institutionalization to the relocation and maintenance of disabled people in their own homes and neighborhoods. This provided opportunities for their integration, although it should also be remembered that it frequently created major problems through the failure to make adequate alternative provision. One particular consequence of this has been the imposition of additional restrictions on the rights of mental health service users who have been left without adequate or appropriate support in the community.

THE SOCIAL MODEL OF DISABILITY

The social model of disability provided a philosophical basis for raising the consciousness of disabled people. Traditionally in the West, disability has been understood in individualized terms as a problem of deficiency in the body, senses, or intellect. From the nineteenth century, this was overlaid with medical interpretations, which provided the dominant basis for both analyses and responses to disability. These were primarily based on a "treatment" model, which frequently equated disability with illness. This is still the dominant popular model of disability in the West.

The social model of disability developed by the disabled people's movement during the last quarter of the twentieth century drew a distinction between individual *impairment*—the (perceived) loss or deficiency of a limb or sense—and *disability*—the social response to such impairment. Disability was understood in terms of a negative social reaction, which manifested itself in prejudice and discrimination against disabled people and the operation of barriers to exclude them from mainstream life. While a dynamic discussion has developed among disabled people exploring the nature of disability and impairment and the relation between them, the social model remains the main model of interpretation developed by the disabled people's movement. It has provided the philosophical basis of the disabled people's movement. Efforts have also been made to extend its application to other groups, including people with learning difficulties and mental health service users/survivors. It has had a profound liberatory effect on many thousands of disabled people internationally. It has provided a coherent basis for consciousness-raising by offering disabled people

an alternative way of understanding. It helps liberate them from a sense of blame, inferiority, personal responsibility, and pathology.

DISABLED PEOPLE'S SELF-ORGANIZATION

The social model of disability has also provided the philosophical basis for the self-organization of disabled people. The aims of disabled people's self-organization follow from the social model. They include seeking to increase the control they have over the support they require, overcoming discrimination that restricts their human and civil rights, and challenging the barriers that disable them in society. The effectiveness of its self-organization has been one of the distinct characteristics of the disabled people's movement. Traditionally in modern Western industrial societies, policies and services for disabled people have been developed and controlled by nondisabled people. They have also reflected their priorities and understandings of disability and disabled people. While the state has intervened systematically to make provision for disabled people since at least the establishment of the English Elizabethan poor law, charitable organizations have also played an important role in defining and providing for disabled people. This tradition has led disabled people to draw a distinction between organizations *for* and organizations *of* disabled people, which reflects their emphasis on and approach to self-organization. By *organizations for disabled people*, they mean those organizations operating in the field of disability that are controlled by nondisabled people. Disability policy and provision have predominantly been shaped by such organizations. The term *organizations of disabled people* has been used to signify those organizations that disabled people themselves control. Disabled people's self-organization has been based on the development of such independent organizations. The emerging organizations of disabled people met with strong opposition from traditional voluntary organizations for disabled people. There are now, however, a large and growing number of organizations of disabled people operating locally, nationally, and internationally. They are now found in North America, Europe, and the majority world.

The self-organization of disabled people has included both parliamentary and extra-parliamentary approaches to making change. There has been a concern with developing new ways of working that include people with impairments. This has extended to the development of new forms of direct action, as well as the development of disability culture, developing the body of disabled people's knowledge and providing user-led services through the development of centers for independent and inclusive living.

What also distinguishes the self-organization of disabled people is that it has tended to combine commitments to self-help and mutual aid with commitments to making broader social and political change. These twin aims help explain the centrality of the idea of empowerment within the disabled people's movement. This is because the idea of empowerment can be used to address issues of both personal and political change. In this way, it can provide a powerful conceptual framework for disabled people's aspirations for both.

Historically, there has often been a tendency to separate self-help and mutual aid from campaigning and political activity. Thus, the self-help tradition in empowerment has tended to be associated with (consensual) voluntary and charitable activity, rather than (conflict-based) political action. In contrast, disabled people's approach to self-organization has been based on an appreciation of the interrelation of the two activities. They have shared this approach with and learned from other new social movements, notably the women's, black people's, and gay men's, lesbians' and bisexuals' movements. The liberatory understanding of empowerment generally adopted by disability activists reunites the psychological and social elements of empowerment.

Disabled people's discourses have also highlighted both the individual and collective aspects of empowerment. Different commentators have placed different interpretations and emphases on the part each of these may play. Some, for example, have stressed the part that individuals' own reevaluation of themselves and their situation may play in leading them to become involved in collection action. In the mental health service user/psychiatric system survivor movement, for example, a particular emphasis has been placed on the part that support and self-help groups can play in

encouraging people to get more actively involved with others.

A stronger strand, however, reflected in the writings of the British disability academic and activist Mike Oliver, sees empowerment as a collective process, whereby powerless people, by coming together with others, come to see and make more sense of their oppression and begin the process of challenging it, both within themselves and in the wider world. Self-organization becomes the means the means for both personal and political empowerment. Thus, the self-organization of disabled people has needed to address both. Just as there have been criticisms that the social model of disability has sometimes emphasized disability at the expense of addressing issues of impairment, so concerns have also been raised that disabled people's self-organization has sometimes inadequately addressed issues of personal empowerment because of the priority given to political change.

This has become a particular focus for discussion as efforts have increased to enable as wide a range of disabled people as possible to be included in the disabled people's movement. This includes, for example, people with learning difficulties, older disabled people, mental health service users, people who communicate differently, and people with chronic and life-limiting illnesses and conditions that are associated with impairment and disability. This has been linked with increasing pressures to address difference in terms of, for example, race, gender, sexuality, culture, and class. These developments have highlighted the need to support all disabled people to be able to exert power, acknowledging the particular personal and societal obstacles they may face.

The experience and activities of disabled people have highlighted that there are both individual and collective aspects to becoming empowered. Collective action can provide the basis for both personal and political empowerment. It provides an effective way of connecting the personal to the political, of making clear that the political is the personal and vice versa. Collective action among disabled people has also crucially been the basis for developing the philosophy, values, and goals of disabled people.

One large-scale initiative was taken in the United Kingdom (by an organization for disabled people) to support the self-empowerment of disabled people who were not involved in disabled people's organizations. This was based on a program of "empowerment training" developed and provided by experienced disabled trainers and offered to disabled people living in institutions as well as in their own homes. This was greatly valued by participants who reported the effects it had in raising their consciousness and understanding as disabled people. So far, however, it has not resulted in the organization involved changing its operation in line with service users' changed expectations and aspirations.

Research has been a major area of activity that disabled people have developed through self-organization. The disabled people's movement has equated much traditional research with broader structures of oppression and discrimination in society. The disability emancipatory research developed by disabled people highlights personal and political empowerment as key aims and has an explicit commitment to emancipation in its understanding of empowerment. Drawing on a social model of disability, it prioritizes a changed process of research production that aims to equalize relationships between researchers and research participants, as well as research primarily concerned with making change at both personal and social/political levels, rather than solely concerned with knowledge production. Such disability emancipatory research provides one of the bases for the development of disabled people's own discourse to challenge traditional, medicalized, individual understandings of disability.

—Peter Beresford

See also Activism; Advocacy; Politics; Politics, International.

Further Readings

Adams, Paul. 2003. *Social Work and Empowerment*. Basingstoke, UK: Palgrave.

Baistow, Karen. 1994. "Liberation and Regulation? Some Paradoxes of Empowerment." *Critical Social Policy* 42, 14(3): 34–46.

Campbell, Jane and Michael Oliver. 1996. *Disability Politics: Understanding Our Past, Changing Our Future*. Basingstoke, UK: Macmillan.

Chamberlin, Judi. 1978. *On Our Own: Patient Controlled Alternatives to the Mental Health System*. New York: McGraw-Hill.

Charlton, James. 2000. *Nothing about Us without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press.

Coleridge, Peter. 1993. *Disability, Liberation and Development*. London: Oxfam.

Evans, C. and M. Fisher. 1999. "User Controlled Research and Empowerment." Pp. 248–369 in *Empowerment Practice in Social Work: Developing Richer Conceptual Foundations*, edited by W. Shera and L. M. Wells. Toronto: Canadian Scholars Press.

Freire, Paulo 1986. *Pedagogy of the Oppressed* (first edition 1972). Harmondsworth, UK: Penguin.

Jack, Raymond, ed. 1995. *Empowerment in Community Care.* London: Chapman and Hall.

Lukes, Stephen. 1974. *Power: A Radical View.* Basingstoke, UK: Macmillan.

Means, Robin and Randall Smith. 1998. *Community Care: Policy and Practice,* 2d ed. Basingstoke, UK: Macmillan.

Oliver, Michael. 1996. *The Politics of Disablement.* Basingstoke, UK: Macmillan.

Pirie, Masden, ed. 1991. *Empowerment: The Theme for the 1990s.* London: Adam Smith Institute.

Shera, Wes and Lilian M. Wells, eds. 1999. *Empowerment Practice in Social Work: Developing Richer Conceptual Foundations.* Toronto: Canadian Scholars' Press.

Solomon, Barbara B. 1976. *Black Empowerment: Social Work in Oppressed Communities.* New York: Columbia University Press.

Stone, Emma, ed. 1999. *Disability and Development: Learning from Action and Research on Disability in the Majority World*. Leeds, UK: Disability Press.

Websites

Disability Awareness in Action, http://www.daa.org.uk
Disabled Peoples' International, http://www.dpi.org
National Empowerment Center, http://www.power2u.org/

END-OF-LIFE CARE

End-of-life care generally refers to palliative care, care that affords relief, but not cure, to dying patients with no reasonable possibility of cure. End-of-life care becomes an increasingly important issue as Americans more often see patients neither improving nor acutely dying, alive but with a dwindling capacity to recover from their injury or illness. Chronic diseases—such as heart disease, cancer, and diabetes—are the leading causes of death and disability in the United States. These diseases account for 7 of every 10 deaths and affect the quality of life of 90 million Americans. Prior to World War II, deaths from these diseases were quick and mostly at home. Since then, advanced medical technology has prolonged the life of people with these diseases when they cannot be cured. Moreover, technology continues to turn acute disease into chronic disease. For example, in the early 1980s, the median life expectancy for AIDS was often less than one year but now it follows a chronic disease trajectory. Those living with serious chronic illness at the end of life generally show three types of trajectory of function and symptoms. Cancer patients generally experience a short period of obvious decline at the end. Prior to that, most cancer patients do not suffer from serious loss of daily basic functions. On the other hand, those dying with chronic organ system failures suffer from long-term disability, with a periodic acute phase during which symptoms are severe and death seems imminent, and then go into temporary remission. The third type of chronic disease is typical of an elderly population—osteoarthritis, osteoporosis, failure to thrive, and dementia, to name a few—and is characterized by self-care deficits and a slowly dwindling course to death. Generally, non-cancer diseases are characterized by long-term disability and an unpredictable timing of death, making end-of-life care for people with these diseases more difficult.

Advanced medical technology also shifted the place of death from home settings to acute care settings in the 1950s. Many of those dying with serious chronic diseases tend to die in the hospital attached to life-sustaining machines. A 1995 study reported on death in intensive care units (ICUs) in hospitals across the country: 38 percent of patients who died spent at least 10 days in an ICU, and 50 percent of conscious patients in the ICU reported moderate to severe pain at least half the time. In response to futile care and unnecessary suffering at the end of life, the hospice movement began in the mid-1960s to provide pain and symptom management in the patient's home where the vast majority of people choose to die. The focus of care is not on curative treatment, but rather the palliation of pain and symptoms through interventions designed to promote comfort and function.

Recognizing the value of hospice care, the National Hospice Reimbursement Act of 1983 created the Medicare Hospice Benefit (MHB) under Medicare Part

A (hospital insurance) of the Social Security Act, which became a permanent benefit in 1986. In addition, states were allowed to develop their own coverage for hospice programs under Medicaid. Currently, 43 states and the District of Columbia offer a hospice benefit to all individuals who qualify for Medicaid. Many private health insurance plans also provide hospice care. Because the scope of services varies by states and insurance plans, contact must be made directly with individual states or private insurance plans for information on hospice care coverage. The following discussion focuses mainly on MHB because the services to be covered under Medicaid/private insurance are essentially those for MHB. Information on MHB is mostly from the hospice section of Social Security Act.

Eligibility for MHB is fairly straightforward: The patient's attending physician and the hospice medical director must certify in writing that the patient is likely to die within six months. On the part of the patient, the patient must, for the duration of an election of hospice care, waive all rights to Medicare A payments for the following services: (1) any Medicare services that are related to the treatment of the terminal condition for which hospice care was elected or a related condition; (2) hospice care provided by a hospice other than the hospice designated by the individual (unless provided under arrangements made by the designated hospice). Upon admission, a written plan of care must be established by the attending physician, the medical director, and the hospice interdisciplinary group prior to providing care and the care provided to an individual must be in accordance with the plan. The plan must include an assessment of the individual's needs and identification of the services including the management of discomfort and symptom relief. It must state in detail the scope and frequency of services needed to meet the patient's and family's needs. The hospice must have an interdisciplinary group that includes at least the following individuals: a physician, a registered nurse, a social worker, and a pastoral or other counselor. The hospice must designate a registered nurse to coordinate the implementation of the plan of care for each patient.

MHB also specifies the standards of care that must be routinely provided directly by hospice employees or contracted staff if necessary. Four types of core services include nursing services, medical social services, physician services, and counseling services. The nursing care and services are provided by or under the supervision of a registered nurse. Medical social services must be provided by a qualified social worker under the direction of a physician. In addition to palliation and management of terminal illness and related conditions, physician employees of the hospice must also meet the general medical needs of the patients to the extent that these needs are not met by the attending physician. Counseling services must be available to both the individual and the family. Counseling includes bereavement counseling for the family, provided after the patient's death (up to one year), as well as dietary, spiritual, and any other counseling services for the individual and family provided while the individual is enrolled in the hospice. In addition to the core services, physical therapy, occupational therapy, and speech-language pathology must be available. Home health aide and homemaker services must be available and adequate in frequency to meet the needs of the patients. Medical supplies and appliances including drugs and biologicals must be provided as needed for the palliation and management of the terminal illness and related conditions.

MHB pays hospices capitated per diem for almost all services needed in a day to treat the patient. The per diem rate varies depending on the level of care: routine home care, continuous care, inpatient respite care, and general inpatient care. The day is counted as routine home care with the rate of $118.08 (as of October 2003 and regionally adjusted) when patients, residing within the home (or nursing facility), under the supervision of the hospice program, receive fewer than eight hours of care per day. Routine home care accounted for 95.1 percent of patient days in hospice care in 2002. A continuous home care day is when continuous nursing care is needed for 24 hours and can be provided for up to five days. It is furnished only during times of crisis and only as necessary to avoid transfer to a hospital usually as death nears. Continuous care accounted for only 0.9 percent of patient days in hospice care in 2002 and its rate ($689.18) is the highest, six times higher than routine home care. The third level of care, inpatient respite care, allows hospice patients to receive care in

approved facilities on a short-term basis (no more than five days at a time) as respite for their caregivers. Inpatient respite care accounted for 0.2 percent of patient days in hospice care in 2002. Finally, general inpatient care permits patients to be admitted into approved facilities for pain control or acute/chronic symptom management that cannot be achieved in other settings. This form of care can be provided in a hospital, a hospice with its own inpatient facility, or a skilled nursing facility. General inpatient care days accounted for 3.8 percent of patient days in hospice care in 2002. The current national Medicare rate for general inpatient care is $525.28 (adjusted for regional wage differences).

The number of Medicare beneficiaries choosing hospice services has grown substantially during the past decade—579,801 beneficiaries enrolled in 2001, more than five times the number that elected hospice in 1991 (108,413). Cancer patients account for more than half of Medicare hospice users, but the most dramatic growth in use is among persons with other terminal conditions, such as heart disease, lung disease, stroke, or Alzheimer's disease. From 1992 to 1998, hospice enrollment by beneficiaries with cancer increased 91 percent, while enrollment among beneficiaries with all other conditions increased 338 percent. By 1998, about 43 percent of Medicare beneficiaries electing hospice had non-cancer diagnoses, compared with about 24 percent in 1992. This growing share of hospice enrollees with non-cancer diagnoses reflects the continuing legislative efforts to adjust the organization and financing of care to match distinguishably different trajectories of chronic diseases. The way benefit periods were organized in the original 1983 hospice legislation was geared toward cancer patients. Patients were allowed to elect hospice care during one of the three benefit periods: two 90-day periods followed by one 30-day period with a limit of a maximum of 210 benefit days. Given the concerns about the complexity of making a prognosis of six months or less for non-cancer patients, Congress later repealed the 210-day limit and replaced it with four benefit periods. It added the fourth benefit period of unlimited duration. At that time, however, beneficiaries could have no more than four benefit periods. The current benefit period system was structured by the Balanced Budget Act of 1997 (BBA). The act established unlimited coverage by changing the four hospice benefit periods to two 90-day periods, followed by an unlimited number of 60-day periods. However, the law also increased the number of times of certification. Under this act, all patients are initially admitted for a 90-day benefit period. At regulated intervals (90 days after initial enrollment, 180 days after initial enrollment, and then every 60 days, indefinitely), a patient must be recertified by the hospice medical director. Once recertified at the required intervals, the patient can stay in hospice care with no limitation. When patients cannot be recertified and have to be discharged because of a change in prognosis due to an improved clinical status or stability over a period of time, the hospice program assists in establishing appropriate follow-up care. When physical status worsens again enough to get recertified, they can elect hospice care again. Most important, patients have the right to return to active disease-modifying treatment during any benefit period, thereby relinquishing the hospice benefit and returning to the usual model of care. Patients who select this option are not penalized for this decision, and are readily welcomed back should they elect additional hospice care. The act also allows patients to change the current hospice provider once during each benefit period.

MHB assumes full financial responsibility for all medications related to the primary hospice diagnosis, for durable medical equipment (e.g., hospital beds, commodes, wheelchairs), and for the participation of staff. A hospice patient pays no more than $5 for each prescription drug and other similar products for pain relief and symptom control. A patient pays only 5 percent of the Medicare payment amount for inpatient respite care, wherein the inpatient hospital deductible under Medicare A ($876 in 2004) is the annual limit for respite copayments. Even though they must waive their rights to all other inpatient hospital, skilled nursing facility, and home health services for the terminal illness, beneficiaries may still be treated for other medical problems under the regular Medicare program. Even though the hospice team includes a physician, patients can continue to use their personal physician. Medicare will help pay for covered services provided by a physician not affiliated with the hospice if the patient is covered by Medicare

Medical Insurance (Part B). Also, if the patient has Part B, he or she can use all appropriate Medicare Part A and Part B benefits for the treatment of health problems unrelated to the life-limiting illness.

Despite a rapid increase in use of hospice care, only one of five hospice-appropriate deaths occurs while in hospice care. Advocates for hospice care cite two barriers among others to access to hospice care. One barrier is related to the focus of hospice care on home-centered care. Medicare does not pay for room and board if a patient lives in a nursing home or a hospice residential facility. Another barrier related to the nature of home-centered hospice care occurs when elderly people do not have caregivers to manage care at home and cannot be safely cared for by hospice in the home. Although some states have passed laws to establish inpatient hospice facilities to house those having no primary caregiver at home, the patients without caregivers may be unable to afford hospice care when Medicare does not cover home and board cost in a inpatient hospice facility. Some states including New York cover the room and board cost through Medicaid for hospice beneficiaries with low income, but the assistance program tends to have a sunset provision, reflecting the financial concerns about increasing Medicaid cost among states.

Another barrier to access to hospice care is related to uncertainty involved in certification of survival of six months or less. Physicians are often confused about how Medicare interprets its terminal illness requirement: Intermediaries in reviewing hospice claims use different guidelines from those used by hospice providers to determine eligibility of beneficiaries for hospice benefits. Physicians often delay certifying patients for hospice care. Sometimes even when the patient's conditions and clinical prognosis do not change, they refuse to recertify patients who do not die within the first six months of the initial certification. It is often difficult for beneficiaries and their advocates to convince physicians that hospice certification may well remain appropriate, that the beneficiary need not have died within six months for the hospice certification to have been legitimate, and that recertification should not result in a fraud claim. The delayed certification has resulted in a decrease in length of stay in hospice care, despite the increase in the number of beneficiaries. Thirty percent of all hospice recipients died within one week and 63 percent died within one month in the year 2000. A government report revealed an increase in the share of MHB users with very short stays over the past years: Beneficiaries using hospice care for one week or less accounted for 28 percent of all users in 1998, compared with 21 percent in 1992. The Centers for Medicare and Medicaid Services, the financing agency for hospice care, formally acknowledged the difficulty in prognosis, reducing the fear of fraud scrutiny among physicians. On the part of hospice care providers, there have been continuing efforts to develop the guidelines for certification based on specific functions and symptoms characteristic of near death for non-cancer diseases.

There has been a call to assist patients who are reluctant to elect hospice care because they do not know anything about it. They need to have their questions answered by a physician who specializes in end-of-life issues or a hospice representative. In response to the call, the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 provides provisions to permit physicians to refer terminally ill patients to a Medicare-certified hospice for consultation services that was not covered by Medicare. The provision applies on or after January 1, 2005. These consultation services include (1) assessing the beneficiary's need for pain and symptom management, including the individual's need for hospice care; (2) counseling the beneficiary with respect to end-of-life issues and care options; and (3) advising the beneficiary regarding advanced care planning.

Advanced care planning has been widely encouraged as a way of avoiding lingering deaths where the quality of life is poor and the patient cannot participate in decision making about continuing futile treatments to prolong life. Advance care planning, encouraged by a federal law, such as the Patient Self-Determination Act of 1991, generally involves two forms: living wills and durable power of attorney for health care. The former is a written document of wills that states the desire to not be kept alive by extraordinary or disproportionate medical interventions. Living wills become effective on the determination of terminal illness or imminent death, when the patient can no longer participate in decision making. Durable power

of attorney for health care is to be distinguished from a living will in that it is a directive executed by a competent adult that appoints another individual to make medical treatment decisions on his or her behalf in the event that the person making the appointment loses decision-making capacity. The appointed surrogate is often referred to as the patient advocate, patient proxy, or patient representative. The laws governing the authority this individual does or does not have may vary from state to state and is dependent on the specific instructions of the document.

The Patient Self-Determination Act of 1991 requires health care organizations including hospice care providers (1) to inform patients of their right to complete an advance directive and (2) to document existing advance directives in patients' medical record. A significant increase in advance directives documentation in nursing home medical records was reported after the implementation of the act. Another study found that having a living will was associated with a lower probability of dying in a hospital for nursing home residents and people living in the community. However, many more studies cast doubt on the role of advance directives on definitive decisions to stop treatment in hospital: Only 47 percent of the physicians for the patients who preferred to avoid cardio-pulmonary resuscitation (CPR) knew that preference; 46 percent of do not resuscitate (DNR) orders were written late in the hospital stays—within two days of death. Studies reported a low level of physicians' compliance with patients' advance directives and a high level of reliance on their own clinical reasoning.

Hospice-appropriate deaths will increase. One of five Americans will be 65 or older by the year 2020. Advanced technology will increase the number of chronic diseases by turning acute disease to chronic disease. Advanced technology will prolong the life of those suffering from serious chronic diseases, probably increasing the difficulty in predicting the end of the life trajectory. Advanced technology will also prolong death, highlighting the need for physician and public education on advance care planning. Americans have generally made the choice to live as long as the quality of life is acceptable. As technology becomes more sophisticated, it is increasingly important for our aging population to indicate their wishes in advance about end-of-life care and what each person believes constitutes an acceptable quality of life. The quality of life standard, of course, differs from person to person. With life expectancy reaching well into the 90s in the foreseeable future, these decisions become critical in caring for our old-old, not only for their own personal dignity, but for the soaring health costs associated with life-prolonging technologies.

—Kyusuk Chung

See also Do Not Resuscitate (DNR) Orders; Palliative Care; Patients' Rights; Quality of Life.

Further Readings

Castle, N. G. and V. Mor. 1998. "Advance Care Planning in Nursing Homes: Pre- and Post-Patient Self-Determination Act." *Health Services Research* 33(1): 101–124.

Center for Medicare Advocacy. n.d. "Hospice: An Important Benefit Enhanced by the New Medicare Law." Retrieved September 10, 2004 (http://www.medicareadvocacy.org/Reform_Act2003ChangesToHospice.htm).

———. n.d. "Physician Education about the Hospice Benefit." Retrieved September 20, 2004 (http://www.medicareadvocacy.org/FAQ_Hospice.htm).

Center for Medicare and Medicaid Services. n.d. "Hospice Data—FY 1991 through FY 2001." Hospice Information Resource for Medicare. Retrieved September 1, 2004 (http://www.cms.hhs.gov/providers/hospiceps/default.asp?).

Centers for Disease Control and Prevention. n.d. "Chronic Disease Overview." National Center for Chronic Disease Prevention and Health Promotion. Retrieved September 23, 2004 (http://www.cdc.gov/nccdphp/overview.htm).

Degenholtz, H., Y. J. Rhee, and R. Arnold. 2004. "Brief Communication: The Relationship between Having a Living Will and Dying in Place." *Annals of Internal Medicine* 141:113–117.

General Accounting Office. 2000, September. *More Beneficiaries Use Hospice, yet Many Factors Contribute to Shorter Stays*. GAO/HEHS-00–182. Washington, DC: U.S. General Accounting Office.

Hardin, S. and Y. Yusufaly. 2004. "Difficult End-of-Life Treatment Decisions: Do Other Factors Trump Advance Directives?" *Archives of Internal Medicine* 164:1531–1533.

Haupt, B. J. 2003. "Characteristics of Hospice Care Discharges and Their Length of Service: United States, 2000." National Center for Health Statistics. *Vital Health Statistics* 13(154).

Lo, B. and R. Steinbrook. 2004. "Resuscitating Advance Directives." *Archives of Internal Medicine 1*64(14): 1501–1506.

Lynn, J. 2001. "Serving Patients Who May Die Soon and Their Families: The Role of Hospice and Other Services." *Journal of the American Medical Association* 285(7): 925–932.

Social Security Act, Sections 1102, 1812 (a)(4) and (d);1813 (a) (4); 1814 (a)(7) and (I); 1862 (a)(i),(6), and (9); 1861 (dd), 1871.

The SUPPORT Principal Investigators. 1995. "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)." *Journal of the American Medical Association* 274(20): 1591–1598.

Websites

National Hospice and Palliative Care Organization, "NHPCO's Facts and Figures on Hospice and Palliative Care," http://www.nhpco.org/files/public/Facts%20Figures%20Feb04.pdf

ENNS, HENRY (1943–2003)

Canadian (Ukrainian-born) activist

Henry Enns was a prominent leader in the disability rights and independent living movement in Canada, whose activities became international in scope through work with the United Nations and his leadership of the Disabled Peoples' International organization. Enns was born in Ukraine and lived in Germany and Paraguay as a child, before settling in Manitoba, Canada, with his family. At the age of 15, Enns contracted rheumatoid arthritis, and gradually became increasingly interested in the issues facing people with physical disabilities. Throughout his adult life, Enns made notable contributions to the initiation and development of numerous disability rights organizations. In the early 1980s, Enns was a leader in the establishment and direction of some of the earliest independent living centers in both Ontario and Manitoba. From his base in Winnipeg, Enns became increasingly active in the 1980s and 1990s in the international disability rights movement. From 1990 to 1996, he served as executive director of Disabled Peoples' International. At the time of his death, Enns was the executive director of the Canadian Centre on Disability Studies (1996–2002). He was the first non-U.S. citizen to receive the U.S. Presidential Service Award in 1992.

—Zana Lutfiyya

See also Canadian Centre on Disability Studies; Disabled Peoples' International.

Further Readings

Enns, Henry and Aldred H. Neufeld, eds. 2003. *In Pursuit of Equal Participation: Canada and Disability at Home and Abroad*. North York, ON: Captu.

Websites

Canadian Centre on Disability Studies, http://www.disabilitystudies.ca

ENVIRONMENTAL CONTROL

Environmental control is a branch of assistive technology that includes the use of adaptive devices to manipulate objects and of electronic devices that enable an individual with a disability to control other electronic devices in a home, school, or work setting.

Devices that may be used to manipulate objects can range from low-tech reachers to high-tech robots. The low-tech devices are often available through mail-order catalogs or through durable medical equipment vendors. The low-tech environmental control equipment can take the form of individual devices that assist with the performing of a specific task. For instance, a wire-frame buttoner can assist with dressing.

For some activities, environmental control equipment can include a range of devices. For meal preparation and eating, environmental control devices can include adapted cutting boards, pot-handle holders, plates with built-up edges, and powered eating aids. For reading, devices can include angled bookholders and powered page-turners. The level of technology appropriate for an individual with a disability is dependent on the person's abilities, goals, support systems, and environment, among other factors.

Environmental control units (ECUs), sometimes referred to as electronic aids to daily living, are devices that enable the user to control devices such as lights, fans, radios, televisions, and powered door openers. The ECU may require direct selection of the controls or offer a scanning feature that lets the user control the device with one or two switches.

ECUs communicate with the devices being controlled through one of four methods: house wiring, ultrasonic signals, infrared signals, or radio frequency signals. House wiring may be used to transmit signals to the electrical outlets in the environment. Devices being controlled must be plugged into a module that receives the ECU's signals and converts this information to control power to the device.

An ECU may use ultrasonic signals to communicate with the devices being controlled. Again, devices

need to be plugged into a module that receives the signals and uses them to determine if power is to be provided or not. Ultrasonic systems are useful when the ECU and devices being controlled are in the same room, as the signals do not go through walls.

An ECU's transmitter may use infrared signals, again going to receiver modules that use the signals to determine whether power is provided to the device, or to determine the level of some settings (e.g., volume). Systems using infrared signals need to be located in the same room, as the signals will not go through walls, and some difficulty may be encountered if the system is used in direct sunlight.

ECUs that use radio frequency (RF) signals have the advantage of controlling devices throughout a home or work environment, as the signals go through walls. The system may need to be set to avoid interference from other RF devices, or by inadvertent control from another ECU.

—Glenn Hedman

See also Aids for Activities of Daily Living; Assistive Technology.

Further Readings

Cook, A. M. and S. M. Hussey. 2002. Pp. 374-408 in *Technologies That Aid Manipulation and Control of the Environment. Assistive Technologies: Principles and Practice*, 2d ed. St. Louis, MO: C. V. Mosby.

EPIDEMIOLOGY

The term *epidemiology* is derived from the Greek roots *epi* meaning on or upon, *demos* meaning the common people, and *logy* meaning the study of. Epidemiology is defined as the study of disease in human populations, their causes, and means of prevention. The term *disease* in the definition refers to a broad array of health and medical problems including disability, injury, and death.

Epidemiology differs from clinical medicine in a number of ways. It studies groups of people, not just individuals. Epidemiology also studies both well people and people with disease to identify the crucial differences between those who are stricken and those who are spared. These differences are compared to identify the underlying causes or etiologies of disease. While the goal of clinical medicine is to diminish pain, restore function, and bring the patient back to full health, the main goal of epidemiology is to understand the causes of disease in order to prevent them from occurring.

Epidemiology addresses many areas of public health. For example, it studies the natural history and prognosis of disease. It is used to measure the extent and burden of disease within communities, states, and nations. Epidemiology is also frequently used to evaluate therapeutic and preventive health measures, such as determining the effectiveness and safety of health screening programs, new drugs, and vaccines. Public policy makers, government agencies, health insurance companies, hospitals, physicians, and others increasingly rely on epidemiology as the foundation for making sound decisions to protect the public's health.

The field of epidemiology is highly interdisciplinary. It relies heavily on the concepts, knowledge, and theories of such disciplines as biology, pathology, and physiology in the health and biomedical sciences, as well as the disciplines of anthropology, psychology, and sociology in the behavioral and social sciences. Epidemiology is also very closely tied to the discipline of statistics, particularly biostatistics.

HISTORICAL DEVELOPMENT

Epidemiology is a relatively new science that emerged in the nineteenth century. However, its historical development spans thousands of years and is best described as slow and unsteady. Over the centuries, many individuals have contributed to the establishment of the modern field of epidemiology.

The first important individual was the Greek physician Hippocrates (428–347 BCE), who is traditionally regarded as the father of Western clinical medicine. Hippocrates wrote the first epidemiologic texts *Epidemic I*, *Epidemic III*, and *On Airs, Waters, and Places*. In these works, he was the first person to attempt to explain the occurrence of disease on a rational rather than a supernatural basis. Since Hippocrates recognized disease as a mass phenomenon as well as one affecting individuals, he is recognized as the first epidemiologist.

Another figure of importance was the English statistician John Graunt (1620–1674). Graunt was the

first person to analyze the *Bills of Mortality*, which recorded the weekly count of births and deaths in London. In 1662, Graunt published the results of his findings in *Natural and Political Observations Made upon the Bills of Mortality*. He found that male births consistently outnumbered female births, yet males no longer outnumbered females by the time they reached their childbearing ages because males experienced higher mortality rates. Graunt also constructed the first life table, a statistical table that uses death rates of a cohort of persons to determine the group's average life expectancy.

James Lind (1716–1794), a Scottish naval surgeon, also helped establish epidemiology. Lind studied the great sea plague scurvy. On long naval voyages, scurvy often killed two-thirds of a ship's crew. To prevent scurvy, Lind conducted the first planned controlled clinical trial, supplementing the diet of a small number of sailors with fresh citrus fruit and lemon juice (the experimental group). He then compared the incidence of scurvy among these men to that of other sailors on the same ship who ate the normal vitamin-poor naval diet (the control group). Finding that citrus fruit prevented the disease, Lind recommended dietary changes for all sailors, which ultimately resulted in the eradication of scurvy from the British navy. Hence, British sailors are still referred to as "limeys."

Edward Jenner (1749–1823), a British surgeon who practiced medicine in the small village of Berkeley in Gloucestershire, England, observed that milkmaids who developed cowpox (a mild disease) never contracted the severe and often disfiguring and deadly disease smallpox. Using matter drawn from the lesions of cowpox on the hand of a milkmaid, Jenner performed the first vaccination. In time, the practice of vaccinating for the prevention of smallpox became widespread. Today, smallpox is the only disease to ever be totally eradicated from nature. And vaccination is a widely used method to prevent the occurrence of many diseases.

William Farr (1807–1883), a British physician who worked as the first compiler of scientific abstracts at the Registrar General's Office in London, helped shape England's vital statistics system. His most important contribution to epidemiology was the establishment of a sophisticated system for classifying the causes of death. This enabled the comparison, for the first time, of mortality rates among different demographic and occupational groups. Farr's classification system still forms the basis of the International Classification of Disease and Related Health Problems (ICD) that is in use today.

Another great pioneer in the field of epidemiology was John Snow (1813–1858). Snow, a contemporary of William Farr, was a well-respected London physician who specialized in obstetric anesthesiology. One of his patients was Queen Victoria, whom he assisted in the delivery of two of her children. Snow became interested in the cause and spread of cholera epidemics that periodically occurred in London. In 1854, when a severe cholera epidemic once again struck the city, Snow undertook an investigation. At the time, most physicians attributed the disease to miasma or "bad air" formed from decaying organic matter. Snow, however, held the radical view at the time that cholera was caused by drinking fecal-contaminated water. Snow started his investigation by plotting the geographic location of all cholera deaths in London. When he found a large number of deaths (more than 500 in a 10-day period) clustered around a public water hand-pump on Broad Street in the Soho District of west London, he informed the local authorities, along with his hunch as to the cause. Although the authorities were skeptical, the next day they had the pump disabled by removing its handle. Immediately, new cases of cholera started to dwindle, and then disappear. However, because cholera deaths were already declining in the city, Snow was unable to attribute the end of the outbreak directly to the removal of the pump handle.

Snow doggedly continued his investigation of cholera and conducted what he called his "Great Experiment." To conduct the "experiment," Snow painstakingly documented the cholera deaths (nearly 1,400) among the subscribers of London's two independent private water companies. The Southwark and Vauxhall Company (which supplied more than 40,000 homes) drew its water from the sewage-polluted lower Thames River, while the Lambeth Company (which supplied more than 25,000 homes) obtained its water farther upriver. Snow conclusively showed that the number and rate of cholera deaths were much higher

for residents in homes served by the Southwark and Vauxhall Company, which supplied the polluted water. Using meticulously gathered data and the power of statistics, Snow brought about the beginning of the end of cholera in Britain. Because of his study methods and insight, Dr. John Snow is generally regarded as the father of modern epidemiology.

BASIC CONCEPTS AND TOOLS

Epidemiology has two fundamental assumptions. First, disease does not occur at random. Second, disease has causal and preventive factors.

Epidemiologists often use models to explain the occurrence of disease. One commonly used model views disease in terms of susceptibility and exposure factors. Specifically, for individuals to develop a disease they must be both susceptible to the disease and be exposed to it. For example, for a person to develop measles (rubeola), a highly infectious viral disease that was once very common among children, they must be both exposed to a person who is shedding the measles virus (an active case), and they must also be susceptible to measles by lacking immunity to it. Immunity to measles may be derived from either previously having the disease or from being vaccinated against it.

Another commonly used model, the epidemiologic triad, views the occurrence of disease as the balance among host, agent, and environment factors. The host is the actual or potential recipient or victim of the disease. Hosts have characteristics that either predispose them to, or protect them from, disease. These characteristics may be biological (e.g., age, sex, and degree of immunity), behavioral (e.g., habits, culture, and lifestyle), or social (e.g., attitudes, norms, and values). The agent is a factor whose presence or absence is necessary for a particular disease to occur. Agents may be biological (e.g., bacteria, fungi, and viruses), chemical (e.g., gases and toxic agents), nutritional (e.g., carbohydrates, fats, and food additives), or physical (e.g., electricity and ionizing radiation). The environment includes all external factors, other than the host and agent, that influence health. The environment may be categorized as the social environment (e.g., economic, legal, and political), the physical environment (e.g., precipitation, temperature, and weather conditions), or the biological environment (animals and plants). To illustrate the epidemiologic triad, consider a case of lung cancer. The host is the person who developed lung cancer. He or she may have had the habit of smoking for many years. The agent is the smoke, tars, and toxic chemicals contained in the tobacco. Environment may have been the workplace where smoking on the job was permitted, and cigarettes or other tobacco products were readily available.

Epidemiologists classify the type of disease cases and frequency of disease occurrence within a population as being either endemic or epidemic. Endemic is defined as the usual occurrence of a disease within a population. In contrast, an epidemic is a sudden and great increase in the occurrence of a disease within a population. It may also be the first occurrence of an entirely new disease. A special type of epidemic is the pandemic, which is a rapidly emerging outbreak of a disease that affects a wide range of geographically distributed populations. Many pandemics are worldwide in scope. To illustrate the three, a small number of people may have the flu (influenza) in a large city throughout the year and these would be endemic cases of the disease. In contrast, the number of people having the flu in the same city may increase enormously in the fall and these would be epidemic cases. Last, if a new variety of flu emerges and people throughout the world get sick from it they would be pandemic cases. An example of a pandemic is the great influenza epidemic of 1918, which spread throughout the world killing an estimated 20–40 million people.

Epidemiologists study the morbidity and mortality caused by acute and chronic diseases. Morbidity is defined as the state of illness, symptoms, or impairments produced by a disease, while mortality is death caused by a particular disease. Acute diseases are those that strike and disappear quickly, within a month or so (e.g., chicken pox, colds, and the flu), while chronic diseases are those that are long term or lifelong diseases, many of which are incurable (e.g., cancer, diabetes, and HIV/AIDS).

One of the most important tools of epidemiology is the use of morbidity and mortality rates. Epidemiologists use rates so that disease cases and deaths can be compared to the unit size of population. A rate is a special type of proportion that includes a specification

of time, and the numerator of the proportion is included in the denominator. Rates can be expressed in any form that is convenient (e.g., per 100, per 1,000, per 10,000, and per 100,000). Infant mortality rates, for example, are typically expressed per 1,000 live births, while cancer rates are expressed per 100,000 population.

The following example illustrates the important role rates play in making epidemiological comparisons. Assume City A has 10 cases of a disease while City B has 50 cases. Although in terms of absolute numbers City B has five times more cases of the disease than City A, the differences may be due to the underlying population size of the two cities. To compare the occurrence of disease in the cities on a unit population basis, rates must be calculated. If City A has a population of 10,000, and City B has a population of 50,000, the disease rates per 1,000 people would be the same for both cities. City A's disease rate is (10/10,000) × 1,000 = 1.0 case per 1,000 population, and City B's disease rate is (50/50,000) × 1,000 = 1.0 case per 1,000 population.

Rates may be crude, specific, or adjusted. Crude rates use the total number of disease cases and the entire population in their calculations. For example, the above rates for City A and City B are crude disease rates. Specific rates differentiate cases and populations into age, sex, race, or other subgroups. For example, if the rates for City A and City B were for disease cases who were 25–34 years of age/the population in each city who were 25–34 years of age, the rates would be age-specific disease rates. Specific rates can be very detailed; age-sex-race-specific disease rates can be calculated (e.g., the number of disease cases who are African American males ages 25–34 years old/the population who are African American males ages 25–34 years old). Adjusted or standardized rates allow for comparison of populations with different characteristics. To calculate adjusted rates statistically constructed summary rates are used to remove age, sex, or race differences in populations. For example, in the United States the population of Florida (a state where many people go to retire) is much older than the population in Alaska, so it would be inappropriate to compare the mortality rates of the two states without adjusting for the differences in their age structures.

Epidemiologists use two types of rates to measure the occurrence of disease: incidence rates and prevalence rates. The incidence rate measures the rapidity at which new cases of a disease are occurring in a population over a period of time. The incidence rate is an important measure for evaluating disease control programs (if any) and has implications for the future problems of medical care. Specifically, the incidence rate is defined as the number of newly reported disease cases in a defined period/the population at the midperiod × 100, 1,000, 10,000, or 100,000. Epidemiologists in health departments, for example, study the incidence rates of HIV/AIDS to see if the disease is spreading and whether AIDS prevention programs are working.

The prevalence rate measures the total number of existing cases of a disease in a population at a given point of time (or sometimes a period of time, or even over a lifetime). The prevalence rate is a useful indicator of the burden of a disease on the medical and social systems of a geographic region. It is useful only for diseases of long duration (months or years). Specifically, the point prevalence rate is defined as the number of known cases of a disease at a given point in time/population at that time × 100, 1,000, 10,000, or 100,000. Epidemiologists at the World Health Organization (WHO), for example, use prevalence rates to determine the medical, economic, and social burden of AIDS in developing countries.

There is a relationship between incidence and prevalence rates. Prevalence rates vary directly with both the incidence and duration of disease. If the incidence of a disease is low, but the duration of the disease is long, such as with chronic diseases, the prevalence will be large in relation to the incidence. Conversely, if the prevalence of a disease is low because of short duration (due to recovery, migration, or death), prevalence will be small in relation to incidence.

SOURCES OF EPIDEMIOLOGICAL DATA

Epidemiologists use primary and secondary data sources to calculate rates and conduct studies. Primary data is the original data collected for a specific purpose by or for an investigator. For example, an epidemiologist may collect primary data by interviewing people who became ill after eating at a restaurant to identify

which specific foods they ate. Collecting primary data is expensive and time consuming, and it usually is undertaken only when secondary data are not available. Secondary data are data collected for another purpose by other individuals or organizations. Examples of secondary data commonly used by epidemiologist include birth and death certificates, population census records, hospital and clinic patient medical records, data from disease registries, insurance claim forms and billing records, public health department case reports, and surveys of individuals and households.

An important source of secondary data is the Centers for Disease Control and Prevention (CDC). The CDC, which is an agency of the U.S. Department of Health and Human Services, consists of 12 centers, institutes, and offices. The various centers collect a wide array of epidemiological data on such areas as birth defects and developmental disabilities, chronic diseases, infectious diseases, injuries, occupational safety and health, and sexually transmitted diseases. Within the CDC, the National Center for Health Statistics (NCHS) conducts, publishes, and widely disseminates the results of numerous health surveys of individuals and health care organizations. Examples of NCHS surveys include the National Health Interview Survey, the National Health and Nutrition Examination Survey, the National Hospital Discharge Survey, and the National Nursing Home Survey.

DESCRIPTIVE AND ANALYTICAL EPIDEMIOLOGY

The field of epidemiology can be divided into two broad categories: descriptive epidemiology and analytical epidemiology. Descriptive epidemiology characterizes the distribution of disease within a population. It describes the person, place, and time characteristics of disease occurrence. It specifically asks the questions: Who is getting the disease? Where is the disease occurring? When is the disease occurring?

A typical example of descriptive epidemiology is an investigation of a food-borne epidemic at a local restaurant. To determine the cause of the outbreak, epidemiologists would investigate how many customers of the restaurant and what proportion or rate of all customers got sick (i.e., determine an attack rate). They would determine the demographic characteristics of those who got sick (i.e., age, sex, and race). They would also determine when the customers were at the restaurant (i.e., time of day, day of the week), and what specific foods they ate (i.e., items on the breakfast, lunch, or dinner menu). The epidemiologists would also work closely with a public health laboratory to test the existing foodstuffs to determine, if possible, what particular pathogen caused the disease. After determining the cause of the outbreak, the epidemiologists would make recommendations and/or mandate changes (i.e., requiring colder refrigeration, more hand washing by employees, or perhaps using higher cooking temperatures for foods) to the restaurant's management to prevent other outbreaks from occurring in the future.

Analytical epidemiology, on the other hand, tests hypotheses to determine if statistical associations exist between suspected causal factors and disease occurrence. It also tests the effectiveness and safety of therapeutic and medical interventions. To accomplish these tasks, analytical epidemiology uses four major types of research study designs: cross-sectional studies, case-control studies, cohort studies, and controlled clinical trials. Each of these types of studies has strengths and weaknesses.

Cross-sectional studies examine the relationship between disease and other variables of interest as they exist in defined populations at one particular time. For example, a cross-sectional study investigating whether residential exposure to the radioactive gas radon increases the risk of lung cancer may examine the level of radon gas in lung cancer patients' homes. Cross-sectional studies have the advantage of being inexpensive and simple to conduct. However, their main disadvantage is that they only establish associations at most, not causality.

Case-control studies start with people with a particular disease (cases) and a suitable control group without the disease and then compares the exposure of the cases and controls to the factor that is believed to have caused the disease. These types of studies are most useful for ascertaining the cause of rare events, such as rare cancers. For example, to determine whether the use of cellular telephones causes head cancers a group of head cancer patients (cases) would be compared to

a group of individuals without head cancers (controls). The two groups would then be compared with respect to the proportion that used cellular telephones and their level of exposure (i.e., how many minutes they talked over the telephone per day). Case-control studies have the advantages of being quick to conduct and inexpensive, and they require only a small number of cases and controls. However, their main disadvantage is that they rely on recall, which may be biased, or records to determine exposure status.

Cohort studies are observational studies in which a defined group of people (the cohort) is followed over time and outcomes are compared for individuals who were exposed or not exposed to a factor at different levels. Cohorts can be assembled in the present and followed into the future (a concurrent cohort study) or identified from past records (a historical cohort study). An example of a cohort study is the Framingham Heart Disease Epidemiology Study. The Framingham study is the longest ongoing epidemiological study in the United States. Starting in 1948 with an original cohort of 5,200 adult volunteers from Framingham, Massachusetts, the study has followed the volunteers and their offspring to identify the risk factors associated with developing heart disease (e.g., cholesterol levels, smoking, obesity, and diabetes). To date, the results from this landmark cohort study have been published in more than 1,000 scientific papers. The main advantage of cohort studies is they can establish the timing and directionality of events. However, their main disadvantages are that they require large sample sizes and a long follow-up time, and they are not suitable for investigating rare diseases.

Controlled clinical trials are studies that test therapeutic drugs or other health or medical interventions to assess their effectiveness and safety. Controlled clinical trials compare the outcomes of new drugs or interventions given to an experimental group compared to another group (control) that does not receive the same drugs or interventions. To minimize bias, individuals involved in clinical trials may be randomly assigned to the experimental and control groups. For example, to determine whether a new drug to treat breast cancer is more effective than another drug, breast cancer patients would be assigned randomly into either an experimental group that would receive the new drug, or the control group that would receive the other drug. The outcomes of the two groups (e.g., number of remissions, and increase in survival time) would then be compared. In the United States, and many other countries, all new therapeutic drugs are subject to rigorous controlled clinical trials before they can be provided to the public. The main advantage of controlled clinical trials is they provide unbiased results. However, their main disadvantage is that they are very expensive to conduct.

SUMMARY AND CONCLUSION

During the past several decades, the field of epidemiology has greatly expanded in size, scope, and influence. The number of epidemiologists has grown rapidly along with epidemiology programs in schools of public health and medicine. Today, epidemiologists investigate the outbreaks of acute diseases such as food-borne epidemics. They also investigate the outbreaks of new emerging diseases such as SARS, and reemerging older diseases such as tuberculosis. At the same time, epidemiologists study the underlying causes of many chronic diseases such as cancer, heart disease, and stroke. They also study the causes of psychiatric disorders, substance abuse, and social problems such as violence. Since the recent terrorist attacks in the United States, Europe, and Japan, many epidemiologists are involved in planning and implementing health surveillance programs to detect and prevent possible bioterrorism attacks. Epidemiologists are also just beginning to examine the determinants of health at the molecular and genetic levels. They are studying how individual genes influence the risk of developing chronic conditions such as Alzheimer's disease. And epidemiologists are beginning to develop new molecular markers to improve the measurement of individually specific exposure and susceptibility factors.

—Ross M. Mullner

See also Acute and Chronic Conditions; Disability Surveys; Disease.

Further Readings

Bhopal, Raj. 2002. *Concepts of Epidemiology: An Integrated Introduction to the Ideas, Theories, Principles and Methods of Epidemiology*. New York: Oxford University Press.

Fletcher, Robert, Suzanne W. Fletcher, and Edward H. Wagner. 1996. *Clinical Epidemiology: The Essentials. Philadelphia*: Lippincott Williams & Wilkins.

Friis, Robert H. and Thomas A. Sellers. 1999. *Epidemiology for Public Health Practice*, 2d ed. Gaithersburg, MD: Aspen.

Gerstman, B. Burt. 2003. *Epidemiology Kept Simple: An Introduction to Traditional and Modern Epidemiology*, 2d ed. New York: Wiley-Liss.

Gordis, Leon. 2004. *Epidemiology*, 3d ed. Philadelphia: Elsevier Saunders.

Greenberg, Raymond S., Stephen R. Daniels, W. Dana Flanders, et al. 2001. *Medical Epidemiology*. New York: Lang Medical Books/McGraw-Hill.

Koepsell, Thomas D. and Noel S. Weiss. 2003. *Epidemiologic Methods: Studying the Occurrence of Illness*. New York: Oxford University Press.

Last, John M., ed. 2000. *A Dictionary of Epidemiology*, 4th ed. New York: Oxford University Press.

Rothman, Kenneth J. 2002. *Epidemiology: An Introduction*. New York: Oxford University Press.

Szklo, Moyses and F. Javier Nieto. 2000. *Epidemiology: Beyond the Basics*. Gaithersburg, MD: Aspen.

Valanis, Barbara. 1999. *Epidemiology in Health Care*, 3d ed. Stamford, CT: Appleton and Lange.

Websites

American College of Epidemiology, http://www.acepidemiology.org/

Centers for Disease Control and Prevention (CDC), http://www.cdc.gov

Epidemiology.net, http://www.epidemiology.net

Epidemiology Virtual Library, http://www.epibiostat.ucsf.edu/epidem/epidem.html

International Epidemiological Association, http://www.dundee.ac.uk/iea/

Society for Epidemiologic Research, http://www.jhsph.edu/Publications/JEPI/ser.html

EPILEPSIES, TEMPORAL LOBE

Epilepsy arising in some discrete location in the cerebral cortices is termed partial, or localization-related, epilepsy and named for the region of cortex from which it comes. It is further classified according to whether it does or does not, *at the onset of a seizure,* give rise to convulsive phenomena—involuntary movements that are rhythmical or sustained. Temporal lobe epilepsies (TLEs) are the most frequently encountered nonconvulsive localization-related epilepsies, although the typical staring with loss of touch from surroundings may at times "secondarily generalize" and become convulsive. The classical temporal lobe seizure consists of nearly motionless staring ("deambulation") and loss of touch with surroundings without generalization of the seizure ("complex" partial).

They are often preceded by an even more focal phenomenon termed an *aura* by Galen, who recognized some aspects of this type of seizure more than 1,800 years ago. Auras include difficult-to-describe internal sensations of which a person is aware and remembers: an epigastric "rising" sensation, unpleasant aroma or taste, auditory or visual hallucinations, strong memories, "forced thinking," and psychic symptoms. The temporal lobe is an important link in systems for olfaction, memory, emotion, feeding, fear, aggression, and sexual matters. "Psychic" auras include strange "dreamy states," fear, déjà-vu and other strong seeming recollections, fear and other alterations of emotion (ranging from despair to exhilaration), time, and space. These prominent phenomena account for the application of "psychomotor" to these seizures. Over time, TLE may be associated with deterioration of memory, alteration of personality, psychiatric symptoms (e.g., depression, anxiety, obsessive diary keeping, hyper-religiosity, self-loathing), and behavior problems. It is of interest to consider that Dostoyevsky's TLE may account in part for the traits he assigned to characters in his novels.

The ensuing *complex* loss of interaction for which the person is *amnestic* represents a spread of seizure activity from the initial focus. This phase may be accompanied by perseverative *automatisms.* These are relatively subtle patterned motor activities carried out without any clear purpose such as lip-smacking, spitting, silly laughter, quizzical facial expressions with seeming attempts to speak, page-turning, posturing of limbs, rubbing some part of the body, or picking at the air or clothing with fingers. The typical duration is in minutes, although a temporal nonconvulsive seizure may go on for many hours. Once it is longer than 5–10 minutes, it is termed psychomotor (or partial complex) status epilepticus. The spell may then terminate with somewhat confused resumption of activities, sometimes with transient loss of speech. TLE may "secondarily generalize," especially in children or untreated adults, giving rise to a generalized convulsive seizure, followed by prolonged sleep.

Galen's prescient recognition that odd and complex behaviors could be epileptic was not pursued to any great extent until the nineteenth century. In France, Calmeil (1824) revived the clinical description and Bouchet and Cazauvieilh (1825) identified some features of the most common pathology of TLE observing with partial correctness that the change was the result rather than the causes of epilepsy. Tissot's (1865) enlargement and classification of auras provided a foundation for Englishman Hughlings Jackson to provide a conceptual framework for epilepsies on the basis of recurrent clusters of phenomena that could derive from particular parts or all of the brain, assigning psychomotor seizures ("uncinate fits") to the temporal lobes and explaining the evolution from aura through dreamy state to generalized convulsion to spread of the epileptic discharge.

This concept proved very important in the neuroscientific view of brain function and provided the foundation for syndromic classification of the epilepsies, which would in time bear importantly on diagnosis, treatment, and prognostication. The focal electroencephalogram (EEG) changes of temporal lobe epilepsy were not detected until the 1930s, based on the pioneering work of Berger of Germany. Additional sophisticated subsequent clinical and pathological investigations have described a family of discrete subtypes of TLE, their natural histories, and treatment. There are now more than 10 valuable drugs employed in the treatment of TLE, only 3 of which were in use before the 1970s. Despite new drugs, TLE has remained a difficult type of epilepsy to manage.

Mesial temporal lobe epilepsy (MTLE) has proven to be one of the most common human epileptic syndromes. It is a highly drug resistant form of epilepsy that arises in the evolutionarily ancient anterior inner portions of the temporal lobe, the amygdala and hippocampus—the region whose pathology Cazauvieilh misinterpreted in 1825. Ounsted in the 1960s set in motion intense study of the biology of this condition. Techniques for the study of slices taken from this brain region were developed, along with increasingly sophisticated physiological studies that have defined MTLE as a focal degenerative condition. Despite various hypotheses about the origins of MTLE, it is not yet known why these regions of the brain are vulnerable. Although we know that the worsening of this form of epilepsy is typically due to seizure-related degenerative epileptic "remodeling," we do not know how the remodeling brings about this effect. The poor response of so many cases to drugs has provided the most important fostering influence on epilepsy surgery, the origins of which date back to work in Germany (Förster) and Canada (Penfield and Jasper) more than 60 years ago. Falconer greatly advanced and popularized temporal lobectomy in the 1960s. At least 80 percent of appropriately managed MTLE patients become seizure free with little or no surgical morbidity and arrest of the epilepsy-associated degeneration of memory and psychosocial disturbances.

EEG video monitoring, computed tomography (CT), magnetic resonance imaging (MRI), and single-photon-emission-computed tomography (SPECT) imaging, psychometric testing, and other techniques have greatly refined disease definitions and surgical planning. Non-MTLE temporal lobe epilepsies have also been identified including (1) "lesional" TLE (e.g., due to tumors, dysplasia, scars, vascular malformations) and (2) comparatively rare "neocortical" TLE arising on the lateral surface of the temporal lobe and marked clinically in some instances by speech arrest, eye movements, and focal twitching that help to set it apart from MTLE or lesional TLE. "Dual pathology" epilepsies occur sharing features of these three TLEs. Benign transient childhood epilepsy arising in the temporocentral region has also been described. Presurgical studies, surgical pathology, and outcomes have permitted localization to be fairly reliably ascertained on the basis of clinical features, since particular manifestations may arise from particular locations and propagate along set "preferential pathways."

Experimental studies of TLEs have provided information and techniques that have greatly enriched understanding not only of the pathophysiology of epilepsy, headache, movement disorders, and other neurological and psychiatric diseases but also of the brain's normal development and physiology. A complex and elegant system of neurotransmitters, receptors, membranes with electrical charge, and chemical pores provides explanations of how the "thinking" neurons work and how they interact with other cells within the nervous system and outside of it and importantly

for treatment, how and where things go wrong and how they might be fixed.

—Robert S. Rust Jr.

See also Epilepsy; Neurological Impairments and Nervous Disorders.

Further Readings

Gloor, P. 1991. "Mesial Temporal Sclerosis: Historical Background and an Overview from Modern Perspective." Pp. 689–703 in *Epilepsy Surgery,* edited by H. Lüders. New York: Raven.

Jackson, J. Hughlings. 1899. "Epileptic Attacks with Warning of Crude Sensation of Smell and with Intellectual Aura (Dreamy State) in a Patient Who Had Symptoms Pointing to Gross Organic Disease of the Right Temporo-Sphenoidal Lobe." *Brain* 22:334–549.

Weiser, H. G. 2000. "Temporal Lobe Epilepsies." Pp. 53–96 in *The Epilepsies, Part 2,* edited by H. Meinardi. *Handbook of Clinical Neurology,* Vol. 73. Amsterdam: Elsevier.

EPILEPSY

Epilepsy is the tendency to experience recurrent bouts of disturbed consciousness, sensation, or uncontrolled motor activities termed *convulsions*. It is the third most common primary, after migraine and depression, neurological condition. At least 1 in 25 people experience a seizure during their lifetime, while slightly less than 1 in 50 develop epilepsy (at least two seizures not explained by some controllable extrinsic influence). Since the beginning of time, it is likely that those with seizures and those witnessing them have struggled to deal with these strange and dramatic events that entail unpredictable loss of control, sometimes including bowel and bladder control, events that can engender shame and an anxious sense of vulnerability. Unmistakable descriptions of epileptic seizures in the ancient texts of China, India, and Babylonia ascribe them to "possession" by spirits—sometimes benevolent, other times demonic.

The ancient Graeco-Anatolian Hippocratic writings (ca. 400 BCE) coined the word *epilepsy* (επιλαμανειν or *epilamanein*) for a convulsive condition viewed as a disease rather than a possession or punishment—a potentially treatable disturbance of the equilibrium of the living organism. The view was not entirely enlightened. Seizures were associated with physical and mental imperfections with which Greek ideals were uncomfortable. In the second century CE, Galen recognized that there were disturbances of consciousness or behavior—nonconvulsive seizures—and that the onset of these or of convulsive seizures might be foretold by a strange sensation he termed *aura*.

Little further progress was made for 1,700 years, and indeed the stigmatizing view that seizures and associated physical or mental imperfections were somehow related to the concept of possession continued to be widely accepted until very recent times. In Christian doctrine arose the not uncontested view that the affliction of children with epilepsy and associated disabilities was judgment on the sins of parents, perhaps for having conceived a child on Sunday. It was recognized from ancient times, however, that epileptic swoons had afflicted such great men as Julius Caesar and possibly Alexander. Yet even here there remained uncertainty as to the boundary between madness and epilepsy, as well as a number of other neurological conditions. This, together with the absence of effective treatments, undoubtedly increased the degree to which epilepsy was feared and reviled. As of the end of the eighteenth century, better definitions began to be formulated and descriptions of transient and usually benign convulsions such as "teething fits" (probably febrile seizures) began to be described.

In the nineteenth century, French, English, and German neurologists and neuropathologists gradually compiled further descriptions of epileptic events. Based on this information and his own observations, the great English neurologist Hughlings Jackson formulated the concept that discrete brain lesions could give rise to particular epileptic manifestations; these, in turn, could predict the location of brain lesion. He also noted that the epileptic event could spread to contiguous areas. Jackson's colleague William Gowers explored the borderlands of epilepsy, enlarging the concept and defining some of its probable boundaries. Seizures and epilepsy came to be understood in the intellectual context that the nervous system was an organized collection of functional centers and interconnecting "wires" with, in part, an electrical function. The study of these relationships in individuals with epilepsy—ongoing to the present day—has made

an enormous contribution to the study of the organization and function of the nervous system and to the diagnosis and management of epilepsy. Various treatments were developed, some very toxic, among which only bromides are now viewed as effective anticonvulsants. The agent had been chosen, however, in the effort to reduce prevalence of masturbation (viewed then and for the ensuing half century as a cause of epilepsy) in institutionalized patients. It improved epilepsy rather than the supposed etiology.

The twentieth century provided increasingly detailed clinical descriptions of epilepsies, their predisposing factors, and varied outcomes. Electroencephalography was added in the 1930s. Additional effective therapies were applied including treatments that remain valuable: phenobarbital (1909), the ketogenic diet (1924), and phenytoin (1937). A number of additional minor and some rather toxic anticonvulsants appeared in the next few decades. From the early twentieth century to the interwar period, patients with epilepsy faced a new challenge. Eugenicists hoping to improve the "gene pool" advocated and courts approved involuntary sterilization of some individuals with epilepsy, since the old and often incorrect notion that many were "feebleminded" persisted. More enlightened individuals opened epilepsy clinics devoted to the study and outpatient management of epileptic individuals, many of whom had found themselves in epilepsy "colonies."

Förster of Germany and Penfield and Jasper of Canada participated in the establishment of effective surgical techniques for management and even cure of epilepsy. In the 1960s, Dreifuss and others demonstrated the importance of long-term video/EEG monitoring of patients with epilepsy, data that they employed to systematically classify epilepsies into better refined syndromes as well as to explore related subjects such as conditions that look like epilepsy but are not (e.g., seizures, movement disorders) and the important topic of whether epilepsy is associated with violence. Additional "minor" medications, some of which carried serious potential side effects, were developed; since phenytoin, the past 30 years have been particularly fruitful, providing 10 new important and effective antiseizure medications. But surgery remains important, since some common categories of intractable epilepsies, such as temporal lobe epilepsy, are particularly suitable candidates for potential surgical cure.

By the 1970s, studies demonstrated that well-controlled seizures in children were often outgrown and that medications could be discontinued after several years of treatment. Long-term outcome studies defined with increasing precision these and other epileptic syndromes, some of which were inherited transient vulnerabilities, presenting at a particular age range and then resolving.

The development of imaging techniques, such as computed tomography (CT), magnetic resonance imaging (MRI), single-photon-emission-computed tomography (SPECT), and positron-emission tomography (PET) scanning, during the past 30 years elucidated structural causes of epilepsies, some requiring surgical management to be discerned. The development of many additional diagnostic interventions permitted other underlying conditions associated with epilepsy to be diagnosed and in many instances treated, thereby decreasing or eliminating the epilepsy that occurred secondarily.

Because of the development of experimental neurophysiology, particularly utilization of brain slices and sophisticated neurochemical and neurophysiological techniques, understanding of the pathophysiology of epilepsy has greatly advanced. A great deal is now known about the manner in which epilepsy may cause enlargement of an initial focus and unfavorably remodel an epileptic region of brain. It is as yet less certain how this process is initiated. It has also become clear that abnormalities in brain development underlie at least some epilepsies. Advances are also being made in defining the pathophysiology of heritable generalized and focal epilepsies, some of which resolve spontaneously. These studies, demonstrating overactivity and hypersynchrony of certain populations of neurons, have also revealed information of considerable importance concerning normal brain function and information pertinent to the understanding of nonepileptic conditions that also result from disturbances of specific neurotransmitters, membrane potentials, and ion channels. These studies help to explain the clinically observed relationships between epilepsy and sleep disturbances, movement disorders, migraine, and some psychiatric conditions.

Attention has been devoted to the understanding of relationships between seizures and conditions that may exacerbate them, such as sleep or lack of sleep, fever, menstrual flow, hyperventilation, and things that directly provoke what are termed *reflex* seizures—specific wavelengths and periodicity of repetitive flashing of lights or from such rare provocatives as certain tastes or even thoughts. Special attention has been devoted to epilepsy and pregnancy, from the vantage points of protection of fetuses from the effects of seizures or antiseizure medications and to the best management of epilepsy for the mother. These studies have discerned the importance of folate supplementation to prevent certain developmental deformities of the fetus that may occur if mother is being treated for epilepsy. Studies of great importance have been undertaken to understand and improve treatment of the sustained convulsive seizures, termed *status epilepticus*, a condition that may severely injure the brain or even prove fatal.

The evolving syndromic classification of epilepsies has permitted an increasing number of available therapies to be selected more intelligently and specifically. With such treatments, it has been proven to the satisfaction of all of the various state legislators that some restrictions on driving could be removed after treatment had achieved control for intervals of 6–12 months and that similar restoration of this important right could safely take place if individuals had remained seizure free for similar intervals after a resolved or adequately treated bout of epilepsy. Clinical experience also identified other important hazards for those with epilepsy, particularly the bathtub. Increasing knowledge of risks and natural history of the various forms of epilepsy together with the ability to tailor more effectively medical treatment to a specific syndrome rendered epilepsies increasingly predictable, alleviating fear and reducing the chance that individuals would experience embarrassment associated with public seizures. Public educational programs have also tried to foster greater understanding of epilepsy. Primary care physicians are educated concerning the recognition of unusual seizure types that require urgent treatment. These advances have greatly improved the lives of a very large number of individuals. Sadly, it is estimated that more than 80 percent of the 40 million people who currently have epilepsy throughout the world have access to few or none of these interventions.

The current approach to epilepsies entails excluding a wide variety of possible alternative diagnoses (including pseudoseizures) and then accurately characterizing the epilepsy syndrome. Electroencephalograms (EEGs) and other tests contribute to this otherwise clinical process. Epilepsies are categorized as to whether they are generalized (whole brain) or focal at onset and whether they are convulsive or nonconvulsive. Nonconvulsive or convulsive focal seizures are classified as to association with disturbance of consciousness (and therefore called *partial complex* or *psychomotor*). Convulsive elements include repetitive clonic movements or sustained tonic stiffening. Nonconvulsive elements of generalized seizures include typical and atypical absences, myoclonus, brief tonic activity, automatisms, and atonic (loss of tone) events. Atonic events may involve only part of the body or gradual incremental loss of tone or sudden and dramatic as in events termed *drop attacks*. Individual seizures may demonstrate evolution of one seizure type into another, most commonly to partial (simple or complex) to generalized convulsive. Some severe syndromes produce multiple seizure types.

Underlying identifiable causes are sought. A syndromic classification is then produced on the basis of the foregoing details and age. Provocative circumstances are identified and if possible alleviated, another anti-seizure medication is selected, and the dose systematically increased. If the drug proves ineffective or is not tolerated, it is replaced by another. In some instances combinations of drugs are employed. Perhaps 5 percent of all epilepsies are severe, intractable, often manifest several different types of seizures, and in some instances are associated with deterioration and even death, usually due to the underlying cause. Some of the most severe epilepsies have been reduced in prevalence because causative diseases have been eliminated or prevented by such things as dietary restriction. But for the majority of patients, epilepsies have minimal impact on their lives and those of their families. These and many patients who have temporarily troublesome epilepsy experience

excellent control, resolution over time, or surgical cure of their epilepsies.

—Robert S. Rust Jr.

See also Epilepsies, Temporal Lobe; Hippocrates; History of Disability: Ancient West; History of Disability: Medieval West; Neurological Impairments and Nervous Disorders.

ESQUIROL, JEAN ETIENNE DOMINIQUE (1772–1840)

French physician

Jean Etienne Dominique Esquirol was a French alienist (a physician who studied "mental alienation," or insanity) who is best known for his attempts to facilitate a shift in early psychiatric practice from a taxonomy focus to a perspective favoring meticulous observation. A favorite student of Philippe Pinel, Esquirol succeeded his mentor at the Salpêtrière, continued to be an advocate of "moral treatment," and developed into an influential pioneer forwarding the idea that asylums were therapeutic mechanisms in themselves. Esquirol's vision of the institution as a place of recovery was based on the premise that isolation from an unhealthy environment was the first, and most crucial, step toward the restoration of "reason." While in many ways still a product of his era, Esquirol conversely attempted to move away from purgatives and bloodletting toward establishing individual relationships with patients; his "discussions" foreshadowed psychotherapeutic approaches in working with those with mental illness. Esquirol was a strong advocate for involving the state in the affairs of medicine—he was one of the originators of the 1838 French law that implemented a system of nationalized institutions. Quite famous in his day, Esquirol influenced a large number of students at the Salpêtrière with a series of lectures in psychiatry—possibly the first formal instruction in the youthful discipline. Looking back, perhaps his greatest accomplishment was his early endeavor at differentiating between insanity and mental retardation, which previously had been treated as one in the same.

—Steven D. Taff

See also Philippe Pinel.

Further Readings

Esquirol, J. E. D. [1838] 1965. *Mental Maladies: A Treatise on Insanity.* New York: Hafner.

ETHICS

Ethics is a branch of philosophy concerned typically with the systematic treatment of issues of right and wrong, good and bad, virtue and vice. The terms *ethics* and *morality* or *moral philosophy* are interchangeable in common parlance, although sometimes ethics is used for the specific moral codes of groups or professions and morality (*mores*) is used for the ethical beliefs or customs of a culture. Morals in that sense can be the object of empirical studies and sociological theories, whereas ethics is a matter of analysis and argument.

In its classical phase (roughly up to the twentieth century), ethicists devised normative ethical systems or first principles and tried to justify them, with the practical aim of giving guidance on how one should live. During the first half of the twentieth century, influenced by the "linguistic turn" in philosophy, ethicists focused on the meaning and use of basic moral concepts, as well as "metaethical" issues such as whether (and how) ethical claims can be justified rationally, and whether differences in moral views among individuals or cultures entail that that universal ethics is impossible. On the defensive, ethicists tried to stave off subjectivist, relativist, and skeptic attempts to undermine ethics itself.

Arguably, moral skepticism and relativism have now run their course as plausible challenges to ethical theory. It is more common these days to believe that morality is universal and objective simply because we regularly, without qualms, grade, evaluate, praise, and blame others and ourselves. More fundamentally, our lives are defined by ethical impulses that are both mundane and universal: We feel gratitude to those who benefit us, sympathy with those in pain, and our sense of justice is offended when the guilty prosper or the innocent suffer. Building on this commonsense foundation, the most recent generation of ethicists have found the confidence to return to normative ethics and traditional questions of the good and the

right, although seeing the need to respect cultural and other differences of moral opinion and to be wary of the effect of class, power, gender, racial, or ableist presumptions in mainstream ethical intuitions.

Since ethics concerns the values and actions of all human beings, ethics is relevant to the lives of people with disabilities. Like everyone else, people with disabilities, and their perceptions of themselves and the social world, are in part shaped by the moral climate in which they live. They use and rely on the basic concepts of ethics and have and express ethical impulses and judgments. This said, there are many particular ethical debates in which disability and the experience of people with disabilities are especially relevant, and some in which they play an important and salient role. Some of these specific issues are found at the interface of ethics, biology, and medicine, and of ethics, politics, and justice; in the field of bioethics and political philosophy. Increasingly, ethicists in and outside of these specialized areas have broadened or modified their analyses to include disability, or, as important, have reconsidered or challenged preconceived notions about disability that are found in classical or modern ethical writings.

The following three areas of ethical debate are examples of the kinds of linkages that have already been explored between disability and ethical concepts and theories, which should give the reader an idea both of what is already in the ethics literature and what the future holds for research at the interface of ethics and disability.

THE GOOD LIFE AND THE QUALITY OF LIFE

What makes a life worth living? What does it mean for a human life to go well? What is the "good life"? Given their antiquity and perseverance, these are arguably the central questions of ethics. A similar question (or perhaps the same question with a different spin) concerns the meaning of life, in the sense of what it is that makes life meaningful (and therefore valuable or good). Finally, and more recently, questions about the good life have been recast as questions about the value of life, about what constitutes human well-being. Arguably, the more ancient question about the good life focuses on the best way to live (or what kind of life one should lead in order to lead a good life), whereas the more recent value-of-life question widens the possible domain of evaluation to include, for example, the value that a person's life may have for other people, for the state, or for some other entity.

Traditionally, there are two general approaches to the good-life question: One can either posit an intrinsic value to human life itself, or else one can try to identify features of a person's life, or the living of it, that are components of the good life or are instrumental to bringing about something else that is, on its own, constitutive of a good life. The first approach offers little scope for expansion or explication: If life is intrinsically valuable, then the value of any particular life is unaffected by what happens in that life. That is, human life has intrinsic value, but there are no gradations or variation in that value. This has the important consequence that every human life has equal value. Most philosophers, however, take the opposing approach and argue that, even if life itself has some intrinsic value, lives are not equally and optimally good, since there is variation in the value, or as it is often put, the quality, of one's life.

The question then becomes, what are the components of life that affect its value or quality? On this question, philosophers from at least Aristotle (384–322 BCE) have had much to say. Aristotle himself surveyed the possibilities (fame, fortune, love and friendship, beauty, health, honor) and insisted that all these were good things, without which a life would not be good, but that in the end, the "good life" itself is what all of these good things help a person achieve, namely, a life of eudemonia—a sort of complete spiritual and intellectual happiness or satisfaction. Other philosophers have assessed the value of life in terms of more mundane, ubiquitous, and achievable experience. Jeremy Bentham (1748–1832) argued that in the end, the goodness or badness of a life was entirely a function of the extent of pleasure or pain that is experienced. Indeed, if one took into account the degree, extent, duration, and probability of the pleasures and pains experienced in a life, one could calculate the value of a life, thereby comparing the good-life outcomes of different kinds of lives a person might lead, or of the lives of different people.

As is well-known, Bentham and his more sophisticated follower, J. S. Mill (1806–1873), went on to

develop a complex moral and political philosophy called utilitarianism, based on this relatively simple premise. In the century and a half since Mill wrote, utilitarianism has undergone a variety of refinements and revisions, to appeal to those with conceptions of goodness that go beyond pleasure, pain, satisfaction, and happiness, and to avoid such disturbing implications as the imperative to sacrifice an innocent person to appease a lynch mob or provide organs to several other people. What all these variations share is the evaluation of actions by their (expected) consequences, however defined; the broader approach is now referred to as "consequentialism," with act-utilitarianism—the appraisal of individual actions by the net utility they yield—merely one historically significant and conceptually simple variant.

Consequentialism retains the two features of utilitarianism that may have the most troubling implications for people with disabilities: the aggregation of the good found in the lives of separate individuals to make an overall outcome assessment—which tends to treat those individuals as mere sources or receptacles of goodness—and the commitment to maximizing whatever counts as good—which in effect places a higher value on those who directly or indirectly contribute more good to the total. Although some philosophers have attacked the aggregative and maximizing features of consequentialism head-on, others have tended to focus on the criteria for assessing outcomes as good or bad. We will touch on the former concern (which is dealt with at greater length in the "Justice" and "Health Resource Rationing" entries), but our focus here is on the latter: the relevance of impairment in assessing how well a life has gone or is likely to go.

Contemporary followers of Aristotle, such as Martha Nussbaum, reject pain and pleasure as a metric of well-being and tend to assess outcomes across people by their conformity to a pattern, such as equality, rather than by their aggregated magnitude. They argue that although there may be many kinds of life that qualify as valuable, still there are essential human "functional capabilities" (mobility, pleasure, happiness, cognition, play, health) without which the good life is unachievable. Because this approach relies on a conception of core or essential human goods, it is often called "essentialist." Whether one adopts Bentham's experiential approach or Aristotelian essentialism, the very endeavor to assess individual well-being, let alone to aggregate the results, is problematic for people with disabilities.

Since impairments are limitations of one capacity to perform actions, tasks, or social roles, and since they often cause pain, discomfort, or distress, is it inevitable on any definition of "good life" that the lives of people with disabilities are of less value? Are any of the "normal" or "standard" functional capacities of human beings essential to well-being, or are they only contingently related? Does severity of impairment matter? Is there a lower threshold of functional capacity below which a life lacks value, whatever else may be happening in the person's life? Are limitations in cognition or the senses more a threat to living a good life than limitations in mobility or strength; is a life of physical pain worse than a life of emotional distress? Does it make any sense to compare impairments in this manner, or to rank them with respect to their impact on the quality of a person's life? These are just some of the kinds of questions that arise when impairment is brought into the domain of moral value in the analysis of the value or quality of a human life.

It is true that classical and modern philosophers have often assumed without argument or discussion that all impairments substantially reduce quality of life. Similar assumptions of inherent inferiority have been made on racial, gender, and cultural or religious grounds. Still, the case of impairment may be different. Even if we rely on the modern conception of disability as an interaction between features of an individual's body or mind and the physical, social, and attitudinal environment, and insist that it is a person's environment, as well as or instead of his or her physical and mental differences, that account for the disability, still impairments have a reality that should not be ignored or glossed over. We may be confident that the lower quality of life of women is entirely the product of sexism, but it would be intellectually dishonest to insist either that chronic pain or severe depression has no effect on the value of a life or, worse yet, that the negative value of pain and depression is somehow "socially constructed."

There are very practical, indeed, life-or-death consequences of this realm of ethical debate for people with

disabilities. If a fetus has a low quality of life because of congenital or acquired impairments, should that be a reason to abort it? Should we insist on prenatal screening to make sure that the children that are born are not disadvantaged from the beginning by a low quality of life? When there is a scarcity of medical resources, should it matter that one potential recipient is also disabled and so would not have as good an outcome as another recipient who is able-bodied? Should we make it easier for people with severe disabilities to kill themselves, or be euthanized, than it is for other people?

In light of these possible implications, some disability scholars have argued that the notions of "quality of life," the "good life," and "well-being" are dangerous nonsense. Some have insisted that what makes life valuable is entirely a matter for the individual—with or without a disability—to decide (so-called experts will inevitably judge lives with disabilities to be worse than individuals with those disabilities think they are). Such radical responses, however, create their own ethical issues. Eliminating the notions of the good life and quality of life from our ethical lexicon would eliminate important ethical dialogue: Surely we want to insist that it is ethically better to live free, to have our basic needs met, and to enjoy equal opportunities. We need to agree on what makes a life go well, what improves the quality of our lives, in order to better the lives of people and reduce what we all perceive as great, undeserved inequalities. What improves or devalues a life, moreover, is not merely subjective opinion: Not even saints or sages are infallible about what makes their lives go well. We may not want to leave it to "experts" to decide on the components of human well-being, but that does not mean that every individual must be the ultimate arbiter of his or her own good; it may be a matter for deliberation and consensus.

Perhaps a standard distinction in ethics may help here. Ethicists say that an experience, action, or state that is a candidate for a good and valuable thing is either intrinsically or instrumentally valuable. Something is intrinsically valuable if that experience, action, or state is valuable itself; instrumentally valuable if it tends to produce or cause something else that is intrinsically good. Now since impairments limit the activities we perform, we can ask whether common activities such as walking, reading, talking, and seeing are intrinsically or merely instrumentally valuable. If some or all of these activities were intrinsically valuable, then a life in which they cannot be adequately performed would lack an important source of value. Alternatively, though, we can maintain that these activities—indeed almost any activity—are merely means to the production of something ultimately valuable (perhaps the experience such as pleasure, satisfaction, or happiness). In that case, not being able to walk or speak need not limit the value of one's life as long as one can achieve the same ultimate end in other ways (e.g., by using a wheelchair or a communication device). In this manner, one could argue that impairments need not have an adverse effect on quality of life, as long as people with disabilities are given the resources they need to pursue alternative means.

This is an interesting moral argument, but it still needs more work. Some impairments do appear to involve the loss of something intrinsically valuable and irreplaceable. If one cannot see a painting, would having it described (say, by the artist herself) ever count as an equivalent means to the end of aesthetic enjoyment? Could we say that listening to a piece of music could produce the same kind and degree of aesthetic enjoyment as seeing the painting? Does this make any sense? Alternatively, could we argue that there are many different collections of activities that people do, each of which is intrinsically valuable (or else of sufficient instrumental value to produce the same degree and kind of intrinsic value) even though no two are identical? While one person cannot see and another has diminished intellectual capacity, with appropriate resources, training, or other facilitation, both their lives could be lived with equal value accruing from very different experiences. Certainly, these are interesting questions that might bring a more realistic understanding of the effect of impairments on well-being. But more work needs to be done to make them concrete and plausible. The onus of doing such work should not, however, rest exclusively on disability scholars. Arguably, the burden of developing a full account of human flourishing should fall on those who, in the absence of such an account, proclaim the lives of people with disabilities to be lacking in the requisites of well-being.

AUTONOMY, COMPETENCE, AND MENTAL DISABILITY

Some impairments affect mobility, others affect perception, fine hand motion, or communication. Still other impairments—those we call "mental impairments"—affect our abilities to make judgments, to reason, or to cope with the stresses of living. When mental illness or brain injury leaves individuals with very serious mental impairments, we may be tempted to say that these individuals lack the capacity to make decisions about themselves or others—a capacity often called "competence"—and others should make those decisions instead. Overriding the right of individuals to make decisions about themselves is a big step, and in many jurisdictions, the law put limits and restrictions on this form of paternalism.

The ethical significance of paternalism links to one of the central notions in the history of ethics: autonomy. Autonomy, or self-governance, was for Immanuel Kant (1724–1804) the foundation of ethics itself. Attempting to meet the challenge posed by David Hume (1711–1776) and others who claimed that reason played no role in ethics, Kant argued in effect that one cannot rationally act immorally, since to act within the bounds of reasons is, roughly, to treat others as you would have them treat you, or more formally, to act in accordance with a rule that you would will that everyone follow—that is, to act in accordance with what you could will as a universal law. Acting immorally, therefore, would in effect to irrationally demand that others act in the same immoral manner toward you. This so-called categorical imperative presumed that moral agents have the capacity to will to do things (indeed, Kant believed that the only truly good thing in the world was a good will). That meant that for Kant, ethics was rationally grounded in the human capacity to will actions, that is, to be autonomous moral agents.

The Kantian tradition is very strong in ethics, and is a source, among other things, of traditional liberal values, in particular, respect for the individual, for individual freedom, and finally, the recognition of individual moral rights (which, logically, apply only to moral agents). The ethical significance of autonomy, moreover, is reflected in the very foundations of our law: The fact, for example, that you can be convicted of a crime only if you have a "guilty mind" (mens rea) is another version of Kant's insistence that only agents with free will are autonomous and so morally responsible for their actions.

This Kantian view on the rational will as the source of human dignity is in one respect highly congenial to disability rights. It regards impairments of physical function, however severe, as contingent and morally insignificant features of the individual, and it opposes any attempt to value human lives on the basis of their productivity or utility. The Kantian injunction that people have worth, not a price, is often invoked to reject the whole project of allocating scarce resources on the basis of physical functioning. Yet at the same time, the Kantian premium on rationality leaves the moral status of individuals with cognitive impairments insecure.

The Kantian tradition underwrites the law of competence and mental illness, which in turn has consequences for disability. A person with a severe mental impairment may, if incompetent, lose his or her status as a moral agent, as a person with autonomy. Mental impairment can undermine what, in this ethical tradition, is absolutely fundamental to moral personhood. This creates a fundamental asymmetry between mental and physical disability. And Kant was well aware of this. He wrote that even if a person is severely physically impaired ("by a special disfavour of destiny or by the niggardly endowment of stepmotherly nature"), and can perform no actions, good or bad, the person will still be a moral agent as long as he or she has the mental capacity to will, that is, to intend to act.

The Kantian liberal ethical tradition is very influential, and a distinction between the physical and the mental is central to it. For those judged to have the mental capacity for practical reason and autonomy, it has been a source of important safeguards. For those who appear to lack that capacity, however, by virtue of mental impairment, it has been used to justify paternalism, as well as a wide range of social and professional practices involving the restraint, forced treatment, and other limitation of freedom. At the same time, the lack of ethical parity between mental and physical disability is hardly unique to Kantian morality. It is evident across modern society, and indeed, is sometimes played out within the disability rights movement itself.

DISABILITY AND THE LANGUAGE OF RIGHTS

The language of rights (human, civil, legal) has dominated the disability movement of the past couple of decades. The political fight for equality and antidiscrimination has been described as a battle for basic human rights. Although we often use the term freely and without much thought, morally speaking rights are vague entities. Probably because of the influence of the "natural rights" movement that dominated seventeenth-century political thought, we tend to speak of rights as if we were describing entitlements people have, rather than, more accurately, asserting a moral proposition about what entitlements people ought to have (but may not have in fact). The temptation, at least in the West, to find rights everywhere ("I have a right to smoke!") suggests that the concept is useful to us precisely because it is empty and vague. But this much seems to be logically required of a right: If it is true that a person has a right to something, then (a) there must be someone (institution or other social arrangement) who (b) has a moral duty to provide it. There is, moreover, an important logical limit to this duty, traditionally expressed by the Kantian maxim that "ought implies can"—namely, that one only has a duty to do something that one can actually do.

These simple, logical features of the concept lead directly to the vagueness of rights language. The United Nations Universal Declaration of Human Rights (1948) declares in Article 3 that "everyone has the right to life, liberty and security of person." But what does this right mean in concrete terms? How many resources can I demand if I truly need them to keep alive? And who has the duty to provide these to me? More troubling still, since everyone has the right to life, and since life-saving resources will always be finite, if not downright scarce, how do we determine whose right to life trumps someone else's when there are not enough resources to go around? And who has the duty to resolve this horrendous practical dilemma?

Given these and other worries, some ethicists have suggested that rights language is mostly rhetorical and not intended to have practical implications. Moral rights should be clearly distinguished from legal rights, which actually can get the job done. Even when they are abstractly expressed, legal rights are embedded within social practices and institutions whose job it is to interpret rights in specific circumstances and for specific individuals, and to transform the rhetoric of rights into precisely operationalized directives to the state or its agents. A legal right, in practical terms, is merely an entitlement to bring a legal action, to cite facts, and to make arguments before a tribunal that is both obliged to adjudicate one's claim and empowered to do something about it.

Some philosophers, most notably Karl Marx, have argued that moral and legal rights are individualistic, indeed egoistic, and so socially destructive. All our moral concern is focused on the demands of particular individuals, at the expense of the general good. In the liberal tradition, however, this is more or less what makes rights so attractive. The individual in a social setting needs rights to protect him or her from the egoistic demands of other individuals, the tyrannies of the majority, or the encroachments on freedom perpetuated by the state itself in its pursuit of what it sees as the common good.

The prospect that rights could protect individuals, or minority groups, against the majority was what attracted the disability movement to rights discourse. In the United States, especially, disability was characterized as mark of a minority subject to historic treatment of discrimination, stigma, and denial of opportunities. As a political strategy, characterizing people with disabilities as an oppressed minority—or more recently, as a social and cultural group—was a success. It is not as clear, however, whether this is the best strategy for the long term. There is the obvious difficulty of creating a "discrete and insular minority" (Americans with Disabilities Act of 1990) out of individuals whose impairments are highly diverse and whose experiences cannot be easily generalized. In addition, physical or mental functional limitations are highly dynamic, unlike race or gender, and, more important, are features of the human condition that everyone will experience over the course of his or her lifetime. The minority rights model that accepts the adversarial relationship and seeks to empower the weaker side conflicts with another, arguably more plausible, model of disability that sees it as a universal feature of humanity and that treats people with disabilities as having precisely the same human rights as everyone else.

It is unlikely that the politics of disability will soon abandon the language of rights. It is important, therefore, to be aware of the limitations of this language as an ethical discourse.

—Jerome E. Bickenbach and David Wasserman

See also Bioethics; Competence; Health Resource Rationing; Justice; Quality of Life.

Further Readings

Aristotle. 1925. *Nicomachean Ethics, in The Works of Aristotle,* Vol. 9. Translated into English by W. D. Ross. Oxford, UK: Oxford University Press.

Bentham, Jeremy. 1988. *An Introduction to the Principles of Morals and Legislation*. Buffalo, NY: Prometheus.

Blackburn, Simon. 2001. *Ethics: A Very Short Introduction.* Oxford, UK: Oxford University Press.

Byrne, P. 2000. *Philosophical and Ethical Problems in Mental Handicap.* New York: St. Martin's.

Kant, Immanual. 1955. *The Moral Law or Kant's Groundwork of the Metaphysic of Morals*. Translated by H. J. Paton. London: Hutchinson.

Mill, John Stuart. 1991. *Utilitarianism.* Oxford, UK: Oxford University Press.

Nussbaum, Martha C. 1992. "Human Functioning and Social Justice: In Defense of Aristotelian Essentialism." *Political Theory* 20(2): 202–246.

Nussbaum, M. and A. Sen, eds. 1993. *The Quality of Life.* Oxford, UK: Clarendon.

Singer, Peter. 1993. *Practical Ethics.* Cambridge, UK: Cambridge University Press.

Wasserman, D. 2001. "Philosophical Issues in the Definition and Social Response to Disability." Pp. 219–251 in *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury. Thousand Oaks, CA: Sage.

EUGENICS

A term coined in 1883 by the British scientist of heredity, Sir Francis Galton, *eugenics* was a movement devoted to "race improvement." Fueled by late-nineteenth and early-twentieth-century scientific advances in the identification and measurement of "defective mentality" (Mendelian genetics, human pedigree charts, intelligence testing), the eugenics movement sought to link social ills such as crime, prostitution, poverty, juvenile delinquency, and promiscuity to people with cognitive disabilities. To diminish instances of social "vice" and the prevalence of mental "defects," eugenicists extolled a wide range of restrictive social policies including marriage laws prohibiting unions of those diagnosed as feebleminded, epileptic, and insane; an expansion of lifelong incarceration in institutions for the feebleminded; laws that legalized state-sponsored sterilization programs; immigration restrictions on people with disabilities; widespread intelligence testing in public schools aimed at identifying feeblemindedness at the earliest possible age; and segregation of "backward" students in special or ungraded classrooms.

The eugenics invention of the category "feeblemindedness" moved from a general classification of "inferior" intellect to a tiered model of "defective" types: *idiots* referred to individuals with a mental age of two years or less, *imbeciles* represented those with an arrested mentality of three to seven years, and *morons* referred to those attaining a mental age of no more than 12 years of age. There were also classifications of varying degrees of backwardness for people occupying the intellectual cusp between "normal" and "feebleminded." Whereas the European construction of feeblemindedness tended to emphasize intellectual capacity, the U.S. definition recognized physical and sensory disabilities as visible bodily expressions of a feeblemindedness residing within.

Eugenics can be broken down into four specific historical stages: the early-nineteenth-century transition from familial and community responsibility for people with cognitive disabilities to a social and state problem, post–Civil War rhetoric that characterized feeblemindedness as a social burden to be alleviated through custodial institutional care, the promulgation during the first two decades of the twentieth century of an extreme version of feeblemindedness as a menace to society, and the post-1920 psychiatry-based mental hygiene movement that began to supplant eugenics with an emphasis on adaptation and adjustment through services that perpetuated segregation and that could be based in the institution or the community.

As an ideological practice cloaked in the empiricism of scientific research, eugenics was widely practiced in Europe, the United States, and Canada. Culminating in the systematic murder of more than 260,000 disabled people by the Nazis between 1939 and 1945, the eugenics movement gave birth to the contemporary forms of nearly every social and therapeutic discipline

that attempts to treat and manage disabled people today: physical therapy, occupational therapy, social work, genetics, genetic counseling, special education, and community and applied psychology.

Beyond Europe and North America, eugenics also achieved global influence by exporting its practices to countries as varied as Africa, Mexico, India, Australia, Japan, Russia, and Israel. In many of these countries, eugenics was implemented with respect to distinct national and cultural contexts; for instance, Bolshevik eugenicists used family pedigree charts to demonstrate the degeneracy of czarist lines, Israel imported eugenics models to bolster arguments for a more robust Jewish citizenry, colonial Africa used eugenics as a rationale to solidify arguments about African inferiority and violent tribal practices such as female circumcision, and Japan sequestered its sensory feebleminded (deaf and blind) populations on islands.

—Sharon L. Snyder and David T. Mitchell

See also Eugenics: Germany; Henry Herbert Goddard; Nazism; Sterilization.

Further Readings

Gould, Stephen Jay. 1996. *The Mismeasure of Man.* New York: W. W. Norton.

Snyder, Sharon and David T. Mitchell. 2003. *Eugenics in America, 1848–1935: A Primary Sourcebook in Disability Studies.* Ann Arbor: University of Michigan Press.

Trent, James. 1994. *Inventing the Feeble Mind: A History of Mental Retardation in the United States.* Berkeley: University of California Press.

EUGENICS: GERMANY

The theory of evolution developed by Charles Darwin and published in his book *The Origin of Species by Means of Natural Selection* (1859) can been seen as a starting point for eugenic thinking in Germany. Already during the 1860s, Ernst Haeckel (1834–1908), a German zoologist, spread Darwin's theory, although in a reduced form. Haeckel saw the concepts of adaptation to the environment, heredity, and struggle for life as essential elements of humankind's history. In public, Haeckel defended his position in numerous disputes and scripts. Mostly, representatives of confessional theories were against him, since Darwin's evolution theory stood in strict opposition to the biblical creation narrative. Haeckel's lectures "Natürliche Schöpfungsgeschichte" ("Natural History of Creation" 1868), written in a clear diction easily understood, had an overwhelming success. The book was published in 12 editions and translated in 25 languages.

With Haeckel as its pioneer, about the turn of the past century eugenics gained more significance in Germany. At 1900, a deep economic crisis combined with a distinctive retrogression of births took place. This situation inspired a fundamental criticism of civilization. It said that the birth decline happened only in the upper classes whereas the lower classes increased in large numbers. As a consequence, a successive degeneration of the German people was feared. One of the first German eugenics representative was Wilhelm Schallmeyer (1857–1919), who advocated for the degeneration theory in his book *Über die drohende körperliche Entartung des Kulturmenschen* (*About the Threatening Physical Degeneration of the Cultural Human Being*, 1891). Schallmeyer argued that under the influence of culture the quality of humankind was deteriorating. To stop this development, he demanded that hereditary biological registration, the population's instruction about hereditary processes, and barriers to marriage be employed. Besides Schallmeyer, the physician Alfred Ploetz (1860–1940) was important for the German eugenics movement. It was Ploetz who coined the term *Rassenhygiene* (racial hygiene) in 1895. This German term was used as a synonym for eugenics until the end of the Third Reich in 1945. In contrast to other countries, German eugenics allied itself under the term racial hygiene with the nationalist and anti-Semitic ideology of "race anthropology." This connection created the conditions for the specific German way of eugenics.

Ploetz, who originally sympathized with the social democrats, turned toward eugenics because he thought that with the "human race" existing in Germany at that time socialism could not be put into practice. He aimed at "racial welfare" by installing measures that should foster the procreation of many "high quality" descendants and simultaneously the weeding out of the so-called inferior parts of the population. Ploetz thought that the "Aryan race" was the best race in terms of culture. As members of the Aryan race he counted all peoples

except "Negros." To him, Jews belonged to the Aryan race as well. In other words, Ploetz's position originally was not anti-Semitic.

Until the end of World War I (1914–1918), eugenic/racial hygiene was debated only by an academic minority. After the war, when the great numbers of casualties caused by the war battles became apparent, during inflation and the crisis of the welfare state, gradually eugenic ideas gained more and more influence within the political establishment of the Weimar Republic (1918–1933). In 1920, the Prussian Ministry of Welfare set up a committee for racial hygiene. In 1927, the German social democrats and the Catholic Centrum Party initiated the "Kaiser Wilhelm Society," whose institutes were to pursue scientific research. The Kaiser-Wilhelm-Institut für Anthropologie, menschliche Erblehre und Eugenik (Kaiser-Wilhelm Institute for Anthropology, Human Genetics and Eugenics) had the task to develop the scientific base for eugenic measures. The model for the Kaiser-Wilhelm Institute had been the Rockefeller Institute of Medicinal Research. Over the years, the German institutes gained such a good reputation among American science managers that they got funding until the United States entered World War II as a combatant in 1941. During the Weimar Republic, it seemed that German eugenics was just one part of the international eugenics movement. The Kaiser-Wilhelm Institute for eugenics was led by Hermann Muckermann (1877–1962), a Catholic priest having good connections with the Catholic Centrum Party. Muckermann had been developing his eugenic approach since 1917. At first, he pleaded for positive eugenic measures only. However, during his work at the Kaiser-Wilhelm Institute his position got radicalized; in 1929 he called for compulsory sterilization.

In general, during the Weimar Republic moderate eugenic positions were more influential than radical ones. A dispute between the social democrat Oda Olberg and Wilhelm Schallmeyer throws light on the socialist eugenic approach. Olberg shared Schallmeyer's opinion about the dangers of the population's degeneration, but she contradicted him in the causal analysis. For her, Schallmeyer was one-sided in primarily emphasizing genetic causes. Instead, Olberg saw the degeneration caused by the pauperization of the working class. Therefore, she pleaded for the improvement of the living conditions of the poor. Consequently, she saw a compatibility between eugenics and socialism whose common starting point was the orientation toward a strong state.

Besides the socialists, the middle-class women's liberation movement had also been open for eugenic positions since the beginning of the twentieth century. In 1905, Helene Stöcker (1869–1943) established the feminist Bund für Mutterschutz (League for the Protection of Motherhood). Stöcker stood up for a "new ethics" in sexuality and family planning. She pleaded for free sexuality in equal partnerships between men and women, but she argued against licentiousness and digression. Rather, the sexual partners were meant to use their liberty for a greater eugenic responsibility for their offspring. Of course, racial improvement was meant to be the result. In opposition to the mainstream racial hygiene approach, Helene Stöcker's position was individualistic. For example, she was against compulsory measures such as birth control and emphasized the human right to free decision. However, only "healthy" persons were meant to use this right. Patients with incurable and hereditary diseases were refused procreation. Concerning these people, Stöcker pleaded for restraint and compulsion. The women's liberation movement of which Helene Stöcker was a main spokeswoman accepted the degeneration thesis but saw their reasons in bad social and economic living conditions. In that respect, they joined the German socialists.

Before 1933, many parallels between the German eugenics and international approaches existed. A draft for a sterilization law, which was worked out by the Prussian ministry administration in 1932 was very similar to the laws that had been discussed or put into force in other countries. In this draft, sterilization was to be undertaken under the condition of the patient's agreement. Before 1933, even the German Society for Racial Hygiene was against compulsory sterilization without the patient's consent. However, it did not primarily have in mind the respect for the individual's right to physical integrity; instead it argued that too little about the hereditary traits of certain diseases was yet known. On the ground of the still insignificant hereditary knowledge the passing of compulsory legal measures was not seen as enforceable, especially in a democracy. With respect to the issue of compulsion, important differences between German eugenicists and their international colleagues did exist. Germans

tended to be more radical in their positions. Owing to a weakly developed democratic culture in their country, they believed in state authority more than others. This belief was one factor why German eugenicists were susceptible to national socialism. Shortly after the Third Reich was established, they came to an agreement with the national socialist state. The state promised them to extend and promote genetic research; in turn, the eugenicists helped to legitimize racist policies and ideologies. During the 1930s, the registration of the supposedly racial and hereditary inferiors took place, and one result was the mass murdering of disabled people from 1939 onward.

After World War II (1939–1945), eugenics had a bad reputation all over the world. It especially lost its credit when as a consequence of the Nuremberg trials against Nazi leaders it got publicly known that in the concentration camps and hospitals scientific experiments with humans had taken place. But the end of the Third Reich did not mean the end of eugenic thinking. Instead, the scientific discipline got a new name and was called "human genetics." Many German eugenicists stayed in the background for some years but continued to dream of genetic enhancement, especially after James Watson and Francis Crick discovered the structure of the hereditary substance in 1953. During the 1950s and until the beginning of the 1960s, German eugenics/human genetics was internationally isolated. Nevertheless, despite history, former Nazi eugenicists managed to get appointments for the first professorial chairs in human genetics at German universities. For example, Otmar von Verschuer (1896–1969), who had been director of the Kaiser-Wilhelm Institute for eugenics during the Third Reich, got a professorship in human genetics at the University of Münster/Westphalia.

At the end of the 1960s, prenatal diagnostics was started in Germany. Since then, the second scientists' generation after the war gradually managed to acquire an international reputation again. When the first steps were taken to establish prenatal diagnostics in Germany, a eugenic argument was used. It was claimed that disabled children meant a burden both for their families as well as society in general. Cost-benefit analyses were undertaken to prove the efficiency of prenatal selection, called "primary prevention" in postwar Germany. The so-called new eugenics at present installed not only in Germany but all over the world certainly differs from the old conception as it is oriented toward individual autonomy and self-responsibility. In contrast to the early eugenics, which aimed at a population's enhancement, today's human genetics appeals to the needs of the individual. In Germany, disabled people have been among the first who criticized individualistic eugenic approaches and disclosed the connections between human genetics, national socialist racial hygiene, and eugenics.

—Volker van der Locht

See also Charles Darwin; Eugenics; Racial Hygiene (*Rassenhygiene*); T4 Program.

Further Readings

Baumunk, Bodo-Michael and Jürgen Rieß, eds. 1994. *Darwin und Darwinismus. Eine Ausstellung zur Kultur und Naturgeschichte*. Katalog einer Ausstellung des Deutschen Hygiene-Museums. Berlin, Germany: Akademie Verlag.

Benz, Wolfgang, Hermann Graml, and Hermann Weiß, eds. 1998. *Enzyklopädie des Nationalsozialismus*. Munich, Germany: Deutscher Taschenbuch Verlag.

Korff, Wilhelm et al., eds. 2000. *Lexikon der Bioethik*. Gütersloh, Germany: Gütersloher Verlagshaus.

Schmuhl, Hans-Walter. 1992. *Rassenhygiene, Nationalsozialismus, Euthanasie. Von der Verhütung zur Vernichtung "lebensunwerten" Lebens, 1890–1945*. Göttingen, Germany: Vandenhoeck & Ruprecht.

Weingart, Peter, Jürgen Kroll, and Peter Bayertz. 1988. *Rasse, Blut und Gene. Geschichte der Eugenik und Rassenhygiene in Deutschland*. Frankfurt/Main, Germany: Suhrkamp.

Weß, Ludger, ed. 1998. *Die Träume der Genetik. Gentechnische Utopien von sozialem Fortschritt*. Frankfurt/Main, Germany: Mabuse Verlag.

EUROPE

See Council of Europe Disability Policy; Disability Law: Europe; European Commission Policy; European Disability Forum

EUROPEAN COMMISSION POLICY

The European Union is founded on the principles of liberty, democracy, respect for human rights, fundamental freedoms, and the rule of law. The right of

individuals to equality before the law and to protection from discrimination is a fundamental right that is essential to the proper functioning of democratic societies. Equal treatment and nondiscrimination are fundamental to the principles for the achievement of the European Union's objectives of promoting economic and social progress and a high level of employment by increasing economic and social cohesion.

The European Union has long been involved in the promotion of equality on the grounds of gender and nationality. It has also consistently shown its commitment to eliminating other forms of discrimination through a variety of instruments—joint declarations, resolutions, directives, and action programs. The 1989 Community Charter of the Fundamental Social Rights of Workers recognized the importance of combating every form of discrimination in order to ensure equal treatment for all.

With regard to disability, the European Union has supported and implemented actions in favor of people with disabilities, principally in the form of European Social Fund interventions that finance training and support the integration of people with disabilities into the workplace. These measures were complemented in the early 1980s by a series of action programs (best known as the Helios Programmes) aimed at facilitating the exchange of information between member states and nongovernmental organizations (NGOs) with a view to identifying good practices, integrating people with disabilities into society. The action programs made an important contribution to raising awareness on the issues affecting people with disabilities and widening the agenda beyond simple financial assistance.

In addition to funding and awareness-raising measures, the EU Council of Ministers adopted nonbinding instruments—recommendations and resolutions—laying down principles concerning the integration of people with disabilities into mainstream employment or education. In particular, the Council Recommendation on the Employment of Disabled People 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."

A further step was taken when the European Commission issued in 1996 a communication on equality of opportunities for disabled people. This communication set out a new European disability strategy. The new policy framework attempted to move the agenda away from a so-called welfare type approach to disability issues and toward eliminating the barriers that prevent the realization of equal opportunity, full participation, and respect for difference. It provided details on discriminatory practices experienced by people with disabilities, held that these practices violated deemed various universal human rights, and affirmed that "the core right at stake is that of equality." This communication was subsequently endorsed by the Council of Ministers representing the member states. For the first time, there was a clear and shared commitment by the European Union and its member states to promote equal opportunities, to eliminate discrimination, and to recognize the rights of people with disabilities.

The new emphasis, often called the "rights-based approach," was no longer about conferring special treatment or measures on people with disabilities but was rather about ensuring that people with disabilities are given equal treatment and equal rights. Although the communication marked an important step toward the recognition of the rights of people with disabilities, the European Community's involvement was limited to encouraging the member states to fulfill the commitments they had made at the European level.

Despite this progress, the European institutions were often criticized for not going further and in particular for lacking a specific legal base to take action against discrimination on the grounds of disabilities.

This changed in Amsterdam, in June 1997, when the heads of state and government agreed to strengthen Europe's capacity to act in this area by introducing Article 13 of the treaty establishing the European Community, which gives the European Community specific powers to take action to combat discrimination based on sex, racial, or ethnic origin; religion or belief; disability; age; or sexual orientation. The inclusion in the treaty of a general nondiscrimination article covering, among other areas, disability has greatly improved the situation for persons with disabilities. Article 13 opened the way for the commission to propose legally binding measures to combat discrimination on the grounds, specifically, of disability.

The disability strategy that the European Community has developed since the mid-1990s finds its clearest expressions in Article 13. This groundbreaking provision endorses the shift from thinking about people with disabilities as passive recipients of charity to viewing them as active claimants of the right to be treated equally. The European Commission moved swiftly to implement the new treaty provisions. After a consultation period, in November 1999 two draft directives and an action program were adopted by the European Commission. The whole package was unanimously adopted in a record time by the council the following year.

The first directive, 2000/43/EC, prohibits discrimination on the grounds of racial and ethnic origin and prohibits discrimination in the fields of employment, education, social protection (including social security and health care), social advantages, and access to goods and services (including housing). The second directive, 2000/78/EC, prohibits discrimination in employment and occupation on the grounds of religion and belief, disability, age, and sexual orientation. Both directives prohibit discrimination in employment and occupation, defined as access to employment, self-employment and occupation, vocational guidance and training, employment and working conditions including dismissal and pay, and membership of organizations.

The directives prohibit any discrimination, direct or indirect, on all grounds mentioned. With regard to disability, the Equal Treatment in Employment Directive (2000/78/EC) requires major changes to existing rules in certain member states. Employers—public and private—will be obliged to accommodate the needs of people with disabilities to ensure that they have an equal opportunity to compete in the labor market. Failure to provide a reasonable accommodation in the workplace can constitute discrimination. In practical terms, such accommodation includes measures to adapt the workplace to people with disabilities, for example, adapting premises, equipment, and patterns of working time to facilitate their access to employment. The directive expands the concept of discrimination with respect to disability in that employers must not only refrain from discriminating but also take steps to accommodate people with disabilities in the workplace to ensure that they are treated equally.

The "reasonable accommodation" requirement in essence should ensure that there is a level playing field for people with disabilities in the employment sphere. The directive, and the obligations contained therein, challenges the equation according to which disability equates unfitness or incapacity. Indeed, it applies only to individuals who are competent, capable, and available to perform the essential functions of the post concerned without prejudice to the obligation to provide reasonable accommodation for people with disabilities. The concept of reasonable accommodation is the keystone of fighting discrimination on the grounds of disability. Reasonable accommodation is not a positive action left to the discretion of public or private operators but an obligation whose failure can constitute unfair discrimination.

The reasonable accommodation obligation necessitates a balancing act between the needs of the employer to conduct a profitable business and the aspirations of people with disabilities to enjoy equal employment opportunities. The obligation therefore does not apply to employers in all circumstances. The directive provides that an employer can deny a reasonable accommodation if it would impose a "disproportionate burden." The directive gives in that respect some guidance as to how to measure and assert the disproportionate burden: "to determine whether the measures in question give rise to a disproportionate burden, account should be taken in particular of the financial and other costs entailed, the scale and financial resources of the organisation or undertaking and the possibility of obtaining public funding or any other assistance."

The directive provides for positive action in that it acknowledges that the prohibition of discrimination should not be without prejudice to the maintenance or adoption of measures intended to prevent or compensate for disadvantages suffered by a group of persons of a particular religion or belief, disability, age, or sexual orientation.

The paradigm shift that has taken place at the European level—transforming needs of people with disabilities into rights—has spread across the international community. The debate around the need to develop a United Nations thematic convention on the rights of people with disabilities has clearly

demonstrated the shortfalls of the existing international human rights instruments in relation to people with disabilities. The European Commission has signaled in a communication its full support toward the development of such a convention that would secure unequivocal protection for the fundamental human rights and freedoms of people with disabilities and acknowledge their legitimate membership in the international human rights system.

—Flaminia Bussacchini

See also Council of Europe Disability Policy; Disability Law: Europe.

Recommendations and Resolutions

Recommendation from the Commission to the Council in order to authorise the Commission to participate in the negotiations of an international legally binding instrument to promote and protect the rights and dignity of persons with disabilities SEC/2003/0116 final.

Resolution of the Council and of the representatives of the governments of the member states meeting within the Council of 20 December 1996 on equality of opportunity for people with disabilities.

Resolution of the Council of 31 May 1990 and the Ministers for Education meeting within the Council concerning integration of children and young people with disabilities into ordinary systems of education.

Further Readings

COM(96) 406 final of 30 July 1996.

Council Recommendation of 24 July 1986 on the Employment of Disabled People in the Community.

Doyle, Brian J. 1995. *Disability, Discrimination and Equal Opportunities: A Comparative Study of the Employment Rights of Disabled People*. London: Mansell.

European Social Policy–Options for the Future. 1993. COM (93) 551. Green Paper.

EUROPEAN DISABILITY FORUM

The European Disability Forum (EDF) was created in 1996 by its member organizations to defend issues of common concern to all disability groups and to be an independent and strong voice for disabled citizens in dialogue with the European Union (EU) and other European authorities. Its mission is to promote equal opportunities for disabled people and to protect their human rights.

EDF has 127 member organizations reflecting a broad geographic base and a wide range of concerns across the disability movement. Its membership currently includes 21 National Disability Councils: one from each of the EU member states, plus Iceland and Norway, Czech Republic, Estonia, Malta, and Slovenia. These national federations are independent organizations of disabled people, including all major impairment groups in each country; 96 organizations representing the various disability groups and interests in Europe and specialized by type of impairment or sector of activity, such as the European Blind Union and the European Union of the Deaf.

EDF's motto and basis for work is "nothing about disabled people without disabled people," as promoted by the Madrid Declaration. Therefore, its scope of work is very large, covering all EU areas of competence that can have an impact on people with disabilities' lives (e.g., employment, information society, social inclusion, transports, media, telecommunications).

One of EDF's most important campaigns was the European Year of People with Disabilities 2003, a proposal presented to the European Commission in 1999. The European Year marked the history of the European disability movement, providing the necessary impetus to advance the disability agenda in all EU member states and accession countries. The future challenge for EDF remains the adoption of a new disability-specific directive that will protect disabled people from discrimination in all fields of life, such as education, transports, information, and leisure. Ensuring that disabled people are able to benefit from the same rights and obligations as other citizens in the European Union will continue to be EDF's main goal; legal instruments to combat discrimination will remain the basis of its work.

—Helena González-Sancho Bodero

See also Disability Law: Europe.

EUTHANASIA

Both in conception and in practice, within and beyond disability communities, euthanasia provokes impassioned contentiousness. The word itself is derived from the Greek for "dying in a good way." How people of different persuasions react to the idea itself encapsulates the debate about practices variously labeled as "euthanasia."

To many people, such a notion is an oxymoron, for it is inconceivable to them that dying can ever be good. Many people therefore conclude that policies permitting euthanasia must be deceptively corrupt. The way that the practice is named is seen as a disingenuous attempt to pass off as instrumentally desirable an outcome that is intrinsically bad and that therefore should be avoided at all costs.

Many other people take a contrary view. To them, euthanasia is a commendable idea for making the best of a bad event that otherwise would be even worse. According to this very different understanding, death inevitably comes to all persons, but whether death occurs peacefully or is reached only through great suffering sometimes lies within our power to decide. In such cases, proponents of euthanasia argue, society owes its citizens at least the option of having a peaceful experience at the end of life instead of an anguished one.

In its broadest sense, euthanasia comprises any action intended to hasten death for the purpose of dispensing a merciful benefit. There are two different kinds of supposed beneficiaries. Euthanasia is said to benefit individuals by offering them death to relieve their suffering. Euthanasia also is said to benefit whoever is burdened by or otherwise disadvantageously implicated in the lives of the aforementioned sufferers. Thus, euthanasia divides populations into two classes of people: those who are supposed to benefit from their own quick deaths and those who are supposed to benefit from others' quick deaths.

Among the theoretically benevolent, but malignant in practice, ideas that have been applied to people with disabilities, euthanasia is one of the most prominent. Indeed, societal permission to commit acts of killing that might be labeled as, or lead to, euthanasia, and the frequency of such acts commonly are cited as evidence of societal disregard of the value of disabled people's lives. For example, although we commonly think of ourselves as mandated to provide nourishment to dependents, our sense of being obligated to do so seems to weaken to the extent that the dependent appears irremediably impaired. As a result, certain societies have condoned withholding nourishment from babies with certain congenital anomalies, people with profound traumatic brain injuries who are in the prime of life, and elderly people with dementia. The reasons for not nourishing them have been that their quality of life is inescapably inferior to individuals without impairments and that it is wrong to condemn them to the prolonged suffering occasioned by their deficits. This practice thus is fueled by societal presumptions that such people necessarily are very unhappy, absent sufficient research or other evidence that its empirical foundation is true.

SUFFERING WORSE THAN DEATH

The degree of suffering that qualifies as serious enough to call for hastening death is as controversial as every other aspect of euthanasia. We sometimes euthanize discarded pets simply because there is no one willing to care for them. Occasions of human suffering that people have thought grave enough to make death preferable include intractable or unceasing pain, hopeless illness, loss of control of bodily function, loss of dignity or autonomy, or becoming dependent or burdensome on others.

Culture and context affect whether or not persisting in any of these conditions is felt to be worse than dying. Of course, both cultural values and personal experience affect assessments of the badness of death. Islam, for instance, proclaims the sanctity of life and also holds that enduring unavoidable pain will be to an individual's credit in the hereafter, the real and enduring life. To take another example, Christian doctrine also usually is committed to the sanctity of life, and the doctrines of some versions of Christianity oppose any end-of-life intervention that reduces an individual's competency to repent in preparation for imminent death. To take a third and contrary example, Japanese Buddhism (but not other Buddhist sects) traditionally does not advance similar claims about sanctity of life and under certain circumstances tolerates or advises

ritualized suicide, abortion, and euthanasia. And as a fourth example, Jehovah's Witnesses do not count life as of preeminent value; they forgo certain medical interventions prohibited by their scriptural doctrine even if the outcome of rejecting treatment will be death.

Personal experience also divides opinion on this subject. As a group, people with chronic impairments or long-standing disabilities are more likely than nondisabled people to consider pain, illness, and dependence as components of ordinary life rather than as reasons to hasten death. To many people with disabilities, therefore, the usual arguments about benevolently hastening death are impositions made from the perspective of the nondisabled majority. Those who hold this opinion presumably prefer to endure all unfortunate future alterations of their current state of life. Maintaining the security to continue living even if existence seems unbearable appears to them to be the best strategy for safeguarding that life itself.

There are many other people with disabilities, however, who are less disposed to relinquish control over their own fates. They want to command decision making about their own medical treatment and to retain authority over the degree of pain and suffering they must endure. For many, such self-determination or autonomy is central to achieving value in their lives. Consequently, to be forbidden to do so by a possibly overprotected state is of overriding repugnance to them. Maintaining the liberty to end life should existence become unbearable appears to them the best strategy for safeguarding the value of that life.

DEFINING EUTHANASIA

Voluntary, Nonvoluntary, Involuntary Death

Variables affect whether or not an act of hastening death genuinely is euthanasia. One variable has to do with whether the person whose death is at issue seeks such acceleration; if so, the expression *voluntary* euthanasia is used. *Nonvoluntary* and *involuntary* euthanasia are the other types, and in theory these are distinguishable. In the latter, the euthanized individual is competent to consent but does not, while in the former no capacity to consent exists.

Passive and Active Killing

A second variable has to do with whether death is accelerated by intervening or by failing to intervene. *Passive* euthanasia is the term applied to failing to provide, or withdrawing, necessary life support, so that a patient dies. *Active* euthanasia is the term applied to intervening by administering lethal medication or applying some other technique that ends life.

A related controversy concerning the boundaries of euthanasia regards the condition of the individuals who die. Some think that to hasten death on grounds of benevolence always is to euthanize, regardless of whether the patient's life already is slipping away. Others hold that euthanasia applies only where individuals would have lived but for being subjected to a fatal intervention.

Private, Professional, and Public Agency

The third significant variable involves the identity of death's agent. Whether or not a terminal intervention is called "euthanasia" may be affected by whether the means of death is self-administered, administered by a health care professional in the course of treatment, or administered by an individual who is not qualified to or charged with giving medical care. There is disagreement about who has the status to euthanize. From one perspective, parents who end the lives of their own disabled children should be described as having euthanized them. Another perspective, however, reserves agency in euthanasia for medical personnel, or for the state. The ground for being concerned with this distinction is the action of a parent in regard to a child who is disabled is morally different, in important ways, from the action of a medical professional or government agent in regard to a population that is disabled. For some people, however, this distinction is morally negligible.

DIVERSITY OF TERMINOLOGY

No Agreement

There is no agreement as to whether these variables should be addressed so as to broaden or narrow the kinds of cases that are counted as true instances

of euthanasia. In some venues—for example, in the Netherlands—only voluntary self-executed and assisted deaths are termed euthanasia. There are other venues, such as the United States, where voluntarily assisted deaths usually are not called "euthanasia" and voluntary self-executed deaths never are. In the Netherlands, nonvoluntary deaths brought about for compassionate purposes are labeled as resulting from "life-terminating acts without explicit request," but in the United States some such nonvoluntary deaths may be the clearest examples of euthanasia.

In the Netherlands, both euthanasia (using the Dutch terminology, which entails voluntariness) and compassionate nonvoluntary life-termination have been deemed to be patients' rights. Physicians who facilitate their patients' exercise of these rights by dispensing euthanasia usually are shielded from punishment. In contrast, in the United States only voluntary passive dying is the right of the patient, made so because competent individuals are permitted to refuse treatment and thereby to reject life-supporting medical interventions. Voluntary active interventions to hasten death are called either mercy killings or assisted suicide, depending on whether the terminal intervention is executed by another party or is self-executed. All these open the U.S. agent or enabler of the death to prosecution, except that in the state of Oregon a patient within six months of death who is legally competent may obtain and self-administer a lethal prescription without triggering punishment for the physician.

Physician-Assisted Suicide as Euthanasia

Contention abounds about whether assisting disabled individuals who seek to self-execute their own deaths is nothing more than a camouflaged version of euthanasia. Physician-assisted suicide (PAS) is where the patient prefers self-administering the means to death over prolonged suffering from illness or injury, but also where procuring the means of death requires assistance from a physician. Some people believe that permitting physicians to facilitate disabled people's suicides is equivalent to killing them because, even when self-executed, such deaths are not really autonomous and therefore are not purely voluntary. They are prompted, it is said, by the disabled person's internalizing society's disparagement of disability. Other people believe it is simply a permissible implementation of people's exercise of the liberty to self-determine the time and manner of their deaths and that disabled people as a class are no more incompetent to enjoy such freedom than other people. Claims to such liberty are based on people's broader right to control when they will be subjected to medical intervention, a kind of freedom much cherished by many people with disabilities.

In the United States, physician assistance to a competent individual who self-determines to die and self-executes the activities needed to do so is suicide, not euthanasia, although opponents marshal the standard objections to euthanasia to combat permissiveness in regard to physician-assisted suicide. In the Netherlands, however, physician assistance in suicide is a form of euthanasia, with no moral difference drawn between a physician's providing a patient with a lethal prescription to be self-administered and administering a lethal dose to the patient. In opposition to U.S. practice, an equity argument with reference to people whose disability prevents them from self-administering is mounted in the Netherlands. This consistency of respect argument contends that physicians ought to accommodate patients who choose lethal drugs but whose conditions prevent self-administering them, as readily as they do nondisabled, as well as manually proficient disabled, individuals.

This argument is extended to people who are not able to give or refuse consent, fueling charges that physician-assisted suicide initiates a slippery slope that catapults a society into widespread practice of euthanasia. The thrust of the argument is that physicians ought to treat patients whose conditions prevent their making or communicating a wish to end their lives as benevolently as they do nondisabled and disabled individuals who are competent to consent to medical treatment. Therefore, in the Netherlands, physicians may end the lives of individuals who have not requested a hastened death but who, in the view of the physician, are or will suffer similarly to competent people who ask not to live. Ending the lives of neonates who almost certainly will not survive, or are dependent on intensive care and have a grim prognosis, or are not dependent on intensive care but are predicted to have a poor quality of life with sustained

suffering, such as with severe spina bifida, is an accepted medical practice under the hospital policy known as the "Groningen Protocol."

Withdrawing Life Support as Euthanasia

At the other end of the spectrum lies the hastening of death passively by refusing or withdrawing measures required to continue a patient's life. Some people think of such actions as killing and therefore characterize them as euthanasia, whereas for others these are decisions to refrain from futile (and arrogant) prolonging of the natural conclusion of a life. For example, in nations under shari'a (Islamic religious law), to withhold nutrition from patients is to euthanize them and is unlawful, while in the United States to do so for a patient at the end of life, and with the patient's or surrogate decision maker's consent, is not euthanasia at all.

Further dispute occurs over what kinds of interventions are artificial. Some hold that providing nutrition is natural because we do so for humans too young to feed themselves but that mechanically effecting respiration is not so. Others contend that all medical intervention is artificial, while still others believe that our better natures categorically call for taking all measures to fend off death.

Such profound differences of view about the propriety of providing patients with perpetual life support explain the different treatment afforded Karen Quinlan and Terri Schiavo, who both were young women with brain damage resulting in a persistent vegetative state (PVS). Believing that she was being kept alive on a respirator in defiance of what nature decreed, Quinlan's parents sued for the right to have her ventilation equipment removed. When doing so revealed she could breathe on her own, however, they maintained her nutrition and hydration using medical means because, they contended, parents have a natural duty to nourish their child. In contrast, Schiavo's husband, who possessed the legal power to represent her wishes, rejected tube-feeding as being so artificial a route to nourishment as to occasion intolerable suffering. But Schiavo's parents, joined by many disability advocates, contended that the overriding value lay in Terri's continuing to live.

LOOKING BACK AT EUTHANASIA

Given such disparities of usage, not to mention profound differences in fundamental conceptualizations, beliefs, and values, it is impossible to say to what extent euthanasia is legally prohibited worldwide, and it is equally impossible to discover how widely it is either openly or surreptitiously practiced. There are, nevertheless, clear historical instances of programs and practices that euthanized people because they were physically or mentally anomalous and thereby were deemed to be disabled and unfit. The most often cited and clearest example is the Nazi program initiated in late 1939 that authorized certain physicians to put to an involuntary "merciful" death people who had been diagnosed with incurable illnesses or who could not conceal their impairments but who were far from dying of natural causes.

This euthanasia program was preceded, in 1933, by the Law for the Prevention of Progeny with Hereditary Diseases, among which were counted schizophrenia, bipolar disorder, epilepsy, Huntington's disease, intellectual retardation, blindness, deafness, physical deformity, and alcoholism. Health care professionals were required to report anyone at risk of developing, or transmitting to progeny, these conditions. Almost 400,000 were sterilized. In 1935, the Marital Health Act forbade marriage between "healthy" people and carriers of "diseased" heredity. The latter were put on trial and then sterilized. The warrant was that citizens should be healthy to be productive and contribute to the social and economic well-being of the nation. Beginning in the previous century, Germans had enjoyed state-funded health and disability insurance, so keeping the population healthy also meant keeping down public spending.

The 1939 euthanasia program focused on the systematic killing of institutionalized individuals without their families' knowledge. Some disabled people living in the community also were targeted, however. Questionnaires disguised as census documents were distributed to physicians and then used to find victims. Those euthanized (initially children and later adults) were mainly individuals with developmental disabilities, psychiatric illnesses, neurological impairments, genetic anomalies, and progressive diseases. As one

German clergyman of the period wrote: "Recently the inmates of old-age homes have also been included. The basis for this practice seems to be that in an efficient nation there should be no room for weak and frail people" (Letter from Dr. Wurm 1940). Opposition, especially from the clergy, led to the program's suspension in late 1941, but a year later it was reinstituted. Instead of transporting "unfit" individuals to be gassed, the unfit, who now included geriatric patients and bombing victims, died from withdrawal of nourishment or lethal injection at treatment clinics or residential institutions. An estimated 250,000 Germans with disabilities were killed by the euthanasia program.

There is no moral ambiguity about the case of the Nazi euthanasia program. Disabled people were exterminated against their interest and without their consent, under the guise of helping them, but actually to relieve and thereby benefit nondisabled people. Such moral clarity is not characteristic, however, of most contemporary cases in which permission for a merciful death is pursued through legal or legislative processes.

CONTEMPORARY CASES

There is a question about whether a sufficiently troublesome resemblance exists between the paradigmatically morally reprehensible Nazi euthanasia practice and instances in which disabled individuals ask courts to permit their obtaining assistance in ending their lives. In the United States, Larry McAfee, a respirator-dependent quadriplegic, successfully sought to shield the individual who manufactured a device permitting him to turn off his breathing support. Elizabeth Bouvia, whose cerebral palsy and arthritis led her to want to cease eating, obtained a court order to prevent nutrition's being forced on her. In Canada, Sue Rodriguez unsuccessfully petitioned to enable a physician to provide a device permitting her to self-administer a lethal dose when she believed her motor neuron disease (MND) had reached an intolerable stage. In the United Kingdom, 19-year-old "A. K.," a MND patient, won the right to have his ventilator removed when he became "locked in" and no longer able to communicate even by blinking. Another MND patient, Diane Pretty, was unable to acquire a legal shield against her husband's being prosecuted should he help her to kill herself.

In these cases, disabled plaintiffs, exercising autonomy, voluntarily sought death, sometimes by refusing life-supporting treatment, sometimes by obtaining physical assistance to execute a lethal act, sometimes by arranging to self-executing the lethal act. Thus, these cases seem to lie very far from the paradigmatic Nazi euthanasia program, where disabled people met death involuntarily and through active interventions by the hands of others. In all these cases, nevertheless, there were disability advocacy groups that opposed the disabled plaintiff's plan. These groups warned against a slide down a slippery slope toward the same societal presumptions that energized the Nazi euthanasia program.

First, they argued, only if prompted by presuming the worthlessness of disabled people's lives could courts find for the plaintiffs in these cases. But it is precisely such a view of the dispensability of this class of citizens that inspired the Nazi program. Furthermore, equal protection would be violated if courts found for these plaintiffs, given that starving or suffocating nondisabled people never is condoned.

Second, courts that create such law in particular cases endanger all the disabled. Law and public policy arguably have an expressivist function: Beyond their letter, they also can send messages of approbation or disapproval, respect or contempt. Excepting disabled people from prohibitions against killing thus may send powerfully broad messages about their inferiority.

Furthermore, these messages may depress disabled people's estimation of themselves, to the extent that some disability advocates report experiencing depression so profound as to have brought them to the brink of terminating their lives. In a society they know very well will reject them, newly disabled people are especially vulnerable to losing hope of having a satisfactory future life. Families or other caregivers who fear being burdened might intentionally or inadvertently induce their disabled dependents to relieve them if an easy death could be found without difficulty. Disabled people or their loved ones also may think of death as a cost-effective alternative to expensive care that prolongs their lives without improving the quality.

Related to this point are concerns about euthanasia's attractiveness as an instrument of cost control. Some disabled people believe that health care

economics recommends using legal routes of causing death to remove patients and so reduce expense. It is unclear, however, whether eliminating the patients who are most readily removable this way serves the profit motive because at least some such patients—for instance, tube-fed geriatric patients—can be profit centers for custodial facilities. Nevertheless, a system to protect vulnerable patients from being sacrificed due to the cost of their care is unlikely to be effective because of the privacy that cloaks physician-patient interactions. It would be difficult to be confident that the patient's consent was voluntary and informed.

Third, the state is obligated to protect weak and vulnerable dependent people, such as the disabled commonly are. In the case of Diane Pretty, for example, the U.K. House of Lords ruled against a disabled woman seeking the right to kill herself on the grounds of the overriding public interest in protecting the weak and vulnerable. One lord remarked that it was impracticable for the law to attempt to distinguish between self-determining and vulnerable disabled people who are assisted in suicide. The U.S. Supreme Court has held that prohibiting assisting disabled people to end their own lives protects the poor, the elderly, disabled persons, the terminally ill, and persons in other vulnerable groups from indifference, prejudice, and psychological and financial pressure to end their lives and prevents a possible slide toward voluntary and perhaps even involuntary euthanasia.

LOOKING FORWARD: FEAR OF A SLIPPERY SLOPE

Two circumstances might prompt a slide toward a program of involuntary euthanasia such as the Nazis practiced. First, given the nature of physicians' access to patients, it might be difficult to prevent physicians from coercing patients into agreeing, or else fabricating patients' agreement, to end their lives. Second, given the nature of patients' reasons for ending their lives, it would be difficult to defend a prohibition against nonvoluntary euthanasia. Arguments for permitting competent disabled people to determine if they want to continue to live could be extrapolated to noncompetent people with similar illnesses or impairments. If a competent person finds living with a particular disability unendurable, courts might presume that incompetent people with similar disabilities would come to the same decision if they could.

Euthanasia policy therefore pits the interests of individual disabled citizens who prize self-determination against disabled people considered as a vulnerable group. A subset of the group of disabled people is especially dependent on strong paternalistic protections. Paternalistic policies, however, threaten opportunities for exercising choice by eliminating seemingly risky options for the group they are supposed to protect. There thus is a question about whether society is obligated to bar fully competent disabled individuals from an end they choose simply because of their membership in the disability classification. A related discussion addresses whether such self-sufficient disabled people are especially obligated to forego self-determination and under no circumstance seek to hasten death in order to safeguard their more vulnerable disabled peers.

POLICY IN THE NETHERLANDS

The developing freedom of ill and disabled people in the Netherlands to voluntarily end their lives increases the urgency of resolving these uncertainties. Until 1973, euthanasia courted prosecution and conviction in the Netherlands. In that year, a physician who had shortened her mother's agonized dying was put on trial but not punished. Courts then set guidelines for permissible medical intervention to hasten death: The patient must be suffering from a terminal illness, and the patient must request an immediate death.

Policy in the Netherlands has been influenced by the standard of community practice, by which is meant the prevailing consensus among physicians about the proper medical intervention once a diagnosis and/or prognosis is made. In 1984, the Dutch Royal Society of Medicine issued "rules of careful conduct" for euthanasia. Physicians had to inform the patient of the prognosis, consult the family (with the patient's permission), consult at least one other physician, keep written records, and obtain the consent of parents or guardian if the patient is a child. The boundaries set by these rules quickly proved elastic, however. In the following year, a court dropped the "terminal illness"

requirement. A physician was not punished for assisting a young woman who did not wish to experience the struggle of living with nonremitting multiple sclerosis to end her life, even though her condition was not terminal.

The Dutch courts and the Royal Dutch Medical Association (KNMG) subsequently established new guidelines for physicians: (1) voluntariness—patients' request must be freely made, well-considered, and persistent; (2) unbearable suffering—patients' suffering cannot be relieved by any other means; and (3) consultation—attending physicians should consult with a colleague. If these guidelines are followed physicians will not be prosecuted. The KNMG chose a narrow definition: Officially, euthanasia is the ending of the life of one person with the help of another but at the first person's request.

Thus, in the Netherlands euthanasia is by definition always voluntary. But there is no punishment for ending the lives of babies with Down syndrome or spina bifida or adults in a persistent vegetative state. In fact, during the past decade, about half of the physician-assisted deaths in the Netherlands would be identified as nonvoluntary or involuntary euthanasia in most other legal systems.

This last observation recalls the danger of creating a slippery slope. Some people conclude that permitting Dutch physicians to perform voluntary euthanasia encourages them to perform nonvoluntary and involuntary euthanasia. Others say that that the data about these nonvoluntary and involuntary deaths merely document the results of a community practice that has long prevailed but only recently been revealed. There is no possibility of resolving this dispute scientifically, however, because the data are drawn from physicians' interpretive reports of their own and their patients' intentions. The Dutch experience therefore does not establish, but neither does it disprove, the inevitability of society's sliding from permitting a disabled person to freely choose to hasten death toward prescribing the deaths of entire disabled populations.

CONCLUSION

Current conflicts and confusions about what should be called euthanasia preclude a global approach to identifying the principles most beneficial to disabled people in regard to policies permitting or prohibiting the hastening of death. This state of affairs makes it difficult to develop evidence about how likely various medical practices and community standards are to evolve into a euthanasia program that mirrors the Nazis' purpose of purging disabled people from the population. Yet such careful study is crucial if we are to create safeguards for the disabled that do not cross the line into paternalism and violate their freedom of self-control.

—Anita Silvers

See also Death; Do Not Resuscitate (DNR) Orders; Ethics; Physician-Assisted Suicide; Suicide.

Further Readings

Brockopp, Jonathan E. 2003. *Islamic Ethics of Life: Abortion, War, and Euthanasia*. Columbia: University of South Carolina Press.

Burleigh, Michael. 1994. *Death and Deliverance: "Euthanasia" in Germany c. 1900–1945*. New York: Cambridge University Press.

California Foundation for Independent Living Centers. 2000. *Euthanasia: The Disability Perspective on the Right to Die Movement*. Sacramento: California Foundation for Independent Living Centers. Retrieved September 7, 2003 (http://www.cfilc.org/projects/cfilc_position_papers/euthanasia.html).

Delany, Joseph F. 2003. "Euthanasia." In *Catholic Encyclopedia.* New York: New Advent. (Online version). Retrieved August 30, 2003 (http://www.newadvent.org/cathen/05630a.htm).

Dowbigginz, Ian. 2003. *A Merciful End: The Euthanasia Movement in Modern America*. New York: Oxford University Press.

Dworkin, Ronald. 1993. *Life's Dominion: An Argument about Abortion and Euthanasia*. London: HarperCollins.

Gallagher, Hugh Gregory. 1990. *By Trust Betrayed: Patients, Physicians, and the License to Kill in the Third Reich*. Boston: Henry Holt.

Glover, Jonathan. 1977. *Causing Death and Saving Lives*. Harmondsworth, UK: Penguin.

Gormally, Luke, ed. 1994. *Euthanasia, Clinical Practice, and the Law*. London: Linacre Center.

Kennedy, Ludovic. 1993. *Euthanasia: The Good Death*. London: Royal Society of Medicine.

Keown, John. 2002. *Euthanasia, Ethics and Public Policy: An Argument against Legalisation*. Cambridge, UK: Cambridge University Press.

Keren, Daniel. 2001. "Nazi Extermination of People with Mental Disabilities." In *A Teacher's Guide to the Holocaust.* Tampa,

FL: Holocaust Learning Center. Retrieved September 1, 2003 (http://fcit.coedu.usf.edu/holocaust/resource/document/DocEuth.htm).

Letter from Dr. Wurm, of the Wuerttemberg Evangelical Provincial Church, to Reich Minister of interior Dr. Frick, September 5, 1940. *Nazi Conspiracy and Aggression*. Washington, DC: U.S. Government Printing Office, 1946, Suppl. A, p. 1223. In *A Teacher's Guide to the Holocaust.* Tampa, FL: Holocaust Learning Center. Retrieved September 1, 2003 (http://fcit.coedu.usf.edu/holocaust/resource/document/ DocEuth.htm)

Perrett, Roy W. 1996. "Buddhism, Euthanasia and the Sanctity of Life." *Journal of Medical Ethics* 22:309–314.

Pool, Robert. 2000. *Negotiating a Good Death: Euthanasia in the Netherlands*. Binghamton, NY: Haworth.

Rosenhaft, Eve. 2001. *The Nazi Persecution of Deaf People*. Panel presentation, Gallaudet University, Washington, D.C.

Special Senate Committee on Euthanasia and Assisted Suicide. 1995. *Of Life and Death*. Ottawa: Minister of Supply and Services.

van der Maas, P. J., J. M. M. van Delden, and J. Pijnenborg. 1992. *Euthanasia and Other Medical Decisions Concerning the End of Life*. Amsterdam: Elsevier.

Verhagen, Eduard and Pieter J. J. Sauer. 2005. "The Groningen Protocol—Euthanasia in Severely Ill Newborns." *New England Journal of Medicine* 352(March): 959–962.

Young, Katherine K. 1989. *Hindu Ethics: Purity, Abortion, and Euthanasia*. Albany: State University of New York Press.

Websites

United States Holocaust Memorial Museum, http://www.ushmm.org/research/center/index.utp?content=endowed/right.htm%23deaf

EVALUATION IN EUROPE

See Disability Assessment/Evaluation, Europe

EVIDENCE-BASED MEDICINE

Evidence-based medicine (EBM) is a shorthand term for an approach to patient care in which decisions about the management of the individual patient are made by the clinician using his or her personal experience and expertise combined with use of the best-quality and most up-to-date scientific evidence. Summarized in this way, it may be thought that there is nothing about EBM to distinguish it from the main traditions that have dominated the science of health care provision for the past 200 or 300 years. While the degree of real originality of EBM is still disputed, it is beyond dispute that in the 1990s a powerful and cogent force swept through medicine, driven by articulate and forceful advocates for EBM, drawing largely on principles based in clinical epidemiology.

The enormous appeal of EBM stems from the very worrying and growing evidence that health services involve enormous and inexplicable variations between clinicians in the management of the same health problem. These variations are seldom explained by differences in either variations in patient characteristics or health care resources. Moreover, medical textbooks, far from instilling standard high-quality practice, have been shown to be major sources of error, producing misleading recommendations out of step with best available scientific research. For example, clear evidence from research about the benefits of intravenous thrombolytic therapy in acute myocardial infarction was available for many years before it appeared in any medical textbooks.

At the heart of EBM is the use of best possible evidence in diagnostic and treatment decisions where *best* is defined by a clear hierarchy of quality-of-study designs providing evidence. The most reliable evidence is generated by properly randomized, controlled trials (RCTs). Below such study designs are well-designed cohort or case-control analytic studies. Less reliable evidence can be obtained from multiple time series with or without the intervention. Least reliable of all, and therefore at the bottom of the hierarchy, is evidence in the form of the opinions of respected authorities, based on clinical experience, descriptive studies, and case reports, or reports of expert committees. Much debate has been provoked by the assertion by proponents of EBM that the RCT represents a gold standard method with all alternatives to varying degrees inferior. However, it is difficult to contest their basic argument that well-designed randomized controlled trials generally are least prone to biased estimates of treatment effects. In other words, if patients are properly randomized, estimates of benefits of an experimental intervention are less likely to be biased by, for example, differences in the pretreatment health status of patient groups or various other selection effects.

Increasingly, EBM emphasizes the central role of systematic reviews rather than individual trials. Where appropriate, systematic reviews of evidence result in a meta-analysis to produce an estimate of the net effect of an intervention across studies. Systematic reviews have their own sources of potential error and bias. For example, publication bias is one risk: Trials with a positive result are more likely to be published than trials showing no effect. As a result, the systematic review often needs to search the unpublished literature. Similarly, individual trials may not all be of similar quality in terms of how well they address risks of bias. A meta-analysis of the net benefits of an intervention across trials may need to omit or downplay the significance of poorer-quality trials.

One of the key developments in EBM was the foundation of the Cochrane Collaboration in 1993. Named after a British epidemiologist, Archie Cochrane, the Cochrane Collaboration is an international nonprofit and independent organization dedicated to making up-to-date, accurate information about the effects of health care readily available worldwide, particularly via its database of systematic reviews (the Cochrane Library).

EBM emphasizes five essential steps in the optimal clinical practice. First, the clinician identifies a clear clinical question arising out of the management of an individual patient, a question leading to a need for information. In the second step, he or she will identify the best source of evidence to address the need. Third, the evidence will then be critically appraised for its validity and applicability to the problem at hand. Fourth, the evidence will be combined with clinical experience and the patient's own preferences and values to determine an intervention. At the last step, the outcomes of the intervention in the patient are subsequently evaluated.

EBM began as a movement to improve individual patient care. Its principles are, however, just as relevant to many other aspects of health care. What are the optimal ways of delivering health care? What are the most effective ways of improving health professionals' practice? What are the most cost-effective methods of promoting healthy lifestyles of populations? It is commonly argued that all such questions are more effectively addressed by synthesis and meta-analysis of best available evidence. Some of the greatest returns from investment may arise from relatively simple interventions in resource-poor populations: hygiene-oriented interventions such as hand washing, nutritional supplements for children, and antibiotic prophylaxis for HIV. The need for randomized controlled trials and evidence-based practice in such global health challenges is enormous.

The initial impetus for EBM came from academic medicine, understandably advocating the application of applied health research to clinical practice. Strikingly, the financial, managerial, and ideological support for EBM of governments and other funders and providers has been of enormous importance in sustaining the movement. This support arises in general terms because of the attractive prospect of services being developed that are more appropriate and cost-effective for the population served. In more specific terms, EBM generates detailed guidelines and explicit protocols for the delivery of services, developments that in principle make it far easier to monitor and steer the performance of health professionals than was the case when professional decisions were essentially a "black box beyond scrutiny." The provision of unbiased information about effectiveness of interventions also has an obvious appeal to patient groups otherwise dependent on commercial or other biased sources of information and advice. EBM would seem an advantageous development for all stakeholders in health care.

Three major issues currently confront EBM: (1) technical and scientific issues regarding the foundations of EBM in RCTs, (2) political critiques, and (3) practical and organizational challenges of implementation. The initial momentum of EBM in some ways resembled the fervor of a religious movement; the current phase of development requires confrontation with many complex realities of health care.

The first complexity is the widely expressed argument that RCTs cannot provide a sufficient knowledge base for all problems in the delivery of health care. There are some important questions in health care that will never be resolved by RCTs for practical reasons. This may occur when adverse events to be avoided are so infrequent that trials would require impossibly large sample sizes or where the health outcomes are so far in the future that there would be major practical problems of maintaining a trial. A quite different problem is that

many questions will not be addressed because of ethical concerns about conducting a RCT to address such questions, for example, in the field of critical care. There may also be political objections to the use of RCTs. For example, methods of funding and organizing primary care in the United Kingdom have repeatedly been introduced without a firm evidence base, their introduction being determined rather by political preferences and intuitions about change.

There is also a continuing and lively debate about whether RCTs have to be the gold standard in proving an evidence base for practice. Several studies have compared the results emerging from meta-analyses of RCTs with those obtained from observational studies such as cohort designs. The conclusion is often that although observational studies are more frequently prone to methodological failures to address bias, well-designed observational studies produce similar results to those obtained from RCTs.

Another important technical problem is the relevance of results from clinical trials and systematic reviews to decisions about individual patients. The research evidence is usually about the average effect of an intervention across all types of patients. The extent to which this average effect is applicable to patients with any given features of disease severity or comorbidity may be unclear, because the evidence from trials does not have sufficient power to analyze trends in subgroups. Where it has been possible to examine evidence in subgroups, for example, in drug and surgical treatments of stroke, it has become apparent that benefits do differ significantly according to patients' baseline characteristics. A related and more general criticism of evidence from RCTs is that trials tend to be performed on a rather narrow range of patients, for example, often patients with more favorable overall health status, so that generalization to more "typical" patients is difficult.

Although the scientific limits of RCTs are increasingly being identified and recognized, these limitations do not fundamentally flaw the basic principles of EBM. They may mean that trials and related studies will need to be increasingly large and complex to address information needs that arise in caring for individual patients.

A second challenge stems from political critiques. One powerful analysis of EBM argues that the movement represents a fundamental (and undesirable) erosion of professional autonomy of health professionals, especially medicine. Some observers argue that the reduction of clinical decisions to explicit guidelines and protocols results in the practice of "cookbook" medicine with all important decisions taken at much higher levels in the overall management of health care organizations. In turn, these higher-level priorities will be largely driven by business models of efficiency and cost control rather than the interests of patients. Such critiques view EBM as one of a number of managerially led developments that lead to the deprofessionalization of medicine, motivated either by the profit motives of business or government concerns to control costs of the welfare state. It is also argued that the significant investments by organizations such as the U.K. National Health Service (NHS) in bodies such as the Centre for Disseminations and Review and National Institute for Clinical Excellence (key bodies assessing the evidence base for health care interventions in the NHS) are the outcome of a conflict for power and resources won by statisticians, accountants, and economists over traditionally powerful groups such as the medical profession.

The political critique forces us to reflect on the broader significance of EBM and usefully draws attention to potentially harmful threats to responsible and professional clinical practice if reduced to mechanical implementation of guidelines. On the one hand, however, the scale, scope, and reality of such threats are probably exaggerated. Moreover, the political critique underplays the extent to which the overall goals of EBM are welcomed by practicing clinicians and overlooks the extent of collaboration of clinicians with statistical and other nonclinical disciplines in developing the scientific underpinnings of EBM.

The third and ultimately the most important issue surrounding EBM is whether it is an approach to medicine that is feasible to implement in practice. Studies from around the world, including Australia, Canada, New Zealand, and the United Kingdom, suggest that only a minority of clinicians report using evidence-based information sources such as the Cochrane Library. One survey found that only 4 percent of a sample of U.K. general practitioners had ever used the Cochrane database of systematic reviews to help in clinical decisions. Studies have identified a range of reasons for the relative lack of uptake. Many clinicians

remain unaware of what constitute high-quality forms of evidence, still relying on traditional reviews and textbooks. Clinicians are often unaware of how to access systematic reviews. In some cases, their offices may simply lack appropriate Internet connections.

In general terms, research evidence suggests that although clinicians do express concerns about the threat to autonomy posed by what seems like guideline-governed medicine, they nevertheless welcome the emergence of EBM. There remain concerns about the importance of intuition, context, and judgment as important factors in the practice of medicine that are devalued by some versions of EBM. The view is also expressed that EBM may jeopardize the role of the doctor as therapist (the so-called placebo effect) regardless of specific interventions that he or she may use.

The biggest single barrier to uptake, however, is lack of time due to heavy workloads. Clinicians feel that it is unrealistic in clinical practice to seek out and appraise relevant scientific evidence to resolve clinical uncertainties. For this reason, the EBM movement has moved on from its original pure conception. Now it is argued that while some clinicians may be "doers" of EBM, in the sense of following all of the steps from problem identification through evidence searching and synthesizing to action and evaluation, they are likely to be outnumbered by two other important categories of clinician. First. there is the "user" of EBM who does make use of secondary reviews already made readily available. Probably even more important in the future is the "unconscious user." This clinician will work in an environment in which EBM-based cues, prompts, and advice will be made available in the course of routine practice without being actively sought by the clinician. To take an example, clinicians may receive specific relevant advice on an automated basis when they enter a prescription into an electronic system. There is very encouraging evidence that such automated prompts induce more appropriate use of prescribed drugs by the doctor.

EBM is now entering a more mature phase where the complexities of what constitutes good evidence are accepted and the difficulties of applying evidence to individual practice are acknowledged and addressed. Constant advances in information technology encourage optimism that feasible applications of EBM will emerge. One outstanding issue is relatively unexplored. Clinicians often identify patients' own views, preferences, and requests within the consultation as a further barrier to EBM, especially when they are in apparent conflict with best evidence. Ways of achieving the active inclusion of the patients' values in the EBM will represent the larger challenge to the evolution of this exciting paradigm.

—Ray Fitzpatrick

See also E-Health Care/Telemedicine; Medicine; Quality of Life.

Further Readings

Black, Nick. 1996. "Why We Need Observational Studies to Evaluate the Effectiveness of Health Care." *British Medical Journal* 312:1215–1218.

Charton, Bruce and Andrew Miles. 1998. "The Rise and Fall of EBM." *Quarterly Journal of Medicine* 91:371–374.

Concato, John, Nirav Shah, and Ralph I. Horwitz. 2000. "Randomized, Controlled Trials, Observational Studies, and the Hierarchy of Research Designs." *New England Journal of Medicine* 342:1887–1892.

Guyatt, Gordon H., Maureen O. Meade, Roman Z. Jaeschke, Deborah J. Cook, and Brian Haynes. 2000. "Practitioners of Evidence-Based Care." *British Medical Journal* 320:954–955.

Mant, David. 1999. "Can Randomised Trials Inform Clinical Decisions about Individual Patients?" *Lancet* 353:743–746.

McColl, Alastair, Helen Smith, Peter White, and Jenny Field. 1998. "General Practitioners' Perceptions of the Route to Evidence Based Medicine: A Questionnaire Survey." *British Medical Journal* 316:361–365.

Sackett, David, Brian Haynes, Peter Tugwell, and Gordon Guyatt. 1991. *Clinical Epidemiology: A Basic Science for Clinical Medicine*. Toronto: Little, Brown.

Sackett, David, Sharon Straus, Scott Richardson, William Rosenberg, and Brian Haynes. 2000. *Evidence-Based Medicine: How to Practice and Teach EBM*, 2d ed. Edinburgh: Churchill Livingstone.

Websites

Centre for Reviews and Dissemination, York, United Kingdom, http://www.york.ac.uk/inst/crd/index.htm

Cochrane Collaboration, http://www.cochrane.org/index0.htm

National Institute for Clinical Excellence, United Kingdom, http://www.nice.org.uk/

EVOLUTIONARY THEORY

The first half of the twentieth century was consistently characterized as an age where the eradication of disability was within Western science's grasp. Beliefs

about the potential for eradicating disability need to be understood with respect to developments in evolutionary theory and the process by which "defective" human bodies were produced in the wake of Charles Darwin's revolutionary notions of natural selection. Briefly, Darwin's theory of species adaptation and diversification rested on three key principles that have great value for disability studies:

1. Most variation is for the good of the species.
2. Adaptation is random and gradual in nature.
3. Fortuitous variations are unpredictable given that shifting environments alone determine organismic viability.

As an important aside, Darwin disapproved of any human intervention efforts to control the process and direction of species variation.

Few theories have had a greater impact and been so misread as Charles Darwin's revolutionary analysis of the origins of the species. Rather than a divine presence overseeing and orchestrating the invention of nature and the organisms that comprise it, Darwin's evolutionary model premised that all organisms evolved from a shared origin and that differentiation is the product of adaptation over time produced by interactions with environmental forces. Previous theories of species development hinged on a belief in a mechanism of internal determinism that guided species toward increasing perfection. Darwin overturned these notions by positing that species development occurs through a haphazard process (termed *natural selection*) where some organismic characteristics prove accidentally fortuitous to certain environmental conditions. Thus, one of the major innovations of Darwinian theory rested on a debunking of an ideology of progress in species "advance" that undergirded Enlightenment thought.

What we often refer to as disabilities today are central to evolutionary theory. Such conditions have been represented as either a failure of adaptation (organismic regression to a prior primitive state) or as a site of potential species innovation. The intellectual history of evolutionary theory is multiple and vexed with respect to the meaning of mutation (those forms of organismic and species differentiation marked as "severe" or most atypical). Following Darwin's philosophical break with the formalist tradition (planned internal design toward perfection), as represented by debates between Geoffrey, Cuvier, Agassiz, and Owen and particularly in theories of gradualism developed by Darwin's primary mentor, geologist Charles Lyell, Darwinian theory's three central themes have been amended and/or extended but not toppled in the sense that the kernel of natural selection remains intact. The solidity of this theoretical foundation is surprising in spite of those who have made relentless challenges to all three key Darwinian domains.

Those who attacked Darwin's theories from the mid-nineteenth century onward included eugenicists such as Galton; the mutationists such as de Vries and Goldschmidt; the catastrophism of Kelvin and Malthus; the "hardening" of Darwinian thought that occurred during the modern synthesis (1937–1963) in the work of Simpson, Dobzhansky, and Mayr; the rise of modern genetic theories that try to locate adaptation exclusively at the molecular level; and finally, the contemporary macroevolutionary theories of Gould and others. The primary argument that has served as a catalyst for evolutionary theory is between those who argue for the excesses of mutancy as superfluous, and thus largely undesirable, deviancy and those who believe that organismic/species creativity originates at the "extremes" of special variation. This structuring dichotomy is the focus of the remainder of this entry as that which is most critical to ongoing evolutionary debates for disability research.

The saltationists argued against the validity of Darwinian natural selection based on limitations ("structural constraints") inherent in the germ plasm or organisms. Following the lead of Sir Francis Galton, eugenicists theorized that species differentiation occurs according to the laws of regression toward the mean where atypical features—both desirable ("genius") and undesirable ("idiocy")—tend to give way to the overreplication of traits considered average or typical across a species. Unlike Adolphe Quetelet, the Belgian statistician who viewed average characteristics as most desirable, Galton's fascination was exercised in favor of extreme points of deviation from the mean. By dismissing the critical principle of Darwinian gradualism as too slow and inefficient to adequately explain species development, the saltationists

advocated directed breeding practices. Unlike Darwin, who argued for an Adam Smith-like laissez-faire attitude toward adaptation, saltationists-turned-eugenicists encouraged the practical application of Mendelian principles to state oversight of human reproduction. Eugenics promoted the adoption of public policies that would better ensure the transfer of "desirable" characteristics (i.e., intelligence, eye color, and other features primarily associated with Caucasian peoples), and discourage the passage of "undesirable" traits (i.e., feeblemindedness, epilepsy, blindness, deafness, congenital impairments, alcoholism, and ethnicity). In other words, saltationist theories encouraged direct intervention in the process of species evolution to artificially cultivate some traits at the expense of others in a nation's germ plasm.

Another aspect of the saltationist debate with Darwinism was the more promising development of mutation theory by the Dutch botanist Hugo de Vries in 1909. Like Galton, de Vries poured his energy and theoretical development into the interpretation of genetic "extremes" (those rarefied cases that comprised the right and left tails of the bell curve). Yet, whereas Galton viewed "deviation" as largely irrelevant to organismic adaptation in nature and across epochs, de Vries's "mutation theory" championed "deviancy" as the locale of species "creativity." As a mutationist who also paradoxically embraced Darwinian principles of natural selection, de Vries argued that the production of "giant" and "dwarf" forms of the *Oenothera* plant signaled the origin of a new variation in an otherwise doomed organismic homogeneity. Consequently, de Vries merged the two extant theories of evolutionism—Darwin's non-directed selectionism with Galton's saltational "facet-flipping" (the sudden appearance of a new organismic form)—in the articulation of one of the first DNA-like arguments of organismic invention. Mutation theory's penchant for rapid and dramatic change in the matter of a generation provided one of the first successful efforts to overturn Kelvin's arguments that the planet was too young to accommodate Darwinian investments in the single species hypothesis. In other words, genetic mutations (many of which are classified as today's congenital impairments) serve as catalysts for species differentiation over time.

DeVries's celebration of mutational principles continue to resonate not only in the much maligned formulation by Goldschmidt in 1940 of "hopeful monsters"—"a completely new anatomical construction" that emerges in "one step from such a change"—but also in more contemporary theories such as Gould and Eldridge's most original contribution to macro-evolutionary theory called "punctuated equilibrium." While Darwin located adaptation exclusively at the organismic level, Galton moved down the evolutionary scale to the level of germ plasm, and de Vries's mutation theory manifested its most significant impact at the species level, punctuated equilibrium formalizes its theory of adaptation at the cladistic level (evolutionary branching at the level of multiple lineages). This theory is distinct from that of most contemporary geneticists who (like the saltationists before them) argue that the molecular scale determines outcomes at all levels above: organisms, species, clades. As a field that relies on narrative methodologies that include history and interpretations of the fossil record, macro-evolutionary theory seeks to analyze the crucial dimension of adaptation as an expression of interactionism between species-individuals and environments. In doing so, evolutionary theory places itself in direct competition with genetic determinist models where the transfer of molecular materials across generations can presumably account for the majority of manifestations of species differentiation.

At stake in these arguments for current disability-based research is the overreliance on molecular analyses as deterministic of human forms perceived as "unacceptable" at the social level. In displacing a social process into the organic, one effectively seals off the complexity of social influences upon an object of study. By locating a gene (or now perhaps a protein) as the origin of "deviancy," geneticists perpetuate the fallacy of the early saltationists who believed that organisms were internally directed in a deterministic fashion. As a direct disciplinary descendant, contemporary genetics threatens to reproduce the value system that powered eugenical practices at the beginning of the twentieth century, namely, by misrecognizing the organism (rather than the messy interactional space that exists between individuals and society) as the appropriate arena of intervention. This

is a critical site where social model approaches to disability can contribute to the growing theoretical base of evolutionary thought.

As with the field of ethics, the meaning of disability functions as the unacknowledged Other in evolutionary theory. The discourse provides significant materials to fuel further disability research efforts to transform impairment from a presumed inferiority into a system of adaptive responses that continue to guide the origins of the species.

—David T. Mitchell

See also Charles Darwin; Eugenics; Mutation Theory.

Further Readings

Darwin, C. [1859] 1995. *The Origins of the Species.* New York: Gramercy.

De Vries, H. 1909–1910. *The Mutation Theory: Experiments and Observations on the Origin of Species in the Vegetable Kingdom,* 2 vols. Chicago: Open Court Publishing Comp.

Goldschmidt, R. [1940] 1982. *Material Basis of Evolution.* Princeton, NJ: Princeton University Press.

Gould, S. J. 2002. *The Structure of Evolutionary Theory.* Cambridge, MA: Harvard University Press.

Mitchell, D. and S. Snyder. 2004. *Cultural Locations of Disability.* Ann Arbor: University of Michigan Press.

EXERCISE AND PHYSICAL ACTIVITY

During the past 50 years, many scientific studies have examined the relationship between physical activity, exercise, and health. The results of these studies have demonstrated that physical activity and exercise have a significant and positive effect on health promotion, disease prevention, treatment of chronic illnesses, and rehabilitation of people with disabilities. At the same time, lack of physical activity or a sedentary lifestyle has been identified as an important risk factor for chronic diseases. Thus, governments and public health agencies have developed policies including recommendations to promote and maintain an active lifestyle. Furthermore, many professional organizations have included exercise as an integral part of various clinical therapeutic and rehabilitative protocols.

Physical activity can be defined as any activity that involves the neuromuscular system and results in energy expenditure. Physical activity can be classified into various categories including occupational, recreational, or sports-related based on the objectives of the activity and the environment in which it takes place. All categories of physical activity have been associated with positive health outcomes in a large number of studies conducted since the 1950s. Exercise, on the other hand, is a subset of physical activity that is planned, repetitive, and structured to improve the physical and psychological health of a person. Exercise can be classified based on the nature of the muscle action involved (static [when there is no joint movement] vs. dynamic), the physiological adaptations induced (aerobic, strengthening, flexibility, or stretching), or the clinical objective of the exercise program.

Many disabling conditions are associated with reductions in health-related fitness. A practical classification of exercise is based on the nature of the specific component of health-related fitness that the exercise program is targeting. The health-related components of fitness include flexibility, muscle strength, muscle endurance, cardiovascular endurance or aerobic capacity, and body composition (percentage body fat or lean body mass). In this context, the type of exercise chosen must be specific for the physiological or functional capacity that needs to be developed. Thus, when the objective is to increase muscle strength, a specific exercise prescription for strength (or resistance) training such as weightlifting is indicated. If the clinical need is to develop flexibility, then a stretching exercise program is recommended. For cardiovascular endurance, and to increase aerobic capacity, exercise programs that activate large muscle groups such as walking, swimming, cross-country skiing, dancing, and many other similar activities are more effective in obtaining the goal. Finally, both strengthening exercises as well as aerobic activities influence body composition in a positive way by reducing body fat and maintaining or increasing lean body mass.

It should be clear that the goals have to be defined first and that the exercise recommendations must be specific for the chosen goals. The process of setting goals, one of the central tenets in the practice of clinical rehabilitation, is guided by the nature of the disease or injury and the physiological or functional losses associated with it. For example, when an injury to the

knee joint results in joint swelling and pain that requires immobilization in a brace to protect tissues from further injury, the range of motion of the joint may be reduced and muscle atrophy can develop. In this situation, a program of flexibility exercises is indicated to treat the joint loss of motion and a strengthening exercise is designed to prevent or restore the loss of muscle mass and strength. Joint contractures and muscle atrophy are examples of impairments that, if not treated, could lead to a permanent disability.

Exercise and physical activity have been shown to be effective in the primary prevention of several chronic diseases that are common causes of death and disability in many countries. For example, epidemiological studies show that physically active men and women have a lower incidence of coronary heart disease, stroke, hypertension, diabetes, obesity, breast cancer, colon cancer, and depression. The evidence is so strong that many professional organizations and public health officials have included exercise as an important component of their health promotion strategies and the World Health Organization has endorsed an international "physical activity day" to promote the benefits of physical activity.

Although primary prevention is important, exercise can also be used for secondary prevention after the disease has evolved to a clinically detectable condition. Patients who have already developed these diseases can benefit from exercise programs because the regular participation in such programs induces adaptations in almost every organ/system of the human body. Some of the physiological and metabolic adaptations to exercise that help in the treatment of these diseases are a reduction in body weight and fat, an increase in lean body mass, lowering of blood pressure at rest and during exercise, enhancement of cardiac function, improvement in peripheral circulation, proliferation of small blood vessels or capillaries, increase in HDL (or good) cholesterol, reduction in LDL (or bad) cholesterol, improved sensitivity to insulin, and increased tolerance for physical stressors.

Finally, patients in rehabilitation programs, for example, stroke survivors, patients recovering from heart surgery or myocardial infarction, patients with pulmonary disease, amputees, and many others can also benefit from exercise programs. In a rehabilitation setting, where disability is prevalent, exercise can be used to normalize the basic pathophysiology of the disease (e.g., carbohydrate metabolism in diabetics), limit impairment (e.g., by increasing motor control in the hemiplegic arm), and correct functional losses (e.g., with gait training in amputees). In other words, physical activity and exercise have been shown to be effective interventions at different points of the pathway to disability. Without offering a cure for a permanent impairment or an incurable chronic disease, exercise can enhance the functional capacity and quality of life of the person with a disability.

It should be noted that although the physiological adaptations to exercise training have received more attention, exercise has also been shown to have important psychological and mental benefits. People involved in regular exercise programs report lower levels of anxiety, reduced depression scores, higher levels of self-esteem, improved well-being, enhanced cognition, and higher tolerance to pain. More research is needed in this area but the scientific evidence in this respect is convincing.

When recommending exercise as an intervention to minimize tissue damage, limit impairment, enhance function, or reduce disability, it is important to be specific. Thus, an exercise program must de defined in terms of the type of exercise and its frequency (sessions per day or week), duration (number of minutes per session, number of sets and repetitions), and intensity (usually expressed relative to the maximal capacities of the person). Although general guidelines exist, more research is needed to define the optimal combination of these elements for different patient populations and for persons with different types of disabilities. Furthermore, many recommendations have been developed for healthy subjects without disabilities and it is not clear that the results of those studies can be extrapolated to all.

The type of exercise is defined by the goal (as mentioned above) and the other three elements (frequency, duration, intensity) are specific for each type of exercise. The selection of the type of exercise is also influenced by the nature of the disability, the personal preference of the individual, and the existing resources in the community to support the choice. In other words, if swimming is ideal, does the person

have access to a swimming pool? Another important consideration is the equipment that may be needed to perform the exercise. A wide variety of options are commercially available and both home- and gym-based options can be considered. Considerable research has been done in this area to develop adapted equipment for the exerciser and the practice of sports modalities for people with disabilities. For example, persons with permanent disabilities such as amputations and spinal cord injuries can use special skis for downhill skiing and wheelchairs to play basketball and compete in track sports.

Exercise programs have to become part of the daily and weekly routines of the individual. If not practiced regularly, the benefits of exercise will be lost, usually over the course of several weeks or a few months. In general, flexibility exercises are practiced daily, strengthening exercises 3 or 4 times a week, and aerobic exercises almost all days of the week. Although each person may have to develop an individualized program, specific recommendations regarding duration and intensity have been published in many forms and are available for specific types of exercise.

In summary, physical activity and exercise can be effective in the prevention, treatment, and rehabilitation of disability. There are no reasons for persons with disabilities to avoid exercise.

—Walter R. Frontera

See also Health Promotion.

Further Readings

Booth, Frank W., Manu V. Chakravarthy, Scott E. Gordon, and Espen E. Spangenburg. 2002. "Waging War on Physical Inactivity: Using Modern Molecular Ammunition against an Ancient Enemy." *Journal of Applied Physiology* 93:3–30.

Durstine, J. Larry and Geoffrey E. Moore, eds. 2003. *ACSM's Exercise Management for Persons with Chronic Diseases and Disabilities.* Champaign, IL: Human Kinetics.

Frontera, Walter R. and Jonathan Bean, eds. 2003. *Strength and Power Training: A Guide for Adults of All Ages.* Boston: Harvard Health.

Frontera, Walter R., David M. Dawson, and David M. Slovik, eds. 1999. *Exercise in Rehabilitation Medicine.* Champaign, IL: Human Kinetics.

Pate, Russell R. et al. 1995. "Physical Activity and Public Health." *Journal of the American Medical Association* 273:402–407.

EXHIBITION

The term *exhibition* is a very general way of describing public presentations of a wide variety of subjects, including art, goods, services, athleticism, and performance. In the context of nineteenth-century popular entertainments in the Western world, "exhibitions" were colossal, grand-scale displays of industry and commerce held in various metropolises on grounds constructed specifically for that purpose. The largest of these were known also as "International Expositions" or "World's Fairs," sponsored by leading citizens and supported with vast government grants. Generally speaking, these events resembled small, rapidly erected cities of massive, architecturally ornate buildings showcasing the greatest recent advances in scientific development. Inside the buildings, visitors could bear witness to the agricultural, commercial, cultural, and technological marvels of the day.

The exhibitions were also known for attracting entrepreneurial vendors, showmen, and cheap service providers who erected ramshackle restaurants, hotels, saloons, amusement booths, and fly-by-night dime museums in hasty conglomerations that attached themselves to the larger, more "official" fairgrounds. These side-exhibitions were known as "shantyvilles" and "dinkeytowns," and they provided a profitable environment for less respectable forms of entertainment. In this *demimonde,* certain persons with disabilities, unusual appearances, or special skills could profitably present themselves as freaks to an audience whose appetite for wondrous entertainment was already whetted.

The first such exhibition in the world was held in London in 1851 and had been so successful and profitable that it spawned American revivals as early as 1853, when an attempt was made to create a New York City World's Fair. This attempt proved abortive, however, despite the fact that the entrepreneur Phineas Taylor (P. T.) Barnum had been invited to the board of directors. In his memoirs, Barnum blames the failure of the event on the refusal of the other prudish, middle-class directors to incorporate popular entertainments (which included freaks as well as musical and dramatic presentations) into the program. Paris would hold World's Fairs in 1867, 1878, 1889, 1900, and 1937.

The next great American exhibition was the Philadelphia "Centennial Exhibition" of 1876, which commemorated the century since the signing of the Declaration of Independence. It operated under no prudish restrictions, and during the six months of its operation it hosted some 10 million visitors (one-fifth of the total population of the United States at the time). The shanteyville it spawned was a mile long and featured some of the most widely known freak performers who appeared as "traveling foreign curiosities." These included the "Wild Australian Children," the "Aztec Children," the "Man-Eating Feejees," and the very famous "Wild Men of Borneo." Freaks who appeared in the context of exhibitions cultivated a performance style that conventional freak performers of the dime museum or the carnival midway adopted with less frequency. This style was distinct in two ways: It was "exhibitive" rather than "performative," and it was "exoticized" rather than "aggrandized."

The freaks of the exhibitions focused less heavily on "performance" than traditional freaks, who habitually included presentations of virtuoso skill in, for instance, acting, acrobatics, contortion, comedy, recitation, impersonation, mental acumen, singing, playing of musical instruments, or craftwork. Exhibition freaks relied less heavily on performance and more strongly on merely appearing in an exoticized manner. This mode of performance required the freak to be understood as an exemplar of a foreign culture. Indeed, the exhibition of disabled persons in such fairs was often wholly conflated with the exhibition of "perfectly ordinary" members of exotic tribes. The exhibits usually wore ostensibly authentic costumes and conducted ostensibly authentic activities in ostensibly authentic backgrounds. It was often the case that the entirety of an exhibit was invented, the elements of the presentation bearing no real relationship whatsoever to actual foreign persons, artifacts, or settings. The great manager George Middleton related an incident where he had employed his roustabout Bill Jackson, an African American from New Jersey, to pretend to be a "Zulu Warrior." Jackson, dressed in a lionskin with a great shield and assegai and a bone in his hair, suffered acute embarrassment when a lady in the audience recognized him and called out his name. The Wild Men of Borneo, in addition, turned out to be brothers of Scandinavian descent from Ohio.

Audiences of the time would not have drawn great distinctions between the presentation of exotic, nonwhite persons and freaks; in the context of the exhibition, both were presented as "scientific" exhibits to "educate and uplift" the public and were associated very much with middle-class Yankee values of courage, thrift, common sense, piety, and patriotism.

—Michael M. Chemers

See also Body, Theories of; Chang and Eng Bunker; Freak Show.

Further Readings

Bank, Rosemarie K. 1997. *Theatre Culture in America, 1825–1860.* London: Cambridge University Press.

Bode, Carl. 1959. *The Anatomy of American Popular Culture, 1840–1861.* Los Angeles: University of California Press.

Bogdan, Robert. 1988. *Freak Show: Presenting Human Oddity for Amusement and Profit.* Chicago: Chicago University Press.

Rydell, Robert. 1984. *All the World's a Fair.* Chicago: Chicago University Press.

Wilmeth, Don B. 1982. *Variety Entertainment and Outdoor Amusements: A Reference Guide.* Westport, CT: Greenwood.

EXPERIENCE

Our aim is to situate the primary experience of the disabled person that wakens to a relation with the lived body, temporality, spatiality, lived speech and in relationship to "others." For to contemplate the experience of disability is to bracket the thing itself. It is to be concerned with phenomenology rather than ontology. In the discourse of disability studies, it is to be concerned with disability over impairment, and with social construction, politics, and self-image over biology. The experience of disability is properly fundamental to disability.

Phenomenology aims at description of the patterns of lived experience. It is a philosophical approach that incorporates the mathematical-scientific point of view while providing access to a primary realm of human experience that remains irreducible. Such experience cannot be understood as merely "subjective" or

Note: Parts of this entry are taken from the authors' "The Phenomenology of Disability: Implications for Vocational Rehabilitation," William Roth and Richard Sugarman, *Rehabilitation Literature,* November/December (pp. 366–369), 1984.

psychological. Phenomenology cuts across the objective-subjective dimensions by which many view reality, and we maintain that a phenomenological perspective can bring important insights to disability that have eluded more traditionally "objective" social sciences.

The lived body maps out our temporal-spatial world through our movements and actions. The lived body is our own, one that experiences directly. It is not merely the residue of the anatomical body and conditions our being situated in a world with others. As Sugarman suggests, "near" and "far," "up" and "down" register as irreducible categories of corporeal existence. For the disabled person, these "directions" may present and raise questions that do not readily occur to others.

The experience of human temporality is measured by meaning and concern before it is calibrated by counting and calculation. This lived time is qualitative, heterogeneous, discontinuous, and purposive. Mathematical time is quantitative, homogeneous, and continuous. The reduction of lived time to mathematical time reduces the human subject to an object.

Recent discoveries, particularly by the French philosopher Emmanuel Levinas, show an irreducible exteriority that demonstrates an "otherness" prior to the distinction between social construct and biological condition. The relation between the other and the self has foundational implications for an ethic of disability. It is in the act of recovering from the encounter with the other that the self recognizes both his or her own subjectivity. This is the locus of responsibility of one for the other.

A philosophical deficit arises from our currently diminishing sense of primary experience. Able-bodied people are in a corresponding position to relearn perceptual experience from disabled people. As examples, the discontinuous character of lived time is punctuated for the disabled person. Waiting for the other person can become a commonplace personal and social experience for a disabled person. This kind of waiting is, or course, found in the everyday experience of the able-bodied as well. Indeed, often the disabled person inhabits the time of the other, perhaps experienced by the disabled person as waiting, anticipation, rejection, in any event, as disruption. For that matter, the disabled person often inhabits the space of the other and does so not as an intruder, but as captive. Even attempts to make space his or her own may be interpreted as confinement (i.e., the phrase "confined to a wheelchair"). The disabled person may simultaneously be apart from and mesh with the space and time of the other. This engagement of the disabled body with space and time, although not unique to disability, is particularly revealed in the experience of disability. With the accelerating pace of the workplace, the impatience fostered by an ever-increasing desire for instantaneous access to information, and an impatience with delayed gratification, the phenomenon of waiting and the virtue of patience are a diminishing part of postmodern industrial life. Indeed, expectations for maturation have left less time for children to act like children. It is possible to imagine social worlds where a disability is not disclosed as dysfunctional, deviant, or pathological. In such worlds, people would have different conceptions of disability and work that would make different demands on persons, whether disabled or not. If the structure of the work world is not necessary but contingent, then the significant message in an advanced technological society may be one of social artifact rather than social necessity. But frequently we regard the world of work as a natural order and try to adjust the disabled person to that world by education, medicine, counseling, placement, advising on the job, and so forth.

While everyone can potentially benefit from advances in information technology, the premature reduction of understanding to mere information benefits no one. Academic lectures now imitate the sound bites of televised news with the result that education itself may proceed in ways less than desirable. In fact, as Roth suggests, the disabled person paradoxically may have more to gain from the revolutions in computer technology than others. The necessity to modify or adapt computer equipment for disabled people returns us to the domain of the lived body and the primary experience of the senses. Using the ball of the foot to control a mouse refers the engineer back to the capacities of a foot that is guided by conscious intention. Intentional movement, understanding, attention, and waiting are all inescapable aspects of irreducible human experience.

Loneliness is a dominant category of contemporary postmodern experience that, as David Reisman showed in the 1950s, can be experienced in a crowd. However, being alone is quite different from loneliness. The impediments for disabled people, and here we include the ill, the sick, the aged, and the young as well, can bring about life-threatening circumstances as well as the desire for human companionship. The nature of such solitude depends on whether it is forced or optional, momentous or trivial, and contingent or noncontingent. Here we see the emerging of a foundation for an ethics where the disabled person performs the role of teacher rather than student. All infants need care, supervision, and nurture. There is an asymmetry involved in the obligation of the parent to the child. Consciousness emerges for the parent as a continuing responsibility for the child. In most cultures, the reciprocal obligation of a child to care for a parent does not bring with it either the same obligations or legal sanctions. This would suggest that there is a concession that is made to the irreversibility of aging. The awareness that our time and the time of the other are different for each of us may be more likely to be known in advance by those who are disabled. This sense that the other approaches us from without—exteriority—forces a doubling of consciousness where we experience ourselves as a body-subject. The first experience is one of positionality or proximity and therefore of a subjectivity.

The disabled person may experience lived time and space with a greater degree of discontinuity born of dependency than many an able-bodied counterpart. In this sense, the life of the disabled person is more likely to be folded into the urgencies, priorities, and concerns of the able-bodied. This creates a surplus suffering over and above physical impairment. Psychological consequences, the experience of depression in particular, may accompany such temporal marginalizing. However, what remains to be explored is the precise relation between pain and suffering, the self and other. It is a commonly held opinion that suffering can exist without physical pain. Such suffering may be understood as psychological, emotional, or spiritual. However, from a radically empirical point of view, it would appear that where there is suffering, it is experienced in a corporeal sense first as pain. Pain may be temporary, even fleeting, like stubbing one's toe or an insect bite. Furthermore, pain can be experienced without a consciousness of an expectation with respect to the source of the pain as being unfair or unjust. Suffering, however, requires pain experienced for a sufficient duration to be memorable. At the same time, suffering arises in relation to expectation and therefore in relation to the expectations of others as well. The element of surplus suffering for the impaired person is unnecessary and therefore, in the language of Levinas, useless suffering. Useless suffering refers to the arrogance that would rationalize the sufferings of the other, our friend or our neighbor.

If we wish to reflect on our own suffering and endow it with some deeper purpose or insert it within some eschatological scheme, we are perfectly free to do so. This rationalizing in the first person superimposes a kind of theodicy that, when applied to others, shows ethical obtuseness. The surplus suffering of others can be decreased and ameliorated. This is done by placing the other before ourselves. Levinas argues that "the only absolute value is the human possibility of giving the other priority over oneself." This, according to Levinas, is the responsibility that founds consciousness in relation to experience. Ethics, according to Levinas, begins with justifying our spontaneity in the presence of the other. What is assumed here is that the other approaches us with immanent demands that we are not free from obliging. There would seem no end to such responsibility. How then would the market place, the workplace, cohesive social groups, function?

It is the third party, the neighbor, who may be present or absent, near or far, a close family member or a stranger, who limits our responsibility so that the order of justice can be installed. In this way, there can be justice for us as well for others and neighbors. By responding to the other, we assume our responsibility as a body-subject. This temporal distance between ourselves and the other is lived in first instance as a responsibility for our passivity. This extreme vulnerability registers in the sensibility through which perception informs understanding.

In this entry, we adhere to what William James called a radical empiricism that brackets issues of essence, ontology, biology or, for that matter, any of

the other issues that may or may not be hidden behind the naked fact of our experience. Yet the experience of social beings is different from that of monads. The population of the experiential world by self and others and its animation by the multitude of relationships among these is not only part of that from which issues the experience of impairment but also, more important, that from which issues the rich complexities of the social experience of disability.

It is only a beginning to note that disability is overwhelmingly social, that is, given by the interactions of the self and others. Of course, others are of enormous variety and complexity. It is in the spirit of suggesting such complexity that we offer a rough-and-ready taxonomy of the other. Others can be divided into friends and strangers. The experience of disability is likely to be different for a friend or a stranger, as is the experience of this experience by the disabled self. Sometimes an other moves from being a stranger to being a friend, and the experience of disability may change accordingly. Another distinction about others, whose primacy we shall not comment, is that between master and slave. This sheds its dialectical relationship and is reified in the writing of Nietzsche through Foucault into the postmodernists. Here it is power that constructs knowledge including, of course, knowledge of disability.

There has been much talk about the medical model of disability. However, in the experience of disability, medicine is reabsorbed from its position of dominance as indeed it has been trumped by other vectors of social power. Gliedman and Roth point out that it has become ever clearer that the medical model is only a special case of the social pathology model. It appears then that power constructs our social world, some even say our non-social world. Hence the question of power is important to our experience and disability and it will be necessary to speak truth to power even if that involves questioning the primacy of power itself. Such indeed has been the trajectory of modern phenomenology.

Another distinction of others can be made between the professional and layperson. Often the professional invents and deploys a power that may be predicated on illusion. Other professionals may share the illusion, and laypeople may share it as well and be humbled before it. When the layperson is disabled, such dynamics become part of his or her experience. However, people of privilege know full well that professionals work *for* them. This has become evident in modern American culture with the displacement of the professional by the entrepreneur. For example, Bill Gates did not finish college, and he hires professionals. This is only part of an ancient tradition.

There are countless other distinctions that can be made between others such as distinctions in gender, age, proximity, class, or ethnicity. All or any can change the experience of the disabled self. For example, whether the other is erotic or neutered and whether the other considers the disabled self, for after all selves are others to others, as erotic or neutered can profoundly effect their relation in being that is contingent on relationships with others.

Thus, the human world is composed of complex aggregations of others. Indeed, the experience of others can make of them bigots actively hostile to people with disabilities. Far more typically, however, they do not know. Such ignorance may issue from their limited experience with disabled people. Often ignorance, or misinformation, echoes through the world of the other through complex mechanisms of culture that include language, practice, education, the media, advertising, or the law. In good measure, the liberation of people with disabilities involves changing such mechanisms. At times, disabled people have been unduly rancorous insisting on notions like temporarily able-bodied. Such nomenclature is often the reflection of the experience of the disabled person. How then are we to adjudicate the truth of experience?

An examination of the experience of disability recognizes the rich complexity of the location of the disabled person in the social and political world. Of course, society is never a monolith; rather it is a collection of ever-shifting people and groups. Often the relationship between these collectivities and people can be subdivided into a sort of taxonomy such as sketched above. Sometimes this taxonomy would seem to express relations of power constructing local and less local meanings to disability. Sometimes these meanings overextend themselves, forcing their experience on people with disabilities and on others. One example is the medical model of disability, perhaps

questionable itself, certainly questionable when used outside of medicine. Understanding the experience of disability can be magnified through the reciprocal experience of self and other. Indeed, it is not only the disabled person who must be concerned with the other, it is everyone, including others. A coherent explanation of the self, disabled and otherwise, is contingent on an examination of the other that transcends even the other as a source of much experience to the self.

Society, social agencies, social actors, and social scientists are governed by a rhetoric that implies a disabled person ought to adjust to the reality of disability and to the physical and social world. The disabled person who does not adjust is presumed to flirt with deviance and stigma. But there is another way to regard adjustment. Reckon that it might not be the disabled person who should adjust, but rather the social and physical world. The social world is composed of others. These others have certain ways they do things, beliefs and values they hold, and certain goals they desire. "Adjustment" expresses a relationship between a person and the environment. This relationship can expand or contract by changes in the person or environment or both.

Usually, we dwell on changes in the person. But corresponding possibilities of change elsewhere in the social structure exist, and we shall refer to them by the word *inversion*. Such terms as *work*, *education*, *productivity*, and *poverty* also express relationships between a person and the environment and are subject to inversion. If we are to understand and legitimate the experience of the disabled person, these terms must be explored with inversion in mind. The social structure is generally assumed to be natural and unchangeable. This is unjust both to society and the disabled person. Indeed, inversion involves not the adjustment of the disabled person to society but more frequently the adjustment of society to the disabled person—the complex reciprocities of adjustment reflecting back and forth through the mirrors of inversion.

Political and social reality is predicated on our experience. It is in the multitudinous reflections and refractions of countless others that a politics of experience is generated. Without the experience of disability, a politics of disability is arduous if not impossible. Stripped of experience, disability collapses into mere biology, bureaucratic case, or object of oppression. With experience the disabled body is activated and must be reckoned with. Of course, the sorts of politics that the experiencing disabled body can engage with are manifold ranging from exercising our bill of rights to voting, from communicating to organizing, from direct action to subtle pressure, from being constructed to constructive, from power to powerlessness, from freedom to servitude.

Perhaps special education, vocational rehabilitation, and other disability-dependent practices and professions exist to further the goals of professionals and an increasingly complex professional bureaucracy. It is possible that a system ostensibly serving a patient, person, or client primarily serves itself. Such inversion is a theoretical possibility and not a necessary fact. A society that discriminates does not know it erects barriers to disabled people and engages in unnecessary repression. This is particularly evident where society has generated a high degree of freedom from nature through technological mastery. The social and political construction of the disabled world by the able-bodied tends to disenfranchise and stigmatize persons with disabling conditions.

Embodiment, the lived body, discloses what a disability is. Disability is a difference in body orientation as well as appearance and anatomy. Or, to be more precise, disability is experienced as difference in the world inhabited by the lived body. It is, then, not only the body—which in most respects may be the same as a nondisabled body—but the way in which that body is informed by life, intentionality, will, intelligence, and other bodies that is decisive. A person with a disability is experienced as a person with a lived body that is different from the lived body of an able-bodied person. Body is a more interesting and fruitful notion than behavior, the sterile response to a stimulus. It is a more direct, tangible notion than that of action—we all are bodies, know what they are, and what they mean.

Sometimes the disabled person may resent being taken for a body, insisting rather that the real person lies within. Phenomenology suggests that the disabled person may be mistaken in this view. The proper relationship of the self to the body is not one of habitation, cohabitation, or possession, but is much stronger, approaching identity. Rather than "I am in my body,"

or "I own my body," or "I and my body go through the world together," it is more accurate to say, "I am my body." From the phenomenological explorations of the lived body by Merleau-Ponty, Ricoeur, Sartre, Straus, Levinas, and others, we have learned that the phenomenon of embodiment holds the central place in understanding the meeting place between the "subjective" and "objective" poles of human experience, products of the division of "mind" and "body," a dualism set in motion by Descartes.

The brain is part of our body. It is an organ of exquisite complexity whose very existence is prima facie evidence of the importance of bodies. Should one give brains attributes like consciousness and the ability to encounter the world with the rest of the body, much of our senses an extension of the brain, the requisite connection of the brain and the rest of the body become self-evident. The experience of our brains is a thorny issue, important nonetheless given the primacy of our brains and our brain's connection to experience itself. At times, our brains function differently, and mental illness, cognitive irregularity, and even the nature of experience itself change. Our brains are connected to our motor functions, senses, memories, and most of the rest that makes us who we are. If multifaceted, our experience of our brains is important. Sometimes we refer to this experience as "mind" (Minsky).

Often it is not our brains we experience, but rather the actions that issue from them and our bodies. Thus, much of our experience with mental illness is the experience of our actions that mental illness causes and the responses that they elicit from others. We all have the experience of being conscious beings, conscious among other things of our actions. An account of the experience of disability must be one of our actions and brains both—or together. Many impairments derive from the human brain or the difficulties it may have in connecting with other parts of the body. Such impairments may include those of the senses, motor system, cognition, mood, and more. Often our experience of a disability includes our experience of impairment. Often our experience of the impairment is an experience of our brain as revealed to us by other parts of our body, the brain having no sensory neurology to reveal experience. With impairments most commonly attributed to the brain such as emotional, psychological, mood, thought, speech, and reading and writing, experience becomes of supreme importance, for it is our experience of these that brings them to our consciousness and our actions, which may occasion responses by others that refract them into disabilities.

The experience of disability by the disability-experiencing self and by the disability-experiencing other and society rubs up against the non-human world. The relationship between the human and non-human world has transmuted into one where people have or expect to have dominance over most of the non-human world. For example, architecture, systems of transportation, education, and production are part of the human environment, and the disabled person's experience of them, perhaps hostile, perhaps inviting, is less experience of implacable nature than it is of human artifact. Usually, what human beings make could have been made otherwise. That it is not, and further that it is not even thought of being otherwise, suggests that the non-human environment is often constructed after the needs of some and not of all or even most. It is not surprising, then, that disabled people's experience of the non-human environment may be painful. It also follows that such awkwardness may in fact be in the face of actions of some people, usually those described as having power. A disabled person's experience of the human environment may be painful as well. Human organizations, bureaucracy, or culture may be experienced as painful by a disabled person. These are often in the service of those in power. Usually, people with disabilities are poor in power and therefore experience power as domination and oppression, rather than as empowerment and freedom.

When the disabled person desires to be accepted for what he or she truly is, rather than as a mere disabled body, that individual really protests against the obscure and tormenting construction of the disabled body by the able-bodied other. Such protest is in order; but if social oppression is internalized into a bifurcation of the disabled person and the body, insult is compounded.

The key to understanding the phenomenon of embodiment is intentionality. Only a dead body can be reduced to an anatomical object devoid of consciousness

and subjectivity. From a purely naturalist or objectivist standpoint, a stillborn child may prove every bit as important to pathological examination as a child born living. The newborn infant moves with precognition to its mother's breast. There is, however, a significant difference between the intentionality of oriented movement and its accomplishment. Here the human experience of disability can be measured by the distance between the intention to grasp, stand, walk, or speak and the ability to do so. Subjectivity is given as embodiment. "Here" and "there," "up" and "down," "before" and "after" are inexplicable abstractions without reference to a world mapped out by an oriented body-subject. Embodiment conditions all spatial and temporal relations. It is embodiment that by engendering perspective compels us to have "experiences." Attempts to devalue human experience run up against the limiting condition of embodiment. Embodiment renders subjectivity universal, and thereby opens up the life-world for indefinite exploration.

In a posthumous retrospective, Merleau-Ponty summarized his own discoveries on the meaning of embodiment while pointing out new directions. For contemporary psychology and psychopathology, the body is no longer merely an object in the world under the purview of a separated spirit. "On the side of the subject, it is our *point of view on the world,* the place where the spirit takes on a certain physical and historical situation" (Merleau-Ponty 1964:5). Merleau-Ponty, Straus, and others have already explored cases of disoriented subjectivity arising from differing corporeality to shed light on the phenomenon of embodiment in general. More simply put, phenomenology has buttressed its case by making reference to disability.

The lived body is more, however, than a medium through which self-transparent thought would express itself without interference from its embodiment, and, therefore, its situated history. As Merleau-Ponty (1964:6) states, "The perceiving subject is not this absolute thinker; rather, it functions according to a natal pact between our body and the world, between ourselves and our body." The inner world, or human subjectivity, is rendered possible and knowable by the concrete experience of human embodiment. Disability, viewed from the perspective of functionality alone, is a limiting condition binding childhood to old age. It is discovered in childhood as the "I cannot yet" and in infirmity of age as "I can no longer." In an emerging world of potentially embodied technology, the nature of disability is arguably changing. Yet with existing technology able-bodied assembly-line workers are not unlike disabled people in contemporary society. By expressing knowledge as power, function, or utility innovations in technology can extend the reach of the able-bodied population as well as the disabled, and thereby close the unnecessary, socially constructed distance between the two groups.

To design programs and policies without understanding the experience of disabled persons does violence to their integrity and engenders their understanding of the world in terms of powerlessness, anger, and discrimination. The surplus suffering experienced by the disabled population is largely socially constructed and begs each of us to return to the sources of intimacy and human relations. The face-to-face encounter is preserved in the body's mutability. So, too, is the empathy and love for the one who is other, strange, different, and so rendered by virtue of his or her embodiment.

The precariousness of the able-body is a counterpart to its soundness, for neither the able-body nor the disabled body is dead. Both experience the dynamic of change and the body's incarnation of the will to self-assertion. Both have pasts, presents, and futures. Both are more alike than otherwise. There is, after all, a substantial measure of truth in the conception of the able-bodied person as a temporarily able-bodied person. If this truth is burdensome it is because it is so close to the able-bodied person and the able-bodied person has a stake in an able-bodied existence. To the extent that "negative attitudes" of the able-bodied population toward the disabled may be predicated on fear, it is not taken lightly. What appears as a fear of the unknown is more accurately fear of the known. And what is known although denied as real, its density making it unavoidable (or to be avoided at all costs), is that time and change are unavoidable and, therefore, disability is universal in its implications.

We are at a crossroads where disabled people inform us of the answer to our humanity: "Every incarnate subject is like an open notebook in which we do not yet know will be written." The meaning of

humanity is open for both disabled persons and others. The latter should ground their encounters with disabled persons by keeping in mind how their own life-worlds were and are influenced by a complex social structure as well as by the possibilities of inversion. And finally—but not so since there is no finality here—the other must recognize his or her own subjectivity given as embodiment and the different subjectivities and experiences of different disabled people with different embodiments. He or she should never presume to know "what will be written," much less to write it. Assistance in the writing—by skill, teaching, counsel, wisdom, and by helping change the social order–is proper and honorable.

A decent society is measured by the way that people hold themselves responsible for the well-being of one another. The realization of social justice recognizes the asymmetrical relation between the other and the self. The experience of disability, or at least, to use Kant's term, "the possible experience," demonstrates the universal reach of ethical responsibility of one for the other. The social responsibility of one generation for another is enhanced with the recognition of the experience of finitude that disability brings. It also marks the achievement of a certain humanity when the framework of meaningful life and work is extended through refining the ethical obligations that elevate the social contract upon which societies are based. In this sense we are able to ground a policy of non-indifference towards the other as the starting point for further investigation into the experience of disability by inseparably linking it to the domain of ethics by which we measure the human within the order of things. Such an ethics begins with the other rather than the self and breaks with the dominant model of cultural and political imperialism that has dominated Western thinking since Hobbes. The idea of the one for the other is found not in the "State of Nature" as Rousseau thought; rather it begins with the capacity that we have to respond to and for the other.

It is the other who renders explanation philosophically intelligible. Explanation begins by turning towards a *someone* to whom such explanatory discourse can be made meaningful. In this way, to reason is to justify. Prior to discourse itself is the phenomenon of the expression that poses a question, asks something of us, and assigns to us a responsibility for responding. This experience of the expression coming from the other assigns us the possibility of recognizing subjectivity as our own, and therefore being inseparably bound up with an awareness of justice that we are called upon to perfect. This consciousness of the experience of a disability common to all serves as the prelude to any education.

—William Roth and Richard Sugarman

See also Body, Theories of; Disability Culture; Disability Studies.

Further Readings

Fisher, Alden, ed. 1969. *The Essential Works of Merleau-Ponty.* In *An Unpublished Text,* edited and translated by A. Dallery. New York: Harcourt, Brace & World.

Gliedman, John and William Roth. 1980. *The Unexpected Minority: Handicapped Children in America.* New York: Harcourt Brace Jovanovich.

Kunz, George. 1998. *The Paradox of Power and Weakness: Levinas and Alternative Paradigm for Psychology.* Albany: State University of New York Press.

Levinas, Emmanuel. 1998. *Entre Nous: On Thinking-of-the-Other.* New York: Columbia University Press.

May, Rollo, Ernest Angel, and Henri F. Ellenberger, eds. 1958. *Existence: A New Dimension in Psychiatry and Psychology.* New York: Basic Books.

Merleau-Ponty, Maurice. 1962. *Phenomenology of Perception.* Translated from French by C. Smith. London: Routledge.

———. 1964. *The Primacy of Perception.* Evanston, IL: Northwestern University Press.

Minsky, Marvin Lee. 1986. *Society of Mind.* New York: Simon & Schuster.

Ricoeur, Paul. 1983. *Freedom and Nature: The Voluntary & Involuntary*. Translated by E. V. Kohak. Evanston, IL: Northwestern University Press.

Roth, William. 1992. *Personal Computers for Persons with Disabilities.* Jefferson, NC, and London: McFarland.

Sartre, J. P. 1968. *Being and Nothingness.* Translated by H. Barnes. New York: Citadel.

Sugarman, Richard. 1980. *Rancor against Time: The Phenomenology of "Ressentiment."* Hamburg: F. Meiner Verlag.

Sugarman, Richard I. 2002. *Emmanuel Levinas: The Ethics of the 'Face to Face' in Phenomenology World,* edited by A. T. Tymieniecka. Boston: Kluwer Academic.

Wild, John. 1968. *The Radical Empiricism of William James.* New York: Doubleday.

EXPERIENCE OF DISABILITY: BRAZIL

Brazil is one of the few countries to include an entire section on disability in its census (2000). Results showed that 14.5 percent of the population, roughly 24 million people, reported having some form of disability. The poorest region, the northeast, reported the highest percentage of people with disabilities (16.8 percent) while the richest region, the southeast, reported the lowest percentage (13.1 percent).

HISTORY

In the first half of the twentieth century, people with disabilities in Brazil had no voice and no representation. They were either living in isolation with their families, or they were institutionalized. They were primarily studied, diagnosed, and "treated" by professionals such as medical doctors, psychiatrists, psychologists, and educators. In the years prior to World War II, Brazilian professionals viewed disability in three ways: a biomedical puzzle (to be solved using modern technology), an educational challenge, and a social problem. The professionals were divided as to whether disability, particularly intellectual disability, was primarily a biomedical or educational issue. As early as the mid-1800s, there were institutions for different types of disabilities—psychiatric hospitals, such Psychiatric Hospital Pedro II in Rio de Janeiro, and schools for the blind and deaf, such as the Imperial School for Blind Children, now called the National Benjamin Constant Institute, and the National Institute for the Education of the Deaf.

Much scholarly attention was focused on the physical and mental disabilities and illnesses of people living in rural poverty, especially those of African or mixed descent. However, due to Lamarkian-influenced eugenics theories, Brazilian professionals believed that improved health and social welfare would improve the genetic inheritance of these groups. Thus, the focus was not on institutionalization or sterilization of "pathological" populations, as was practiced in the United States and Europe, but rather efforts were primarily focused on improving public health and social welfare. However, laws were passed mandating prenuptual examinations that were specifically designed to deny marriage to people who were deaf or had intellectual disabilities.

Prior to the 1930s, educational programs for children with intellectual disabilities were located in psychiatric hospitals, and children who were blind and deaf were sent away to residential schools. In 1932, however, educator Helena Antipoff founded the first Pestalozzi Society—a community-based school for children with intellectual disabilities. In 1954, influenced by the Arc (formerly called National Association for Retarded Children/Citizens) movement in the United States, parents of children with intellectual disabilities opened the first APAE chapter (Associação de Pais e Amigos de Pessoas Excepcionais [Association of Parents and Friends of the Exceptional]). By the end of the twentieth century, there were 146 Pestalozzi Societies and more than 1,700 APAE chapters throughout Brazil. Many public and private schools currently strive to include children with disabilities, but issues such as proper teacher training and accessibility make inclusion a challenge.

Independent Living Movement in Brazil

After World War II, Brazilians with physical disabilities organized around sports and recreation clubs. There was no existing national public policy on disability. People with different types of disabilities did not have a unified group identity, nor were they represented as a group through the constitution or legislation. What opportunities and rights existed for people with disabilities were the result of isolated initiatives, mainly led by professionals and parents.

In the late 1970s, however, Brazil began to prepare for the International Year of Disabled Persons in 1981. By the early 1980s, there were hundreds of local organizations representing different disability groups. These groups began to work together, for the first time adopting a cross-disability perspective. People began to connect to the international disability rights movements and organized disabled people's councils in most Brazilian states and major cities. For the first time, there were people with different types of disabilities working together and representing themselves.

The experience of self-representation led to further initiatives in both advocacy and service provision.

The first center for independent living (CIL) in Brazil was founded in Rio de Janeiro, Brazil (CVI-RIO) in December of 1988. CVI-RIO was spearheaded by a group of activists with disabilities from the grassroots Brazilian disability rights movement. They differentiated themselves from preexisting advocacy organizations by offering services such as peer counseling, employment placement, and skills training. CVI-RIO established a new organizational model by adapting the philosophy and the services from the CILs in the "first world" to the Brazilian context. As the independent living (IL) philosophy spread throughout Brazil, the demand for personal services for people with disabilities quickly generated more than twenty new centers around the country, each adapted to meet specific needs of the communities in which they are located. In 1999, the National Council of ILCs (independent living centers) was established to ensure that organizations using the term *independent living* in their title adhered to the philosophies of the movement and provided services as well as advocacy.

Priorities of the Brazilian ILC include peer support, personal assistance, personal autonomy, information and assistance about civil rights, accessibility, technical assistance in development and counseling, ILCs led and staffed by people with disabilities, training for leadership, and professional training programs where none are offered by local or national organizations.

In 1992 and 1995, CVI-RIO organized, in partnership with other groups, two international conferences on disability issues called DefRio. Hundreds of participants from more than two dozen countries attended. During DefRio 95, participants drafted a document titled "Goals of the ILM." This document delineated the basis for the independent living movement (ILM) in Brazil, whose goals and objectives were applicable to current and future ILCs. Since financial support is not provided by the government, the ILCs struggle for sustainability through a variety of means, including grant writing, producing adaptive equipment, and acting as an employment placement service for people with disabilities. The employment placement services benefit from federal laws instituting a quota system that generates job-contract opportunities between companies and organizations of people with disabilities.

DISABILITY IN CULTURE AND POLITICS

Brazil has progressive policies toward disability. The Brazilian Constitution includes sections on the rights of people with disabilities and laws have been passed with regard to accessibility, education, and employment. The laws are enforced by the Office of the Public Defender on local, state, and national levels. Discrimination is penalized with prison and fines. This office, called Ministério Público, also promotes public awareness campaigns on legislation and civil rights of disabled people, among other minorities. They reach out, for instance, to big companies and pressure them to comply with employment regulations. As a result of the laws and partnerships to enforce them, individuals with disabilities are participating in the society in record numbers and the cultural impact is in proportion to this increased visibility.

On the national level, people with disabilities are elected to office in large enough numbers for there to be an association of national members of Congress with disabilities. Within the Secretary of Human Rights of the Ministry of Justice, there is a National Council on Disabilities and CORDE, the main Disability Office for the Inclusion of People with Disabilities. This office is responsible for the development of policies on social inclusion, protection of rights, and promotion of citizenship for people with disabilities.

Brazil is a Catholic country with a paternalistic structure of family relationships. In contrast to a cultural model where "independence" is achieved when adolescents or young adults leave their parents' home, Brazilian children often do not leave home until they get married, and may even return if the marriage ends in divorce. This homecoming is not necessarily dependence, but rather a form of interdependence reinforced by economic necessity. People with disabilities may not have the possibility to attain this type of "independence" and may rely completely on family to fill all their needs, while those without disabilities may have more opportunities to maintain autonomous spaces for themselves through their work, friendships,

and romantic relationships. Although there is still a persistent lack of visibility and equal opportunities for people with disabilities to fully participate in society, there is more potential for IL than ever before in Brazilian history, due to Brazil's social development process as a whole and the progress made by the disability sector, specifically.

Through the disability rights movement and the support of the new laws and enforcing mechanisms, disability groups are taking important roles, both as advocates and service providers, to move the disability agenda forward. The IL concept is now beginning to be understood and spread all over the country: autonomy, empowerment, and self-determination as keys to a new human rights approach to inclusion and full participation.

—Pamela Block and Rosangela Berman Bieler

See also Advocacy, International.

Further Readings

Bieler, R. B. 2003. "Independent Life in Latin America: Adapting a 'First World' Philosophy to the Realities of the 'Third World.'" In *El Movimiento de Vida Independiente: Experiencias internacionales.* Spain: Fundación Luis Vives.

Block, P. 1997. "Biology, Culture and Cognitive Disability: Twentieth Century Professional Discourse in Brazil and the United States." Unpublished doctoral dissertation, Duke University, Department of Cultural Anthropology.

———. 2002a. "Sexuality, Parenthood, and Cognitive Disability in Brazil." *Sexuality and Disability* 20(1): 7–28.

———. 2002b. "Sterilization, Sexual Control, & Intellectual Disability in Brazil." Pp. 76–89 in *Health of Women with Intellectual Disabilities,* edited by Patricia Walsh and Tamar Heller. Oxford, UK: Blackwell Science.

———. Forthcoming. "Prisons and Utopias: The Development of Cognitive Disability in Brazil." In *Engaging Anthropology in Disability Studies,* edited by Devva Kasnitz and Russell Shuttleworth. Westport, CT: Greenwood.

Websites

For more information on Brazilian statistics and policies concerning disability, go to the following Portuguese-language websites:

Brazilian Institute of Geography and Statistics (IBGE), www.ibge.gov.br

Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência (National Coordinator for People with Disabilities–CORDE), http://www.mj.gov.br/sedh/dpdh/dpdh.htm

CVI Brazil's Internet page, http://www.cvibrasil.hpg.ig.com.br/

SACI Network, www.saci.org.br

EXPERIENCE OF DISABILITY: CHINA

There are 60 million disabled people in China (includes sensory, physical, intellectual, and mental health impairments). Discrimination and disadvantage are daily experiences. Long-standing negative attitudes combine with structural barriers, making it harder for disabled people to attain personhood through work and marriage. In a country ambitious for economic and scientific progress, disabled people have to show they are not a liability.

Inevitably, given the scale of underdevelopment in many parts of China and the size of the population, there is limited state provision and heavy reliance on self and family. A series of laws and initiatives, led by the China Disabled Persons' Federation, have increased visibility and awareness and have affected hundreds of thousands of people, but the quality and availability of medical and support services vary widely, are heavily concentrated in large cities, and are accessed only by those with money and good social networks. There is growing demand from some city-resident parents of disabled children and educated disabled adults for services and opportunities; this has potential for positive change if helped to develop. Prospects are bleaker in parts of rural China where poverty is entrenched and disabled people fare worse.

ATTITUDES

Attitudes are changing, especially among urban élites, but there is extensive evidence of discrimination in all aspects of life. Confucian legacies of bodily difference as nonnormal persist, deepened by the construction of the active and productive body during the socialist Mao years, and the emphasis on economic growth and mobility since the 1980s. The language of disability is inscribed with notions of sickness, deficit, and worthlessness. Positive attempts to promote

neutral terminology have yet to trickle down through China's social strata. Pejorative words are widely used, but less so face-to-face than in the past. Pity and disdain increase with the severity of impairment. Particular stigma attaches to intellectual impairment and mental illness, especially in urban areas where education and employment are markers of personal status and ability. People with congenital impairments (seen as evidence of wrongdoing or neglect in pregnancy, bringing particular shame on the mother) are treated more negatively than people with impairments acquired through illness, accident, or military service.

DISABLED CHILDREN

Since the economic reforms of the 1980s, families with disabled children have faced increased socioeconomic vulnerability and pressures. Former sources of (limited) support from work units or collectives have been eroded, particularly the practice of providing employment in the parents' work unit upon adulthood. The one-child policy and increased opportunities to make money for those with ability (*nengli*) have intensified parental hopes for their children, making diagnosis of childhood disability even more devastating.

Having a disabled child is seen as a major misfortune for the household as well as the child, whose own prospects for making a decent living, having a family life, and supporting parents in old age will generally be diminished. For the household, it signifies reduced productive labor, including from family members required to provide care; damaged social standing and perhaps damaged marriage prospects for nondisabled siblings; and increased costs of seeking medical treatment. Family and societal expectations to seek a cure are very high. The search begins locally, can last for years, and takes families far from their homes, with rural families traveling to the cities to get the best help they can afford. Parents take on additional jobs, sell their assets, and incur debts. Both Chinese and Western medicine are used, doctor-swapping is expected, and diagnoses of incurability may go ignored for years. Advertisements promising cures for deafness or paralysis add to the pressures, but a cure is seen as the best guarantee of averting the poverty that, as the saying goes, is bound to follow disability (*fengcan biqiong*).

Abandonment is illegal but still occurs for girls (nondisabled and disabled) and for disabled boys, despite permission to have a second child if the first child is disabled (the government also operates relaxed rules for domestic and foreign adoption of disabled children). The practice of keeping a disabled child hidden at home has reduced with increased educational opportunities (since 1994, schooling has been compulsory for disabled children). Notwithstanding, many parents are highly protective and may restrict the extent of interaction that their children, including adult children, have in the local community for fear of abuse or being taken advantage of. In urban and some rural areas, children with mild physical impairments access mainstream schools; children with visual or intellectual impairments and deaf children attend segregated schools or classes (Alison Callaway has done an insightful study of Chinese deaf children, their families, and education). In poorer areas, school is a luxury for parents, who may struggle to pay the fees, although some families prioritize education for their disabled child.

ADULT PERSONHOOD

Work and marriage are the central markers of personhood in China. How far disabled people attain these is often shaped by gender, impairment, and location.

Opportunities for mainstream employment are limited. Even the tiny number of high-achieving disabled graduates has encountered serious difficulties in getting a job, due to negative employer attitudes in a highly competitive labor market. Most state and private employers prefer to pay a fine than comply with the quota system of 1.6 percent disabled employees. There is evidence from welfare and commercial enterprises of disabled people on the payroll who have been paid to stay at home, often against the wishes of disabled people who want to work. Around 1 million disabled people work in social welfare enterprises (sheltered employment provided in factories or local workstations). However, a qualitative study by Pearson, Wong, and Pierini on the employment experiences of young adults with learning disabilities suggests that welfare enterprises are struggling despite tax relief (in Guangzhou Province a drop from 3,113 welfare

enterprises in 1995 to 394 in 1999) and that low-waged, low-status work and phantom employment frustrate young people's ambitions to work and contribute to the family income, and thereby attain adult status.

In cities, more disabled people are becoming self-employed, perhaps assisted by vocational training, tax relief, and/or permission to buy a three-wheeled welfare-motorbike that can carry a passenger or goods. Often disabled people work in basic-level and stereotyped jobs (visually impaired masseurs or piano tuners, appliance repair, tailors, data entry, packing, cleaning). In poor rural areas, prospects are bleak for disabled adults whose impairment reduces their ability to do physical work or join the so-called floating population of 100 million migrant men and women who leave the countryside to find work in the cities and Special Economic Zones.

Economic self-reliance increases marriage prospects but is no guarantee. A complex hierarchy of attributes comes into play: gender, type and severity of impairment, whether impairment is congenital or acquired, residence (rural/urban), education, family status, and background. While Chinese men are more likely to be never married than Chinese women, the incidence of never-married disabled men is dramatically higher than among disabled women. Matthew Kohrman's analysis of the experiences of middle-aged men with a wobbly gait (mostly polio survivors) attributes this to the smaller gap perceived to exist between the female disabled body and dominant constructions of female personhood (at home, bringing up children), compared to that between the male disabled body and constructions of manhood (out of the house, mobile, active).

Hierarchies of normalcy intersect with gender, location, and education to shape what makes an appropriate match. For example, an urban disabled woman might be expected to marry a nondisabled man but he would probably be from the countryside with lower education. Deafness and intellectual impairment may be less stigmatizing in rural than urban areas, and for women than men, reflecting the different ways in which livings are earned and social status acquired. The process of marriage exclusion can be protracted and painful, particularly for disabled men. For disabled women, finding a (nondisabled) spouse may be easier but little is known about the quality of their marriages and incidence of domestic violence.

IMAGES AND IDENTITY

The China Disabled Persons' Federation has endeavored to improve public images of disabled people, showcasing entrepreneurs, athletes, and artists who have contributed to China's economy and international standing. There has been a proliferation of manuals, magazines, research, and creative writing, including by disabled people (Shi Tiesheng is one of China's most popular writers), and also films such as *Beautiful Mama* (1999) starring internationally acclaimed Gong Li as a divorced mother putting her deaf son through mainstream school. All challenge negative attitudes of disabled people as worthless (*canfei*). They also put ordinary disabled people under intense pressure to demonstrate their worth and aspire to be better than so-called healthy or normal people.

There are signs of shared identity among some strata of disabled people. Kohrman has written about identity and brotherhood among urban men with physical impairments; there is an emerging Deaf cultural community; there is increasing collective action among parents of disabled children, ready to set up support groups and services where permitted. The extent to which disabled people and families identify with the China Disabled Persons' Federation and the term *canji* (disabled) is likely to reflect what the individual can expect to gain. Parents may delay registering their child as disabled in case this restricts access to mainstream school. In contrast, growing numbers of disabled men register to get help with starting a business or a license to drive a three-wheeled welfare-motorbike. Some commentators are pessimistic about the scope for civil society and a grassroots disability movement in the People's Republic of China. Certainly, this is unlikely across much of China where basic needs preoccupy families and local governments, and where strong legacies of negative attitudes act against individuals and families acting to draw attention to themselves. But among urban élites, as domestic and international networks expand and as more disabled children finish school and college, supported by family and friends, there is cause for cautious optimism.

—Emma Stone

See also Advocacy, International; Confucius; Cultural Context of Disability; Disability in Contemporary China.

Further Readings

Callaway, Alison. 2002. *Deaf Children in China.* Washington, DC: Gallaudet University Press.

Kohrman, Matthew. 1999. "Motorcycles for the Disabled: Mobility, Modernity and the Transformation of Experience in Urban China." *Culture, Medicine and Psychiatry* 23:133–155.

———. 2000. "Grooming *Que Zi*: Marriage Exclusion and Identity Formation among Disabled Men in Contemporary China." *American Ethnologist* 26(4): 890–909.

Ma, H. 1993. *Reintegration into Society: The Desire of Disabled People* (in Chinese). Beijing: Huaxia Publishing House.

Pearson, Veronica, Y. C. Wong, and Jane Pierini. "The Structure and Content of Social Inclusion; Voices of Young Adults with a Learning Disability in Guangzhou." *Disability & Society* 17(4): 365–382.

Stone, Emma. 1999a. "Making Connections: Using Stories from China as an Example." Pp. 171–192 in *Disability and Development: Learning from Action and Research on Disability in the Majority World,* edited by E. Stone. Leeds, UK: University of Leeds, Disability Press.

———. 1999b. "Modern Slogan, Ancient Script: Impairment and Disability in the Chinese Language." Pp. 136–147 in *Disability Discourse,* edited by M. Corker and S. French. Buckingham, UK, and Philadelphia: Open University Press.

Websites

Centre for Disability Studies, University of Leeds, http://www.leeds.ac.uk/disability-studies

China Disabled Persons' Federation, http://www.cdpf.org.cn/english

EXPERIENCE OF DISABILITY: COLOMBIA

Colombia is a country in South America, in the northwestern part of the continent, south of Panama. The capital and largest city of Colombia is Bogotá, with a population of about 7,000,000. In 2001, the total population of Colombia was reported at about 43,000,000, with 73 percent of the population living in urban areas. The majority of the country's population is young; 54 percent of the total (18 million people) under 18 years of age. Life expectancy at birth for the overall population is 72 years. It is estimated that about 95 percent of the population is Roman Catholic. Religion has played a critical role in how disability is perceived. Some view disability a punishment from God. Others see it as a challenge imposed by God to prove one's faith and courage. Children with disabilities are often hidden from public view, in part because of family members' shame, guilt, and lack of education about disabilities. This entry covers incidence of disability, current disability laws and policies, living conditions for people with disabilities, and current efforts to address disability concerns.

INCIDENCE OF DISABILITY

The 2003–2006 Plan Nacional de Atención a las Personas Con Discapacidad (National Plan of Attention to Persons with Disabilities) estimated that 18 percent of the general population has some type of disability. However, the government recognized the difficulty in having an accurate estimate due to the lack of adequate methods to conduct a census in rural areas and families displaced by violence and insurgency. It is also difficult to assess the characteristics of the homeless population. Moreover, there is a tendency for families experiencing shame not to report the presence of a family member with a disability. It is estimated that of those identified with a disability, 68 percent have sensory, physical, and/or cognitive impairment; the majority experience blindness, deafness, paralysis, and/or loss of limbs. It is estimated that 12 percent of people with disabilities are under 14 years old and 27.6 percent are over 60, and that over 60 percent of people with disabilities are males. Disability in the infant population is mostly due to prenatal, congenital, or infectious conditions. Young male adults also experience a high rate of disability, mostly associated with injuries, accidents, and the current violence and guerrilla war.

CURRENT LAWS AND POLICIES

In 1991, Colombia promulgated and passed into law a new constitution, which was intended to recognize and protect the rights of people with disabilities. The adoption of the new constitution provided a national policy in which people with disabilities had opportunities for social participation in the areas of education,

communication, health, well-being, work, transportation, information, sociocultural development, and recreation and sports. Specific policies that were enacted included entitlement programs to assure benefits to eligible disabled individuals and discretionary grant-in-aid programs. In addition, supplementary financial assistance was approved to support specified activities for people with disabilities, and incentives (appropriations bills, tax legislation, and loans) are provided for covered entities to comply with the existing regulations regarding the rights of people with disabilities. Examples of these regulations include access to local and nationwide television channels, as well as access to sport activities through the Paralympic Federation. Much of the new constitution of 1991 focused on general rights and social and recreational programs with little or no emphasis in the areas of education, housing, employment, public accommodations, and transportation.

In 1997, the government passed the General Act for People with Disabilities also known as the Disability Act: Law for Opportunity, which includes five titles covering basic rights, education and rehabilitation, social welfare, accessibility, and transportation and communication. The implementation of these national policies is coordinated by the Ministry of Health and the year 2000 budget allocation was US$3.6 million. Yet many people with disabilities are not aware of the law, the national plan, or of their benefits. As of 2001, Colombia had 37 disability-related legal policies. The majority of these regulations are national civil rights statutes that provide people with disabilities with human rights and liberties, such as the protection against discrimination based on one's disability. Despite the existence of these laws, the government provides limited spending on programs that protect the rights of people with disabilities, and the lack of enforcement of disability rights is a major concern.

DAILY LIVING CONDITIONS

In the areas of daily living, people with disabilities face a number of barriers and challenges. People with disabilities are often marginalized in employment, education, and housing. Colombia has faced an economic crisis and guerrilla violence since the 1950s. These problems have led to an overall unemployment rate close to 25 percent as of 2003, the highest in its history. As a result, many young adults and families with small children sell goods on the streets. With such conditions, people with disabilities are not a priority when it comes to job placement, and as a result, 80 percent are unemployed. It is not unusual for individuals with physical disabilities to become street vendors.

In the area of education, access to free elementary education is available and much effort has been devoted to eliminating illiteracy. However, children with disabilities are often rejected by public and private schools resulting in a high rate of illiteracy. Forty percent of people with disabilities are illiterate. These rejections result from lack of accommodations, lack of accessibility, and lack of trained teachers to assist children with disabilities. Upper-class families with children with disabilities often send their children to expensive private segregated schools for children with special needs. A limited number of public educational centers are available for children with disabilities, and such centers often face funding problems.

Housing is an area in which people with disabilities face many challenges. In Colombia, public and private funds to remodel and accommodate homes to meet the needs of people with disabilities are not available. Most people with physical disabilities depend on family members to move around and to have their needs met.

In terms of welfare benefits, the only disabled people in Colombia who receive a pension are either military personnel who become disabled while on duty or insured workers who become disabled while on the job. No other individuals with disabilities receive pensions, social security, or health care coverage. There is no welfare system to assist them.

Accessibility around Colombian cities and small towns can also be challenging because many are more than 400 years old. Small rural villages and towns are not wheelchair accessible, since streets are often made of dirt, stones, or gravel. Furthermore, only people with disabilities who come from wealthy families have access to technology (e.g., adapted computers to communicate) and equipment (e.g., power wheelchairs) that they import, mostly from the United States.

Some efforts have been made to increase accessibility and mobility in the large urban areas such as

Bogotá. For instance, the new public transportation system, Trans Millennium, involves a system of rail buses that provides fully accessible transportation for people with physical disabilities including ramps and wide accessible entrances. This system is one of the first accessible transportation systems in Latin America. In large urban areas, most streets have curb cuts and most modern buildings have elevators.

CURRENT EFFORTS

Another component of the 2003–2006 National Plan of Attention to Persons with Disabilities has been to develop community awareness efforts throughout the country. These 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 ASCOPAR (Colombian Association for the Development of People with Disabilities), and media awareness campaigns to stop the use of negative language and characterization of people with disabilities. Some programs have gained national recognition such as Foundation Teletón, the Foundation for the Development of People with Disabilities, which sponsors rehabilitation and recreational programs for people with disabilities. DAVIDA (Give Life) was created by a mother of a child with a disability and provides comprehensive services for children with disabilities at one center.

Despite current laws and efforts to protect the rights of people with disabilities in Colombia, much remains to be done to further the implementation and enforcement of existing laws and policies.

—Yolanda Suarez-Balcazar and Adriana Gonzalez

See also Advocacy, International; Poverty.

Further Readings

Fernández, Carlos F. 2000. “Las Personas con Discapacidad dentro del Contexto Normativo Nacional e Internacional” (People with Disabilities within the National and International Normative Context). *Journal of Medicina Física y Rehabilitación* 14(2).

Gonzalez, Adriana. 2003. “Disability and Social Policy: An Evaluation of the Colombian Legislation on Disability.” M.Sc. dissertation, Department of Disability and Human Development, University of Illinois at Chicago.

Instituto del Seguro Social. 1999. “Estudio Estándares Nacionales de Población con Discapacidad en el Seguro Social”(Study of the National Standard of the Population with Disabilities in the Social Security Program). Bogotá, Colombia: Institute of Social Security. Retrieved March 12, 2003 (http://www.iss.gov.co/).

Presidencia de la República. 2002. “Plan Nacional de Atención a las Personas con Discapacidad 2003–2006” (National Attention Plan for Persons with Disabilities 2003–2006). Bogotá, Colombia: Presidency of the Republic. Retrieved October 9, 2002 (http://www.clopatofsky.com/Proyectos%20de%20Ley/discapacidad.pdf).

Rodríguez, Sarah. 2001. “Revisión de los Estudios sobre Situación de Discapacidad en Colombia 1994–2001” (Revision of the Studies on the Situation of People with Disabilities in Colombia). Bogotá, Colombia: Presidency of the Republic, Red de Solidaridad Social.

Universidad del Valle. 2001. “Prevalencia de Discapacidad en el Departamento de Valle del Cauca” (Study of Prevalence of Disability in the Valley of Cauca, Cali, Colombia). Universidad del Valle. Retrieved January 20, 2003 (http://www-bib.univalle.edu.co/cgi-olib/opac.sh?session=2049585582&infile=start_frame.glu&style=kws).

Vejarano, Fernán. 2000. “Homologación de las Variables de Discapacidad” (Homologation of Disability Variables). Centro de Investigaciones sobre Dinámica Social, CIDS. Universidad Externado de Colombia. Retrieved August 27, 2002 (http://www.hist.umn.edu/~rmccaa/colipums/discap~1_lmw.doc and www.encuentro21.org.co).

Websites

Asociación Colombiana para el Desarrollo de Personas con Discapacidad (ASCOPAR), www.discapacidadcolombia.com/modules

Disability Act: Law for Opportunity, www.discapacidadcolombia.com

EXPERIENCE OF DISABILITY: COSTA RICA

As many other countries, Costa Rica has been influenced by the traditional, medical, and rehabilitation models that led societies to consider a disability as a “problem” and the person with disability as the cause of that problem. Those models reinforced the view of people with disabilities as dependent, ill, incompetent, limited, or even subnormal. The concept of being “normal” is a fallacy that still persists in the imagination of

those who are not aware that being different is in fact being "normal." The purpose of this entry is to share with the reader a descriptive analysis of the experience of living with a disability in Costa Rica.

During the past decade, the experience of disability in Costa Rica has been changing, an ongoing but slow process. Quantitative as well as qualitative changes have had an important impact on the public and private services offered by various sectors of the Costa Rican society such as education, health, employment, culture and recreational activities as well as the accessibility to information and communication. Considering living conditions from a human rights development perspective and the increasing participation of disabled people and their families' organizations have contributed to these changes.

The social and economical context in which the majority of people with disability live in Costa Rica, in many cases conditions of extreme poverty, has influenced the quality of life of disabled people and is still limiting their access to services particularly in their own communities and in rural areas of the country. Furthermore, these economic limitations have definitely interfered with the efforts being made in terms of legislation and the promotion of human rights and opportunities. Despite all the actions taken to change attitudes and awareness about the needs of disabled people, experiencing disability in Costa Rica is closely related to and cannot be separated from economic and social development.

> After a half century of economic performance that was well above average for the region, Costa Rica has begun to experience a significant slowdown. The worsening economic situation is reflected in a stagnant poverty rate, which has remained constant at 21% over the last eight years, and an increasingly large gap in the distribution of income between rich and poor. (National Institute of Statistics and Census 1998)

According to the Ombudsman Office, the population with disabilities is among the most excluded sectors of Costa Rican society. Two surveys provide data about the general population and the percentage of disabled people. The Multipurpose Household Survey, conducted in 1998, reported that the population of the country totaled 3,340,909, of whom 261,371 persons, approximately 8 percent, had a disability. The National Census included for the first time information about disabled persons, and it reported that the total population was 3,810,179 and persons with a disability were approximately 5 percent of the general population. The difference in percentages was interpreted as methodological, since there are factors such as how disability is understood by the interviewers and who provides the information.

Based on the country's economic conditions, there is no doubt that the social model, as it applies to disability experience in Costa Rica, inevitably leads us to concentrate on the priorities established by the government regarding social policies, the provision of additional funds to provide accessible services, and the inclusion of specific indicators related to disability experience as an effective measure to monitor the national development with regard to disabled people's lives.

One of the turning points, during the past decade, was the approval of the Law 7600 in May 1996, called Equal Opportunities for People with Disabilities in Costa Rica. Before the existence of that law, there were already various projects presented by members of the General Legislative Assembly and the Costa Rican Parliament, and there was already a long list of demands presented by disabled people and their families at the Ombudsman Office, most of them related to lack of access to buildings, services, and educational accommodations.

The law was also inspired by the United Nations Standard Rules on the Equalization of Opportunities for Disabled People, published in 1993 by the United Nations and prepared by a group of experts who were people with disabilities themselves. The General Legislative Assembly in Costa Rica ratified this document. Even though the Costa Rican National Constitution guarantees the same rights to all Costa Rican citizens, it became obvious that these rights with regard to disabled citizens were not guaranteed on an equal basis with others.

Disability experience in Costa Rica has been definitely transformed in many areas as a result of the mandates of this generic law. There is no question about the fact that people with disabilities and their families in Costa Rica started to use this legal instrument as a strategy

to empower themselves and to become aware of their rights as well as understanding the role of the state in accomplishing its responsibilities.

Education has been historically a priority for the Costa Rican government, and a significant part of the national budget is invested in education in general. Traditionally, as in many other countries disabled students have received their education in special schools. The first special school in San José was opened in 1940, and many young disabled people ended their education process in vocational training programs offered in sheltered workshops, some of them administered by nongovernmental organizations.

Even though access to educational programs was mainly offered in special settings, an increasing number of disabled students are attending regular primary and secondary schools as well as regular schools at the higher education level. According to the implementation of the law, support services have to be provided at all levels and modes of education, from early stimulation programs up to higher education. Support services include access to the curriculum as well as curriculum accommodations.

Experiencing disability in the Costa Rican educational context is still a continuous and great challenge for the national educational system, public and private. At present, one of the main educational barriers for young students and adults with disabilities seeking to finish their studies is the lack of professional resources, mainly educators who are trained specifically to teach students at the secondary or adult level. In a special report from the Ministry of Public Education, presented to the National Council of Rehabilitation and Special Education (CNREE), the national institution responsible for monitoring institutional progress in the field of disability, it was stated that "the model of teaching students with disability-related educational needs has shifted towards a new model that aims at providing schooling opportunities in less restricted environments" (Ministry of Public Education 2002). Presently, the diversity of programs in education include special schools, integrated classes in regular schools, and support services specialized in different disabilities. Teachers working in these services work together with the regular teachers so that the education program responds to the special educational needs of the students based on the regular curriculum.

The Statistical Department of the Ministry of Public Education indicated, based on growth rates in 2000–2001, that there were approximately 79,600 students with educational needs related to different disabilities attending regular classes in 2002. The majority of students with disabilities have access to regular education classrooms, but some are receiving their education in special classes located in regular schools or special schools. It was reported in 2002, by the Department of Special Education of the Ministry of Public Education, "Students with special educational needs comprise about 10.13% of the total number of students. Thus, out of a student population of 937,154, there are approximately 95,000 students with disabilities" (Ministry of Public Education 2002).

The transitional stage from education to work remains a challenge for professional training as well as for some nongovernmental organizations administrating sheltered workshops with a very low budget and little technical support. Systematic efforts have been made recently to provide access to technical education for young people to increase their competence at applying to jobs. For example, the National Institute for Learning (INA), which offers educational opportunities for all people in many regions of the country, has been putting into practice a variety of measures such as providing curriculum accommodations for people with intellectual disabilities who traditionally have been segregated from such programs.

Higher education for students with disabilities is mainly offered by public universities. Most disabled students are concentrated in public universities. Some private universities have started to introduce services for disabled students. There are four public universities that have been working together in a special committee to share experiences on accommodations and to prevent discrimination acts against students. Support services offered by these universities to students include sign language interpreters in classrooms, Braille printing, tutoring, text recording, note taking, and access to computers by training students on the use of text reading software, which is taught by a blind student. Deaf instructors offer courses on Costa Rican Sign Language (LESCO), and the

national association monitors the quality of education for the deaf. It should be highlighted that during the past few years more disabled students have enrolled in various graduate programs, such as linguistics, law, project evaluation, and interdisciplinary disability studies.

Access to employment it is still a challenging experience for people with different disabilities, mainly for people with intellectual disabilities. Even though Law 7600 refers to specific measures to be taken by the Ministry of Labor, it has been very difficult to put them into practice. The ministry's national director of employment acts as a facilitator to contact potential employees, but this process seems to be very slow. It was reported by the Ombudsman Office (1999) that "only 15 disabled workers were hired." This office also promotes self-employment and the development of small businesses; however, people with disabilities often cannot meet loan requirements and therefore their opportunities are limited. The National Council on Rehabilitation and Special Education offers loans through a rotating fund so that people with disabilities can initiate their own businesses.

Recently, some positive actions have started to promote access to employment. A special unit was established to facilitate accessible conditions as an incentive to public institutions and the private sector so that they hire disabled employees. Some organizations of disabled people have estimated that the unemployment rate among this population is approximately 65 percent. This situation means that many disabled people and their families live in a constant struggle to survive and have limited participation in society.

Health services in Costa Rica are available through a public health system; a public institution, the Costa Rican Social Security Fund, also covers rehabilitation services. These are mainly offered by the National Rehabilitation Center (CENARE), a hospital located in San José, the capital of Costa Rica, and the National Psychiatric Hospital, which provides temporary and permanent services to people with mental disabilities.

General health services are available in regional hospitals and clinical settings, and recently there has been a new development, Comprehensive Health Care Units, called EBAIS, which have been located in urban as well as rural areas of the country and cover smaller communities. Some of these units are training their personnel to support disabled people in their communities.

Though there is a large coverage and access of people with disabilities to the general health system, rehabilitation services are not available at the community level and not all the infrastructure is accessible. Another important limitation of the system is the limited provision for technical aids and assistance devices, which according to Law 7600 should meet the requirements of disabled persons. In some cases, wheelchairs are provided by private organizations as part of a social welfare program, reinforcing the traditional view of disability and not as part of the obligations of the state or as a human right.

Other areas covered by the law include access to housing, buildings, transportation, information, communication, and recreational activities. The inclusion of accessibility as part of public life is a slow process. According to the law, new buildings have to be designed to meet accessibility requirements in order to obtain the construction permission given by the government. The concept of universal design is not yet incorporated into construction planning, and professionals working in this field are starting to be trained with regard to accessibility guidelines.

In some cases, accessibility is considered during the process of designing but is not well implemented or supervised by the government. Since San José and other regions of the country had not been planned to be accessible, it is still very common to find partially accessible places, where there are ramps to access the first floor but no elevators or accessible bathrooms. There is an increasing effort from the private sector to build accessible hotels and to offer accessible facilities in restaurants and shopping areas. A project provides guidelines to National Parks to have pathways and signals accessible for visitors.

Public transportation is starting to become accessible. The National Council on Rehabilitation and Special Education has negotiated with private enterprises and the Ministry of Public and Transport to start accessible services with a percentage of their units and routes and continue increasing these services until all buses are accessible. According to Law 7600, 10 percent of the taxis must be accessible. Many drivers who are interested

in this kind of service have already obtained registered plates but are unable to obtain vehicles to operate because of their high cost. There is still much to be accomplished in terms of public transportation. Drivers should become aware of the needs of all people including persons with different disabilities and be trained on how to properly provide this kind of service.

As a general consideration, it becomes obvious that experiencing a disability in Costa Rica is relative to the living conditions and opportunities of all Costa Rican citizens. All the social and economical policies that affect the majority of people in this country have an impact on the quality of life of disabled persons. Nevertheless, the results during the past decade show systematic progress toward improving the living conditions of disabled people in Costa Rica and the continuing efforts toward including their particular needs, such as access to education, health, work, housing, transport, and recreation, as part of the national development planning. A crucial factor to accelerating this process is the pressure and participation of an organized movement of disabled people as a way of vindicating their human rights. Universities have an essential role in promoting access and supporting disabled students but also should educate all professionals with regard to their attitudes, knowledge, and skills necessary to develop an accessible society.

—Roxana Stupp Kupiec

See also Advocacy, International; Education, International; Housing: Law and Policy.

Further Readings

La Discapacidad en Costa Rica: Situación actual y perspectivas. 2004. San José, Costa Rica: Ministerio de Salud, Consejo Nacional de Rehabilitación y Educación Especial y la Organización Panamericana de la Salud, Oficina Regional de la Organización Mundial de la Salud.

Jiménez Sandoval, Rodrigo, ed. 2002. *Las Personas con Discapacidad en la Educación Superior.* Una propuesta para la Diversidad e Igualdad. San José, Costa Rica: Fundación Justicia y Género.

Law 7600, *Igualdad de Oportunidades para las Personas con Discapacidad en Costa Rica* (Equal Opportunities for People with Disability in Costa Rica). San José, Costa Rica: La Gaceta Oficial.

Ministry of Public Education. 2002. *The Impact of Law 7600 on Equal Opportunities for Persons with Disabilities in the Costa Rican Educational System*. Report presented to CNREE, San José, Costa Rica.

National Institute of Statistics and Census. 1998. *Encuesta de Hogares y Propósitos Múltiples* (Home and Multiple Purpose Survey). San José, Costa Rica: Ministry of Economics, Industry and Commerce.

Ombudsman Office. 1999. *Annual Report of the Ombudsman* 1998-99. San José, Costa Rica: Ombudsman Office.

United Nations. 1993. *Standard Rules on the Equalization of Opportunities for People with Disabilities*. New York: United Nations.

EXPERIENCE OF DISABILITY: INDIA

The history of experiences of disabled people in India has never been recorded systematically. It would be unwise to generalize disability experiences because they are contextualized in a culture and region that is very diverse in a country the size of India. There is a dearth of historical investigation and resources. What little is available is archived in the interpretation of folk tales, mythology, special education, social welfare policy, and the Hindu and Islamic religious texts and other scriptures. An analytical study of these sources exhibits the following characteristics. First, in urban settings where it is being recognized that disability is an issue of development and rights, there has been a remarkable change in attitude toward disabled people. This change has come in the past 10 years, partially due to globalization and the self-help movement of disabled people. Second, Indian scholars tend to interpret disability experience in the context of mythology and other historical sources, viewing it as a result of as extreme neglect, past sins, or evil epitomized in the crooked body. Third, in the pre-colonial period the attitude of religious charity existed and care and welfare of disabled people were the responsibility of families, the state, and religious institutions. Fourth, archival evidence suggests that disabled people did not enjoy an equal status and were denied the opportunity of education and development. Attention to their education started with the emergence of Christian missionaries in the colonial period. Fifth, the level of acceptance, discrimination, and stigma varies with the type of disability, its onset, family's educational background, and also the region.

References to disability can be found in the two prominent mythological epics, *Ramayana* and *Mahabharata,* which form the basis of societal responses to disability and help in exploring the meaning of disability in India. A study of disabled characters in these texts demonstrates, on one hand, acceptance of disabled people in positions of power (although marginally); on the other hand, these images go a long way in perpetuating the idea of equating disability with evil, weakness, and inflicted as a form of punishment. In *Ramayana,* Manthra—Queen Kaikeyi's (consort of King Dasaratha) favorite maid—though hunchbacked, enjoyed an exalted status. However, she is held responsible for the exile of Lord Ram—heir to the throne after King Dasaratha—by her machinations. Another episode is that of Shurpanakha, the she-demon. She was Ravana's (the chief antagonist) sister who had eyes on Rama and wanted him for her husband. On sensing that Rama was not interested in her, she pounced on his wife Seeta, upon which his younger brother Lakshmana cut off her nose and ears and thus defaced her.

In *Mahabharata,* King Dhritrashtra of Hastinapur is blind. But he is a weak ruler and his status is used as a rubber stamp by his sons called *Kauravas.* The episode of Bhagwad Geeta (holy text of Hindus) in this epic sets the code of conduct for rulers to follow in their treatment of the disabled. It prescribes that people with visible disabilities such as being blind, crippled, or otherwise deformed, and especially the war veterans and their dependents, should be treated with sympathy and care. Bhagwad Geeta also establishes the rules for practicing charity and lays down the theory of good and bad karma (deed)—that disability is a result of moral sins committed in former life. It further prescribes the forms of charity—*artha* (money), *vidya* (education), and *abhaya* (courage). There is evidence that charity of *artha* was practiced generously but other forms of charity, that is, of education and courage, were rarely followed. It can be said that although disability was a social construct, it was not seen as such. It was perceived more as an economic problem and therefore remedies were provided in the form of charity. In this way, disability was intricately associated with poverty. The solution was seen more in terms of handing out doles rather than empowering them with education and other skills. The dictates of Manu—the ancient Hindu lawgiver—in his work Manusmriti, written between 200 BC and AD 2 and translated into English from Sanskrit in the colonial period, exhibit a dichotomy. On one hand, he lays out that those who are afflicted should be given food, clothing, and shelter, and be exempt from paying taxes; on the other hand, he refuses to give them the right to social equality since he deprives them from inheriting property and occupying any position in the decision making. In the rules for householder, he prescribes that he should "wed a female free from bodily defects." He treats physically and mentally disabled people, women, people of low caste, and aged at par with insects and dogs.

Thus, in ancient India, disability was believed to be a consequence of actions done in past or present life. This was corroborated even by the medical works such as *Charaka Samhita* (an authoritative book on the Indian system of medicine). The folk tales and ballads of Bengal, on the other hand, also hold mothers responsible for producing disabled babies. There is no evidence of the neglect of disabled people by the families, caste, and rulers; however, there definitely are images of blind beggars in folk tales and ballads. They also give evidence of blind people as talented musicians, singers, and poets. This has gone a long way in keeping the visually disabled out of the purview of other vocations. Even in independent India, the government jobs reserved for the blind in several states have been those of music teachers.

The position of disabled people improved in the reign of Maurya Dynasty between 322 and 299 BC. During this period, Buddhism and Jainism emerged as a powerful influence. They emphasized the virtues of nonviolence, charity, truth, purity, selfless service, and compassion to the disabled. For the first time, vocational rehabilitation for the disabled was looked at in ancient India. Kautilya, the prime minister of Chandragupta Maurya, wrote a manual for administrators and politicians called *Arthshastra,* where he called on them to employ dwarfs, the hunchbacked, and otherwise deformed people as political spies as well as secret agents in the royal palaces. In the reign of Ashoka, medical rehabilitation also started.

In medieval India, between the thirteenth and eighteenth centuries, the Mughal rulers continued with the practices set by their Hindu predecessors. They

strictly adhered to the five *rukans* (duties) enshrined in the holy Qur'an, one of them being *zakat* (charity). As Mani describes,

> The forms that this charity took were: alms to the poor and the infirm: construction of mosques, rest-houses, erection of ponds, hospitals and orphanages. The Mughals had a special department with a head (sadr) to supervise charities and endowments. During the reign of Emperor Akbar, the benefits of such charitable institutions were extended to include even the non-Muslims.

The period of India's colonization by the British is seen by scholars as the beginning of the era of institutionalization of disabled. Prior to this there was no concept of educating and institutionalizing them and family was still the primary caregiver. It was seen more as an infringement and an attempt to break the traditional systems. They promoted a culture of custody rather than care. Special education institutions for the hearing and visually disabled were established in 1880s in Mumbai and Amritsar, respectively, by Roman Catholic missionaries. If, on one hand, the advent of colonial rule in India resulted in the creation of segregating environment for the disabled, on the other hand, it also helped in the formulation of welfare policy, which included disability. The first census of disabled people also commenced in this period—a practice that was discarded in the postcolonial period and restarted in 2001 after a lot of agitation.

The modern disability movement in India began in the early 1990s. The responses to disability by the government and society prior to this were more in terms of catering to the medical, rehabilitation, and welfare needs of disabled people. Disability groups had started organizing themselves and groups of visually disabled took the lead. They were successful in getting reservations for themselves in education and government employment, tax concessions, and travel concessions. Other disability groups also started demanding similar benefits and entitlements. Their demands were accepted, but they were more a piecemeal measure. They were not entitled to any benefits as a matter of right. Cross-disability groups started joining hands in the early 1990s to demand for a comprehensive disability rights legislation and protection of rights. After a prolonged struggle, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act was finally passed by the Indian Parliament in 1995. The enforcement of this act has brought some change in the experiences of and responses to various categories of disabled people in India, especially in the urban areas. According to a Cross-Cultural Applicability Study conducted in Bangalore, Chennai, and Delhi—three metropolitan cities of India with high rates of literacy—mental disability, HIV/AIDS, and substance abuse remain the most stigmatizing, and mobility impairment and blindness are the least stigmatizing. Provision of accommodations for the disabled in the physical environment—for example, by construction of ramps—is at a very basic stage. Awareness among the general public, judiciary, government, and disabled themselves regarding their rights is gradually increasing. Employment and accessibility are the crucial issues that are being raised today. Little attention has been paid to the issues of disabled women. Overall, though, Indians still see support to disabled as a matter of charity and an act of kindness rather than a development and human rights issue. In the absence of any substantial archival material, it is difficult to map the experiences of disabled people in India. However, it could indicate the areas of future research.

—Meenu Bhambhani

See also Disability in Contemporary India; Economic and Social Development, International; Education and Disability; Housing: Law and Policy; India, Impact of Gender in; India, Marriage and Disabled Women in.

Further Readings

Abidi, J. 1995. "No Pity." *Health for the Millions* (November-December): 15–21.

———. 2000. "India: Home to 70 Million Disabled Persons" *RANAP* Newsletter, March.

———. 2002. "The Invisible Minority." *Combat Law* (June-July): 53–54.

Baquer, A. and A. Sharma. 1997. *Disability: Challenges Vs Responses.* New Delhi: CAN.

Bhatt, U. 1963. *The Physically Handicapped in India.* Bombay: Popular Book Depot.

Holzer, B., A. Vreede, and G. Weight. 1999. *Disability in Different Cultures: Reflections on Local Concepts.* New Brunswick, NJ: Transaction Publishers.

Kundu, C. L., ed. 2000. *Status of Disability in India—2000.* New Delhi: Rehabilitation Council of India.

Mahajan,V. D. 1960. *Ancient India.* New Delhi: S. Chand.

Mani, R. D. 1988. *The Physically Handicapped in India: Policy and Programme*. New Delhi: Ashish.

Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act. 1995. New Delhi: Universal Publishing Company.

Ustun, B. T., S. Chatterji, J. E. Bickenbach, R. T. Trotter, R. Room, J. Rehm, and S. Saxena, eds. 2001. *Disability and Culture: Universalism and Diversity*. Seattle, WA: Hogrefe & Huber.

Websites

"The Ramayana: A 'Telling' of the Ancient Indian Epic," adapted by Larry Tominberg, http://www.maxwell.syr.edu/maxpages/special/ramayana/RAMA.html

EXPERIENCE OF DISABILITY: IRELAND

PREVALENCE OF DISABILITY

Over the past 20 years, there have been repeated criticisms about the lack of reliable data on disability in Ireland. Since the late 1990s, the Irish Health Research Board (HRB) has undertaken the measurement of the numbers of people with intellectual disability and those with physical and sensory disability in Ireland. In 1995, the HRB began compiling the National Database of individuals with intellectual disability in the country. The HRB is also currently compiling the Physical and Sensory Disability Database, which will be used for planning developments and prioritizing service needs. A recent report shows that there were 26,668 people registered on the National Intellectual Disability Database in 2001, representing a prevalence rate of 7.35 per 1,000 of the population. The report noted that the total number with more severe levels of intellectual disability has grown by 31 percent since 1974 when the first census of this population was conducted. This increase is attributed to the general population increase over the period, improved standards of care, and an increase in the lifespan of people with intellectual disability.

The report also shows an increase in longevity in those with intellectual disability with those ages 55 years and older, who now represent 11.3 percent of all those with intellectual disability in Ireland. However, a most significant change is the large increase in those with disability currently in the ages 34–54 group. This cohort has now grown from 19 percent of the overall population of those with intellectual disability in 1974 to 32 percent of the overall population in 2000. The impact of this aging population of people with intellectual disability has major implications for service planning and provision. It is likely that data compiled on numbers of people with physical disabilities will show similar patterns of increased life expectancy.

NONGOVERNMENTAL ORGANIZATIONS IN SERVICE PROVISION

A unique aspect of the provision of services to disabled people and their families in Ireland is the major role played by voluntary (nongovernmental) organizations in the development of services for those with disability and their families. The growth of such organizations is often derived from the work of individuals, concerned groups, and religious orders trying to address gaps in state service provision. Other disability services have evolved from other medical services founded to respond to specific medical situations such as the tuberculosis epidemic of the 1940s and a serious outbreak of poliomyelitis in the late 1950s. Some voluntary organizations address the specific needs and issues of a single condition such as cystic fibrosis, muscular dystrophy, or multiple sclerosis. Fewer, larger organizations encompass a wider range of disabilities in their brief such as the Irish Wheelchair Organization for adults with a variety of physical conditions that impact on their mobility. Services for those with intellectual disability are also largely provided by voluntary organizations and are provided primarily on a geographic basis to individuals and their families.

Traditionally, Irish voluntary organizations have played both a pioneering and a reactionary role in the development of services for people with disabilities. They have also played a key role as pressure groups, trying to keep the issues of a particular condition or the situation of people with a range of disabilities on the political agenda. In the absence of state provision, they have played a major part in creating and providing a wide range of health and personal social services such

as physiotherapy, occupational therapy, speech therapy, social work, family support, and respite care. Voluntary organizations rely on a combination of state funding and resources raised from fund-raising. Over time, state funding has become an increasingly significant factor in service provision, and the laissez-faire arrangements for such funding have been replaced by contractual agreements between the statutory payers and the voluntary providers in which the respective obligations of accountability and transparency are defined.

ACCOMMODATION

In Ireland, many of those with disability were traditionally cared for in residential facilities, but from the 1980s, Ireland has followed international trends in deinstitutionalization and community-based care. However, the ideal of care in the community in which those with disability can live a full, inclusive life, nurtured by those around them, has never been fully achieved and many disabled adults live long-term in the family home. The provision of home-based support services is underdeveloped and, as a result, parents still approach old age without the reassurance of alternate services when they can no longer take care of their child. From the viewpoint of disabled adults, scarcity of alternative accommodation can limit life choices and some may only leave home on foot of a crisis, primarily the illness or death of a parent. While respite provision and some supported independent living accommodation have been provided, they are inadequate to meet current needs.

EDUCATION

Education for people with disability in Ireland is provided in a mixture of mainstream and special schools. Over the past decade, the number of disabled children in mainstream education has increased while the numbers attending special schools has remained constant. In 1990, two landmark legal challenges were instigated that highlighted a lack of any education for children with severe and profound disability. The first of these, the *O'Donoghue* case (1994), resulted in many children with severe and profound intellectual disability being granted the right of a formal education for the first time. In the second (*Sinnott v. Minister for Education* [2001]), the Supreme Court held that the state's constitutional obligation to provide for free primary education ceased at the age of 18. Both of these cases attracted much public attention and pressurized the government into reviewing its education provision to disabled pupils. Many of these reviews have been integrated into aspects of the Education Act (1998) and the Education for Persons with Disabilities Bill (2003). The Education Act requires schools to provide education to students that is appropriate to their abilities and needs. It specifies that a school must use its available resources to ensure that the educational needs of all students, including those with disability or with other special needs, are identified and provided for. However, the level of actual provision leaves a gap between aspirations and reality and the paternalistic approach to the educational provision for people with disabilities has been attributed to the continuing dominance of the psychomedical model.

EMPLOYMENT

Since 1977, the Irish public sector has had a 3 percent quota program for people with disabilities, which has never been fully realized. This quota does not apply to the private sector where efforts to secure jobs for those with disability have concentrated on facilitating and encouraging employers to take them on voluntarily.

The Irish Employment Equality Act (1998) is based on the principle that all individuals are entitled to equal treatment in training and employment opportunities regardless of gender, marital status, family status, sexual orientation, religious, age, disability, race, or membership of the traveling community. The 2002 annual report for the Irish Equality Authority (Irish Equality Authority 2003) noted that that the number of employment equality claims brought by disabled people discriminated against by the public/semi-state sectors at the point of access to employment has been striking. The report notes that the effectiveness of the Employment Equality Act to deter such discriminatory behavior is hampered by the low fines that employers found in breach of the act can be asked to pay. Put simply, employers in public or semi-state organizations may prefer to pay the maximum fine of €12,700 ($12,000) at 2002 rates, rather than incur the

expense of taking on a suitably qualified disabled person as an employee.

A more hopeful initiative in the area of employment and disability has been the development of supported employment programs for those with disability. These have been effective in the integration of people with disabilities into the open labor market. They are built on the principle of person-centered planning and have helped to place people with disabilities into jobs to which they are suited and that offer them personal fulfillment.

IRISH DISABILITY POLICY AND LEGISLATION

The *Report of the Commission on the Status of People with Disabilities: A Strategy for Equality* noted that people with disabilities were the neglected citizens of Ireland, many of them suffering intolerable conditions because of outdated social and economic policies and unthinking public attitudes. The report itself represented an important development as 60 percent of the membership of the Commission on the Status of People with Disabilities consisted of people with a variety of different disabilities, and carers. The result was a document that highlighted the multitude of problems facing those with a disability in Irish society, and it presents a number of policy measures to address them based on the fundamental concept of rights.

Recent European directives on employment and social inclusion have resulted in the development of new Irish equality legislation that encompasses people with disability. In addition, the period from 1998 onward has seen an unprecedented focus on the need for specific legislation on service development for people with disability. This was first addressed in the Disability Bill (2001) published on December 20, 2001. Many hoped that this new legislation would offer Irish disabled people and their families a rights-based piece of legislation on a par with the Americans with Disabilities Act. However, the bill was met with a storm of protest over the government's perceived failure to underpin the rights-based approach in the bill that had been advocated in the *Report of the Commission on the Status of People with Disabilities* (1996). Particular criticism was leveled at Section 47 of the bill, which purported to deny people with disabilities the right of appeal through the courts to seek improved services or judicial redress. A number of powerful advocacy groups organized a high-level publicity information campaign. This campaign, along with a growing sense of unease about the bill from the public in general, put pressure on the government to withdraw the bill on the evening of a mass meeting in Dublin in February 2002. An extensive consultation process with interested groups was then initiated in preparation for the redrafting of the bill. The redrafting of a new Disability Bill has suffered from continuing delays. However, any new legislation is unlikely to be full rights-based and may well be limited by that frequently used qualification that services are to be provided "where finance allows." This follows the tradition in Ireland of providing services for people with disabilities on a discretionary rather than mandatory basis.

—Bairbre Redmond and Suzanne Quin

See also Disability Law: Europe.

Further Readings

Commission on the Status of People with Disabilities. 1996. *Report of the Commission on the Status of People with Disabilities: A Strategy for Equality*. Dublin: Stationery Office.

Quin, Suzanne and Bairbre Redmond. 2003. *Disability and Social Policy in Ireland*. Dublin: University College Dublin Press.

Redmond, Bairbre. 1996 *Listening to Parents—The Aspirations, Expectations and Anxieties of Parents about Their Teenagers with Learning Disability*. Dublin: Family Studies Centre, University College Dublin.

Robins, Joseph. 1986. *Fools and Mad: A History of the Insane in Ireland*. Dublin: Institute of Public Administration.

Ryan, Annie. 1999. *Walls of Silence*. Kilkenny, Ireland: Red Lion.

Websites

National Disability Authority, http://www.nda.ie

EXPERIENCE OF DISABILITY: JAPAN

Experiences of disability (*shogai* in Japanese) in Japan are as unique as those in other countries. Disability movements and disability studies in Japan have

developed with the strong impact of Aoi Shiba, a group that raised fundamental and radical questions about disability and society. Disability movements in Japan are vocal and work closely with other Asian and Pacific as well as international movements.

RADICAL QUESTIONS ABOUT DISABILITY AND SOCIETY

A Murder in Yokohama in 1970

In one way, disability studies as well as modern disability movements in Japan were born when members of Aoi Shiba (*aoi shiba* literally means green grass), a group of people with cerebral palsy, made their views publicly heard in 1970. It was another murder. A mother killed her two-year-old daughter who had cerebral palsy. These killings of disabled people by their parents had been happening every year. When the murder was reported, the community was sympathetic to the mother. This was a usual response. Neighbors and members of the local family organization asked the court for leniency. More than 700 neighbors signed a petition expressing sympathy to the mother. The family organization protested the city government saying that since there were no institutions or support, there was no other choice but to kill disabled children whose right to life was denied by the society. This was to be just another murder of a disabled person and another typical response from the community.

But then, something unusual happened. Adults with cerebral palsy who were members of Aoi Shiba protested against these sympathetic views publicly for the first time. One leader of Aoi Shiba in Kanagawa Prefecture wrote in August 1970 that "in today's production-oriented society, people with cerebral palsy tend to be marginalized and their rights are denied. Even their life is not taken seriously" (Yamakita 1970:1).

Platform for Action

Then in October 1970, in the newsletter of Kanagawa Aoi Shiba, the four-point platform for action titled "We Act Like This" was announced as follows (author's translation):

- *We identify ourselves as people with cerebral palsy (CP).*

  We recognize our position as "an existence which should not exist," in the modern society. We believe that this recognition should be the starting point of our whole movement, and we act on this belief.

- *We assert ourselves aggressively.*

  When we identify ourselves as people with CP, we have a will to protect ourselves. We believe that a strong self-assertion is the only way to achieve self-protection, and we act on this belief.

- *We deny love and justice.*

  We condemn egoism held by love and justice. We believe that mutual understanding, accompanying the human observation, which arises from the denial of love and justice, means the true well-being, and we act on this belief.

- *We do not choose the way of problem solving.*

  We have learnt from our personal experiences that easy solutions to problems lead to dangerous compromises. We believe that an endless confrontation is the only course of action possible for us, and we act on this belief.

The following fifth point was added in 1975.

- *We deny able-bodied civilization.*

  We recognize that modern civilization has managed to sustain itself only by excluding us, people with CP. We believe that creation of our own culture through our movement and daily life leads to the condemnation of modern civilization, and we act on this belief.

Activities of Aoi Shiba

Throughout the 1970s, Aoi Shiba campaigned successfully against the revision of the Eugenics Protection Law of 1948, which was proposed to legalize abortion based on fetal impairments, protested against the mandatory segregated education, worked successfully against the national census on disability, moved against amniocentesis for the identification of fetal

impairments at prefectural hospitals, and took to the street to stop inaccessible buses.

In addition to these visible actions, they claimed that "shogai was an indispensable part of their identity." Aoi Shiba also made an effort to create its own culture, as mentioned in the fifth point of the platform. Though they did not fully succeed in this project, they have at least managed to bring the "cultural revolution" permanently into the disability agenda.

Ideas and claims of Aoi Shiba have left a strong and lasting impact on disability activism and disability thinking, leading to the advancement of the independent living movement in Japan as well as to the later formation of *shogaigaku* (disability studies).

Aoi Shiba's fundamental objection to the production-oriented society led to the critical review of the U.S. Americans with Disabilities Act of 1990 (ADA), which had much impact in Japan. Though the majority welcomed this landmark antidiscrimination legislation across the Pacific, some did not agree with the overall emphasis of ADA on integration into the market.

Also, Aoi Shiba's criticisms against women's claim of right to self-determination over abortion in general sparked the initially bitter debate in the early 1970s and later led to some collaboration between the disability movement and the women's movement. Prenatal screening in Japan is not as widespread as in other industrialized countries, partly because of the disability movement, which was informed by Aoi Shiba.

NATIONAL, REGIONAL, AND INTERNATIONAL DEVELOPMENTS

Japanese movements, which included Aoi Shiba, joined the regional and international movements in the establishment of Disabled Peoples' International (DPI) in 1981, which was the International Year of Disabled Persons, organized by the United Nations. When the UN Decade of Disabled Persons came to an end in 1992, disability movements in Japan initiated the Asian and Pacific Decade of Disabled Persons from 1993 to 2002, declared by the Economic and Social Commission for Asia and the Pacific (ESCAP) to maintain the momentum created by the UN Decade nationally and regionally. The success of the Asian and Pacific Decade, owing largely to the efforts of regional and national nongovernmental disability organizations, promoted similar regional efforts in other regions, such as Africa and Europe.

International and regional work also served as a catalyst for the formation of a unified national organization, Japan Disability Forum (JDF), in October 2004. JDF, a loose umbrella organization, includes major organizations of disabled people and their allies and serves as the national representative organization. JDF, for instance, has regular dialogues with the government. JDF focuses on the following four major areas: (a) UN Convention on the Rights of Disabled People, (b) promotion of Asia and Pacific Disability Forum, (c) national disability plan, and (d) prohibition of discrimination against disabled people and the establishment of rights legislation. These are the priority areas for the movements in Japan.

DISABILITY STUDIES

In 1995, the intellectual impact of the deaf culture movement was keenly felt in Japan with the "Declaration of the Deaf Culture," by Harumi Kimura and Yasuhiro Ichida. By its emphasis on an independent culture as well as the denial of impairment and disability, this manifesto led to rethinking of impairment and disability not only in the context of the deaf/Deaf field but in the disability field in general.

Against this background, in 1999, "Invitation to Disability Studies," coedited by Jun Ishikawa and Osamu Nagase was published. This initiative resulted in the establishment of the Japan Society for Disability Studies in October 2003 at the University of Tokyo. Ishikawa, a blind professor at the University of Shizuoka, was elected the first president.

Disability studies in Japan, with its emphasis on disability as a form of discrimination as well as a meaningful way of living, has roots in Japan at least as far back as Aoi Shiba in the 1970s and today has a critical mass of people, disabled and nondisabled, who are committed to its development.

—Osamu Nagase

See also Advocacy, International; Housing: Law and Policy.

Further Readings

Ishikawa, J. and O. Nagase, eds. 1999. *Shogaigaku eno shotai* (Invitation to Disability Studies). Tokyo: Akashi Shoten.

Tateiwa, S. 1997. *Shiteki shoyuron* (On Private Property). Tokyo: Keiso Shobo.

Yamakita, A. 1970. "Ayumi," No. 10, August 10.

EXPERIENCE OF DISABILITY: THE NETHERLANDS

Many terms and definitions in the area of disability, disablement, handicap, and invalidity exist. They vary depending on the aim, time in history, context, country, and the person who is using the terms and definitions, and it is important to explain the terms and definitions used. Because the World Health Assembly of the World Health Organization endorsed in 2001 the International Classification of Functioning, Disability, and Health (ICF) for international use and urged member states to use the ICF in research, surveillance, and reporting, in this entry we use the ICF terminology and definitions. The description of the situation of persons with disability in the Netherlands in 2002 is derived from the *Report on the Disabled* 2002. This report is published every two years at the request of the Ministry of Health, Welfare and Sport. Many persons with and without activity limitations (physical activity limitations or mental impairments) have been questioned on their situation in different population surveys.

TERMS AND DEFINITIONS

The ICF provides a framework and a standard language for the description of health and health-related states from different perspectives: the perspective of the body (body functions and structures) and the perspective of the individual and society (activities and participation). *Functioning* is the umbrella term encompassing body functions, structures, activities, and participation. *Disability* is the umbrella term for impairments, activity limitations, and participation restrictions. The ICF lists also environmental factors that interact with all of them as facilitators or barriers.

The ICF is to be seen as a supplement to the International Statistical Classification of Diseases and Related Health Problems (ICD-10), which includes morbidity and mortality causes and diagnoses. ICF and ICD are the core classifications of the Family of International Classifications of the World Health Organization (WHO-FIC).

In Figure 1 the relations between the components of the ICF in relation to the ICD domain are reflected. Table 1 shows the key terms and definitions derived from the ICF.

In the next paragraphs, we describe the disability situation in the Netherlands by using ICF terms. The information source is mainly dealing with disability in terms of participation (restrictions) by persons with activity limitations (physical activity limitations or mental impairments) and does not include the level of body function and structure (impairments) as such. It means that we present a short paragraph on the number of persons with activity limitations, a more extensive paragraph on participation (restrictions) in major life areas, and a paragraph on the use of existing services as facilitators by persons with activity limitations.

PERSONS WITH ACTIVITY LIMITATIONS

There are currently around 500,000 people living independently in the Netherlands with severe physical activity limitations, and around 1 million persons with moderate physical activity limitations, that is, people who have severe or moderate difficulty in carrying out day-to-day tasks relating to personal care, mobility, or household activities because of a health condition. In addition, there are around 9,000 people under the age of 65 living in residential facilities and 150,000 persons age 65 and older living in residential facilities because of severe or moderate physical activity limitations. There are more than 100,000 persons with mental impairments, roughly half of whom live in supported housing.

These people, excluding persons age 65 and older living in residential facilities, form the target group for Dutch government policy on disability. The core objective of this policy is to offer effective, high-quality support that is directed toward enabling the

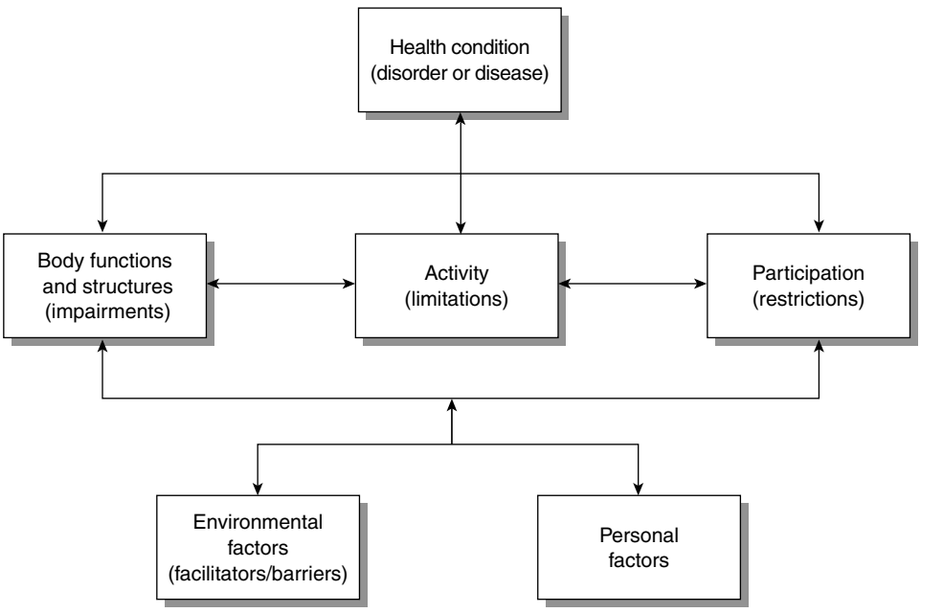

Figure 1 *Interactions between the Components of ICF*

persons with impairments and activity limitations to play a full part in society.

The next paragraphs describe the extent to which people with activity limitations (including those with physical activity limitations and with mental impairments) in the Netherlands participate in society in a wide range of major life areas (education, employment, economic life, recreation, and leisure) and how they make use of available facilitators (care and housing). The question of whether this participation and use is adequate is, however, difficult to answer, since there is no norm against which the participation of people with activity limitations can be measured. In the absence of such a norm, the social position of persons with activity limitations is consistently compared with that of people without activity limitations. Implicitly, this presupposes that both parts of the population ought to participate equally.

Participation in Major Life Areas

Education

Only a fragmentary picture is available of the school careers of people with physical activity limitations. Nothing is known about their participation in mainstream education, and they can only be partially identified from the records of the main special provisions (peripatetic support and special education). What is apparent is that pupils with moderate or severe activity limitations generally leave school with a lower level of achievement. This offers an important explanation for the relatively low participation of people with physical activity limitations in the labor market.

The amount of peripatetic support used in mainstream education has tripled since the early 1990s, and in special schools has increased by 40 percent. This growth is striking, since it is unlikely that the number of young people with activity limitations has risen so much faster over the period than the total number of young people (8 percent increase). The reasons for this growth in the take-up of provisions is not known. It may be that there was some underuse in the past, but it may also be that children with relatively slight activity limitations have begun making more use of these relatively "heavyweight" provisions.

It is also unclear to what extent people with mental impairments participate in mainstream education, though a clear trend can be seen whereby people with Down syndrome are increasingly participating in mainstream education: Today almost half of them

Table 1 ICF Key Terms and Definitions

Body functions/impairments
Body functions are the physiological functions of body systems (including psychological functions).
Impairments are problems in body function or structure such as a significant deviation or loss.

Body structures/impairments
Body structures are anatomical parts of the body such as organs, limbs, and their components.
Impairments are problems in body function or structure such as a significant deviation or loss.

Activity/activity limitations
Activity is the execution of a task or action by an individual.
Activity limitations are difficulties an individual may have in executing activities.

Participation/participation restrictions
Participation is involvement in a life situation.
Participation restrictions are problems an individual may experience in involvement in life situations.

Environmental factors/facilitators/barriers
Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives.
Environmental factors may be a facilitator or a barrier.

Personal factors
Personal factors are the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states, such as: gender, race, age, fitness, lifestyle, habits, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character style, individual psychological assets, and other characteristics, all or any of which may play a role in disability in any level.

Functioning/disability
Functioning is the umbrella term encompassing body functions, structures, activities, and participation.
Disability is the umbrella term for impairments, activity limitations, and participation restrictions.

Table 2 Disability in the Netherlands in 2002: Number of Persons with Activity Limitations (physical activity limitations and mental impairments)

Number of Persons	*abs 1,000*	*%*
Persons with		
severe physical activity limitations living independently	512	3.5
moderate physical activity limitations living independently	980	6.6
Persons aged below 65 living in residential facilities	9	0.06
Persons aged 65 or older living in residential facilities	150	1.0
Persons with mental impairments	103	0.7
Total persons with activity limitations	1,754	11.8

attend mainstream schools, at least for a few years. Strikingly, there has been an enormous increase in the size of the education sector for children with severe mental impairments, which has grown by 70 percent in the space of 10 years. There are no indications that the total number of children with mental impairments has grown so strongly.

One out of 10 persons with a physical activity limitation has at some time given up a course or been prevented from following a course because of their activity limitation. Almost all of them cite physical problems (pain, fatigue, absence due to illness or therapy) as the reason. They feel that adapted facilities (enlarged computer screens, adapted furniture) and the ability to

follow lessons at their own pace are important conditions for their participation in education courses.

Employment

Physical activity limitations form a major obstacle to people's participation in the labor market. This is apparent from the fact that only 38 percent of people with activity limitations perform paid work, compared with 61 percent of the general population ages 15–64 years. The participation rate is even lower where people with activity limitations also have a low education level, are older, or are female.

A large body of new legislation and regulations has been implemented in the Netherlands in the past 10 years aimed at tightening up the rules on incapacity for work and encouraging more people with activity limitations to find employment. The results of these legislative changes have been disappointing: The proportion of persons with activity limitations performing paid work is still small and the number of people helped into jobs is only a fraction of the number who find employment by their own efforts.

People requiring more protection and support than the mainstream labor market can offer can seek admission to sheltered employment or day centers. Around the turn of the century, approximately 30,000 people with mental impairments were in sheltered employment and some 15,000 people were visiting a day facility for adults. Research among the users of these facilities suggests that the vast majority have a positive view of them, though around 10 percent of the parents/carers of the employees feel that the pressure of work in sheltered employment placements is too high, while roughly a third of the persons themselves would rather be carrying out activities other than those they are performing at present.

Economic Life

On average, 18- to 64-year-olds with severe physical activity limitations have a gross personal annual income that is more than €3,000 lower than that of those without physical activity limitations (€21,600 and €24,800 per annum, respectively). These income differentials occur largely because people with activity limitations participate in the labor market less frequently than people without activity limitations. At the household level, too, households in which (at least) one member has severe physical activity limitations have a lower income than households where no members have activity limitations (the difference is just under €2,000 per annum). People with mental impairments almost all have to live with a very low income.

Roughly 80 percent of people with physical activity limitations incur health-related expenses each year (e.g., for dentistry, nonprescription medicines, or their own contribution to home adaptations). These expenses average €750 per year, though can vary widely; for example, around 10 percent of persons with activity limitations spend more than €1,360 per year. It is not known what costs are incurred by people without activity limitations, and it is therefore not always possible to say that having an activity limitation necessarily leads to extra expenses.

Of people with physical activity limitations, 23 percent experience social deprivation. This means that financial reasons prevent them from doing or having a number of things that are necessary to function socially in the community (such as going out or inviting people for a meal).

Recreation and Leisure

People with an activity limitation participate in sports less often and also less frequently visit cultural or recreational amenities than people without activity limitations. The more serious the activity limitations, the greater the difference compared with people without activity limitations. The majority of people with an activity limitation see their own health status as the most important obstacle to leisure activities. They also cite the poor accessibility of buildings and problems with transport. People with severe physical activity limitations in particular are often unable to use public transport and are then forced to rely on adapted transport. Currently, around 860,000 transport provisions have been granted, almost half of which concern collective transport facilities. Local authorities are increasingly opting for collective transport; however, the fact that lots of people use these facilities does not mean that they are satisfied with them. The main complaints are that the transport often does not run on time and it is difficult to meet the requirement of asking for

transport an hour before wishing to make a journey. This makes adapted transport relatively inflexible.

Roughly half of all adults with a mental impairment engage in leisure activities via an association or club. By far, the majority of these are associations that are used mainly by people with mental impairments. Around a third to 40 percent of people with mental impairments express a need to go out more. The main obstacle preventing them from doing so is lack of a suitable social network. Many are dependent on their family or carers from their residential facility, and as a result, the majority of people with mental impairments do not appear to be very socially integrated.

Use of Available Facilitators

Take-up of Care

In 1999, around 9 percent of households were receiving informal help with household tasks or personal care, while 8 percent were using private care facilities. Approximately 7 percent were receiving help from the home care services with household tasks or personal care. This figure is somewhat higher than in 1991 (5 percent). The increase is related to the fact that the number of people with disabilities has increased as the population ages. The average number of hours of care per client has, however, declined; approximately 40 percent of home care institutions ration the amount of care afforded to each client in order to be able to provide care to as many people as possible. These people receive an average of almost three hours per week less care than that for which they have an indication. More than a quarter of clients themselves feel that they receive too little care.

One of the biggest problems in the care sector is the waiting lists. In March 2001, there were around 30,000 people on the waiting list for home care services. Roughly 40 percent of them do, however, receive "bridging care" (i.e., another product or fewer hours than indicated).

Housing and Care

The vast majority of people with physical activity limitations live independently. The accessibility of their home is an important condition for their being able to do so. And yet 60 percent of those who have difficulty climbing stairs live in a home with a staircase (either indoors or in order to reach the front door). Only a small number (6 percent) have a stairlift.

A minority of people with moderate or severe physical activity limitations live in adapted housing, though the number of people with adapted homes increased by around 40 percent between 1995 and 1999. In many cases, these adaptations are carried out using grants pursuant to the Services for the Disabled Act (WVG): Each year 70,000 (in 1996) to 100,000 (in 1999) adaptations are approved the under the act.

Around 60 percent of the 80,000 adults with mental impairments live in supported housing units (total capacity: 17,500 places) or in a general institution for people with mental impairments (35,000 places). The capacity of these latter institutions increased by more than 30 percent between 1980 and 2000, and that of the supported housing units doubled over the same period. Those living independently or with their parents generally have less severe mental impairments, fewer physical limitations, and fewer behavioral problems than those living in institutions. In the Netherlands, as in other countries, the aim is to enable more people with mental impairments to live independently, with support where necessary.

CONCLUSIONS

An enormous amount of government policy has been implemented in recent years aimed at improving the living situation of people with activity limitations (including those with mental impairments) and increasing their participation in the community. These efforts have met with only partial success. To some extent, this is because the legislation brought in is still too new to expect its implementation to have had any impact yet. Where legislation has been in place for longer, as is the case with the WVG, for example, the picture is very mixed. Thanks to this act, a great many people with activity limitations have access to home adaptations, which enable them to continue living independently for longer. However, users are less positive in their views about the WVG provisions in the area of transport; whereas in the past people with activity limitations often received benefits for which they could pay for whatever form of transport they themselves chose, they are now often forced to rely on collective transport, which is characterized by a lack of flexibility.

The information presented in this entry reveals that the Netherlands is still not sufficiently accessible to people with activity limitations and so creates participation restrictions for them. This applies across a whole range of fields: education, the labor market, public buildings, people's own homes, public transport, care provision, voluntary work, and associational and club life. Although the government does pursue policy designed to improve this accessibility, the measures often have a nonobligatory character.

A minority of people with activity limitations in the Netherlands live in poverty, partly because of a lack of income from employment. Increasing the labor market participation of people with activity limitations ought therefore to be one of the central planks of government disability policy. As well as employment placement services, training and improving the school achievements of younger people with activity limitations are among the ways of achieving this.

Adults with mental impairments increasingly live independently in average neighborhoods. However, the expectation that this will enable them to play a greater part in the community is not being fulfilled; in practice this integration encounters numerous problems. For example, people living independently are found to play virtually no part in general social activities. People with mental impairments often lack a network of people with whom they can undertake activities; many of them remain dependent on their family or carers from a residential facility for this.

Living in an institution often causes people to become dependent on others and to have little autonomy. On the other hand, life in an institution does often result in an integral provision of diverse amenities, both residential and with respect to filling residents' days. This cohesion is lacking when people live independently.

Choosing between a residential facility and living independently is still too much a matter of choosing the lesser of two evils: In the former case people with mental impairments have too little autonomy, while in the second they are in danger in the present situation of losing quality of life.

—Marijke W. de Kleijn–de Vrankrijker and Mirjam M. Y. de Klerk

See also Disability Law: Europe; Education, International; Employment; International Classification of Functioning, Disability, and Health; World Health Organization.

Further Readings

Kleijn–de Vrankrijker, M. W. de, Y. F. Heerkens, and C. D. van Ravensberg. 1998. "Defining Disability." Pp. 11–18 in *Introduction to Disability,* edited by M. A. McColl and J. A. Bickenbach. London: Saunders.

Klerk, M. M. Y. de, ed. 2002. *Rapportage gehandicapten 2002, Maatschappelijke positie van mensen met lichamelijke beperkingen of verstandelijke handicaps* (Report on the Disabled 2002, Social Status of Persons with Physical Activity Limitations or Mental Impairments). Den Haag: Social and Cultural Planning Office of the Netherlands. (With summary in English).

World Health Organization. 1992. *International Statistical Classification of Diseases and Related Health Problems*, 10th revision (ICD-10). Geneva: World Health Organization.

———. 2001. *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization.

EXPERIENCE OF DISABILITY: NEW ZEALAND

New Zealand is one of the most recently settled major land masses. Polynesian settlers arrived around AD 500–1300. The first European expedition to New Zealand was led by Abel Tasman in 1642. The name New Zealand comes from the initial Dutch settlers. Around the 1760s, Captain Cook started surveying the islands, which opened the way for trade and whaling expeditions. This led to the colonization of the islands predominantly by European settlers.

In 1840, a treaty (Treaty of Waitangi) was signed between Maori chiefs of New Zealand and a representative from Queen Victoria. This treaty promised complete chieftainship over resources. Today, the exact meaning of the treaty is being debated and it remains a source of resentment for both Maori and Pakeha (Europeans).

New Zealand became an independent dominion in 1907 and gained full independence from the United Kingdom in 1931. New Zealand is still a constitutional monarchy in the Commonwealth, although there is a growing movement to establish New Zealand as a republic. This change would also include shifting governmental representation from a governor-general appointed by the queen (on advice of the government in power) and a prime minister to a president.

New Zealand has two main islands (North and South Island) and a number of smaller islands. The

total land mass area is 268,680 square kilometers, meaning that it is smaller than Japan or the United Kingdom and just slightly larger than the state of Colorado. New Zealand extends to 1,600 km through its main north-northeast axis.

Its closest neighbor is Australia, more than 2,000 km away to the west, with Antarctica to the south and Fiji, Samoa, and Tonga to the north. Due to New Zealand's isolation from other countries and the number of uninhabited islands that come under its jurisdiction, its economic zone is the world's fifth largest, totaling 4.2 million square kilometers.

Colonial life in New Zealand was tough with accidents more likely to cause death due to shock or loss of blood; nowadays people who experience an accident are more than likely to survive due to the advanced medicines and treatment available. However, in the 1800s a death of the breadwinner (usually a man) resulted in the family being destitute. Diseases such as whooping cough, measles, diphtheria, and poliomyelitis were also major causes of death or impairment. Alcohol also caused a fair amount of physical and psychological damage. Between 1863 and 1865, there were 42 admissions into an asylum in Dunedin and it was thought by the medical superintendent at the time that half of the admissions were the result of alcohol (450 out of 909).

One of the first pieces of legislation passed, the Lunatics Ordinance Act 1846, dealt with the issue of insanity and gave the right to detain or arrest those people who were deemed likely to cause danger to the general public. The first asylum was built in a suburb of Wellington and opened in 1854 with places for 10 people. This was followed in short time by a number of asylums throughout the country. Staff members at these facilities were appointed because of their ability to handle a large number of people rather than any skill in the area of working with or caring for people. In fact out of all the asylums opened only Auckland appointed a person with a medical background.

An early piece of legislation specifically affecting disabled people was the 1882 Imbecile Passengers' Act. The act required a bond from a ship's captain who brought into New Zealand anyone who was deemed to be a lunatic or someone who would become a burden by requiring charitable aid. The 1899 Immigration Act prohibited any immigrant that was seen to be an idiot or suffering from a disease to enter the country. Neither of these pieces of legislation was stringently enforced. The first piece of education legislation was passed in 1877 and introduced free and compulsory education; however, there was no acknowledgment of special education. The act did state that a temporary or permanent infirmity was grounds for exemption from attending school. Mother Aubert founded the Sisters of Compassion, which took in disabled children with spina bifida, Down syndrome, and a variety of other impairments. However, most of the institutional care provided in the late nineteenth and twentieth centuries was for people with mental illness.

Around the same time, the first institute for deaf and dumb people was established in Sumner near Christchurch in 1880. Instructions for deaf students were conducted orally because there was a ban placed on the use of sign language. It was not until 1979 that the ban was repealed.

While plans for the first asylum for blind people were made in 1874, the building was delayed due to the low numbers of people eligible for housing; at that time it was thought there were only about 12 people in the Auckland area with significant visual impairments. It was not until 1889–1891 that a school to teach blind children was established in Parnell. At that time, Parnell was an outlying suburb of Auckland and a difficult journey. The town was in the heart of the market gardening area, and funds were provided by a bequest from a strawberry grower who left $12,000 in 1905 (the sum is equivalent to $200,000 today). The building of the school started later that same year, was finished in 1907, and officially opened two years later. In present day, the Royal New Zealand Foundation of the Blind is in the heart of the city and a major landmark in the Parnell area. Individuals are housed in any of the original buildings.

At the start of the twentieth century in New Zealand, there was a feeling that the affairs of the country were historically linked to the United Kingdom. As a result, New Zealand eugenicists based many of their arguments on data and information received from England. In 1903, W. Chapple published *The Fertility of the Unfit*, in which he proposed that the increase in crime, destitute people, and insanity

was the result of society being born of defective stock. The book was well received not only by the public but also by the chief justice of the time (Sir Robert Stout), who thought the work was excellent and helped to have the book published in the United Kingdom. According to Chapple, "the unfit" were those who, because of mental and physical disabilities, were unable to support themselves. This classification included criminals, paupers, and those who were defined as idiot, imbecile, lunatic, or alcoholic. When the New Zealand Society formed in the early twentieth century, it sought to directly replicate the London Eugenics Education Society. It was widely believed that New Zealanders were stronger and fitter than people from other countries; however, this perception was challenged when 57 percent of conscripts for World War I were rejected from serving.

A question in the census of New Zealand was framed to ask about infirmity in the household, in other words, to identify those people who were unable to work due to injury or illness. The question was withdrawn after the 1916 census, which identified 206 people as deaf and dumb, 566 as blind, 3,741 as lunatic, and another 777 as feebleminded. The reason for the question being dropped was a growing reluctance on the part of the population to acknowledge such impairments. The question was brought back into the census in 1996 and revealed that 20 percent of the population had some form of impairment. The elder population—those over age 60—had the greatest percentage of people with impairments.

In 1907, the Education Amendment Act was passed, which mandated the education of "defective" or epileptic children from the ages of 6 to 21. The minimum age for disabled adults in education today still stands at 21.

World War I resulted in New Zealand having a large number of returned servicemen in need of support due to the nature of their wounds. The government offered monetary compensation to these returned servicemen, and it was expected that the pension received would replace what the soldiers could have earned. The government offered no services to people, just monetary compensation. One of the returned servicemen was Clutha Mackenzie, who lost his sight at Gallipoli. Prior to enlisting, Clutha was on the board of the Auckland Institute for the Blind and it was through his lobbying that the government passed the Pensions Amendment Act in 1924, which introduced pensions only to blind people over age 21. It was not until a number of years later (1936) that pensions were offered to other impairment groups.

Also as a result of World War I, new procedures and organizations introduced in orthopedics and plastic surgery to returned servicemen were now offered to people with congenital disabilities. The war also had the effect of raising public awareness of people with mental illness—particularly in the form of neuroses—and this led to a halfway house and an outpatient's clinic being established. Finally, there was a need for more masseurs to treat wounded soldiers and this increase eventually resulted in the establishment of a Registration Act in 1920.

In 1925, a Royal Commission into the health of New Zealanders believed that the country was losing its colonial and pioneering energy. One of the committees of the commission, the Inquiry into Mental Defectives and Sexual Offenders committee, was the most openly eugenicist-minded committee in the Royal Commission. This committee also linked mental defectives and sexual offenders for the first time. Three years later, in 1928, the Mental Defectives Amendment Act was passed, and this led to the setup of the Eugenics Board, which was charged with compiling a register of people who were deemed to be mentally defective.

Templeton Farm was established in 1929 for the institutional care of people who were diagnosed as either imbecilic or feebleminded but without "psychotic complications." A number of people with physical impairments ended up in Templeton on the advice of doctors to their parents. These medical personnel during the early and middle part of the twentieth century advocated for the placement of children with disabilities in institutions.

In the early 1930s, New Zealand experienced another polio epidemic, which led to Alexander Gillies, a noted orthopedic surgeon, establishing the New Zealand Crippled Children Society (now known as NZCCS) in 1935. The organization was charged with helping the crippled child and in no way to usurp the local authorities or government obligations to those defined as "defective." The society sought to work in a supportive and cooperative way. During its

formation, Lord Nuffield, who was visiting from the United Kingdom, donated £50,000 towards it establishment. Along similar lines, the Wilsons (one of the founders of the major morning newspaper, *The Herald*) donated a family home to assist in the rehabilitation of children under the age of 21 who were recovering from either illness or an operation.

World War II again added many veterans to the number of disabled people in New Zealand, and it was estimated in 1946 that 23,000 (or approximately 11 percent) of the returned servicemen and servicewomen were paid some form of pension. Again there were spin-offs with new technologies developed to treat wounded soldiers and these would again be used to treat the general public. Also occupational therapy became a professional career option for people who wanted to work with disabled people.

The 1940s brought two distinguished visitors to New Zealand; in 1947 Helen Keller visited on behalf of the Royal New Zealand Foundation for the Blind, and in 1948 Earl Carlson, a specialist in the treatment of people with cerebral palsy, recommended a facility be built for their care. This facility was duly completed in 1951 at Rotorua. In recognition of his influence, a school was named after Carlson in the Auckland area.

The postwar years brought about a view that people with disabilities deserved to have the same rights as other members of society. Through the Depression and war years New Zealand sought safeguards to prevent a repeat of eugenics in order to establish a fairer society so that the cause of the wars would not be in vain. In earlier years, an attempt was made to form an organization that represented the parents of children with intellectual disability called the After Care Association. While it did meet some of the needs of family members, parental voices still went unheard. In 1949, another attempt to bring about the first parent-driven association for children with intellectual disability was attempted. A group of 22 parents met on October 25, followed less than a month later by the establishment of the Intellectually Handicapped Children's Parents Association. The major focus of the group was to be a voice and support for those parents connected with people with an intellectual disability.

The 1950s saw the establishment of other specific-impairment groups, including the New Zealand Epilepsy Association and Hoehepa Homes (based on the Rudolph Steiner principles). Also in the 1950s, the first vaccinations of children against poliomyelitis took place. The Asthma Association was formed in 1962. The 1960s saw a settling-down period of single-impairment groups as efforts began to work with children, young adults, adults, and family members of people with impairments. A residential facility for blind children was established in the Auckland suburb of Manurewa and eventually children from this school were integrated with the local area schools.

The 1970s saw the introduction of three key pieces of legislation that would have long-term effects on the disabled community. In 1972, the Labour government passed the no-fault Accident Compensation Commission Act. This act gave people monetary compensation when they were a victim of an accident—no matter who was at fault. This monetary amount was based on the level of impairment suffered; the greater the level of impairment, the more compensation. This compensation was given only to people who gained their impairment from an accident after the introduction of the act in 1972. It did not and still does not apply to people who have the same level of impairment due to birth or illness.

In 1975, the Disabled Persons Community Welfare Act (DPCWA) was passed. The act gave assistance to disabled people, parents, and guardians, as well as voluntary associations. The act defined a *disabled person* as someone who has or suffers from any physical or mental disablement to a degree that the person is seriously limited in the extent to which he or she can participate in activities of everyday life. The DPCWA also introduced a program to give parents or guardians a chance to take up to four weeks of respite leave and have someone either come in and care for their child or send the child away to be cared for at either an organization or other type of facility.

The final act that had an impact on New Zealand's disability population was the passing of the Human Rights Act of 1977. This act made it illegal to discriminate on the grounds of gender, marital status, or religious or ethnic belief. Disability, however, was not included as a recognized grounds for discrimination.

The International Year of Disabled Persons was in 1981, and this saw a plethora of disabled people and

organizations promoting disability issues. A telethon was held to celebrate the year, and it raised more than $6 million (New Zealand at that time had a population of just over 3 million people). In 1982, the Disabled Person's Assembly was formed to represent the voice of disabled persons. Its charter stipulated that the national executive committee had to have a majority of disabled people on the board.

CONCLUSION

New Zealand has grown from a small isolated island with strong ties to the United Kingdom. As has been shown, key events along the way have shaped the country's response to disabled people. What lies ahead for disabled populations will be more challenges as the community fights to establish an identity as disabled people rather than a group needing "welfare."

In fighting for this identity, what may happen is an explosion of smaller impairment groups as happened in the 1950s. This will lead to government departments having to contract to a large number of impairment groups rather than the "big four": CCS (provider of support and services to people with physical disabilities), IHC (provider of services to people with intellectual disabilities and their families), the Blind Foundation, and the Deaf Association. The first task will be to include disability as a group against whom discrimination is outlawed.

—Russell Vickery

See also Education, International; Eugenics; Housing: Law and Policy; Mental Illness.

Further Readings

Brookes, B. and J. Thomson, eds. 2002. *Unfortunate Folk: Essays on Mental Health Treatment 1863-1992*. Dunedin: Otago University Press.

Carey, H. E. 1960. *The History of the New Zealand Crippled Children Society's First Twenty-Five Years 1935-1960.* Wellington: New Zealand Crippled Children Society.

Catran, K. and P. Hansen. 1992. *Pioneering a Vision: A History of the Royal New Zealand Foundation for the Blind 1890-1990.* Newmarket: Royal New Zealand Foundation for the Blind.

Millen, J. 1999. *Breaking Barriers: IHC's First Fifty Years*. Wellington: IHC New Zealand.

Mitchell, D. R. J. W. Mitchell. 1985. *Out of the Shadows: A Chronology of Significant Events in the Development of Services for Exceptional Children and Young Persons in New Zealand: 1850-1983.* Wellington: Government Print.

New Zealand Government. 1972. *The Accident Compensation Act.* Wellington: Government Print.

———. 1975. *The Disabled Persons Community Welfare Act.* Wellington: Government Print.

Tennant, M 1989a. "Disability in New Zealand: An Historical Survey." *New Zealand Journal of Disability Studies* 2:3–33.

———. 1989b. *Paupers and Providers: Charitable Aid in New Zealand.* Wellington: Allen & Unwin.

EXPERIENCE OF DISABILITY: SERBIA

Serbia is located in the central part of the Balkan Peninsula, on the most important route linking Europe and Asia, occupying an area of 88,361 square kilometers. Serbia is in the West European time zone (one hour ahead of Greenwich time).

The ethnic population of the Republic of Serbia is heterogeneous, a result of the country's turbulent past. The majority of the population of Serbia are Serbs, but another 37 ethnicities also live on its territory. All citizens have equal rights and responsibilities and enjoy full ethnic equality. The Constitution of the Republic of Serbia guarantees rights to minorities, in accordance with the highest international standards. The last 2002 census puts the population of Serbia (excluding Kosovo-Metohija) at 7,498,001, which is 92.3 percent of the population of the State Union of Serbia-Montenegro. The main religion of Serbia is Christian Orthodox.

GEOGRAPHIC INFLUENCES

This overview of rights for people with disabilities begins from a geographic perspective. This perspective is important because Serbia has shared similar experiences of disability with neighboring countries of Southeast Europe such as Croatia, Bosnia and Herzegovina, Serbia and Montenegro (Yugoslavia), Macedonia, Albania, Hungary, Bulgaria, Romania, and Moldova. All countries in this region had communist regimes in the past and poverty was widespread. These demographic factors significantly influenced the position of people with disabilities in the region.

As a research area of social importance, the topic of disability is poorly investigated. Internet resources are rare. This situation represents a problem for developing research on Serbia and people with disabilities, but at the same time, it also represents a challenge and an opportunity to make recommendations for future research.

Documents authored by the organization Disability Right Advocates (DRA; 2001) have proven both invisible and neglected. Yet one can find insights on the situation of people with disabilities in Central Europe spread throughout such reports. A summary of these analyses will occupy the bulk of this entry. Such documents present a starting point for research in this part of the world. Their analyses reflect global issues of disability oppression and deal with key perspectives and issues of importance for people with disabilities. They also present a special focus on the education of people with disabilities. The DRA report starts by describing the situation of people with disabilities in Central Europe:

> Indeed, although many of the nations of Central Europe stand poised to assume their places as essential political and economic partners with Western Europe, many are like third world countries in their treatment of people with disabilities. Thus, throughout Central Europe, very few people with disabilities have the opportunity to lead a full and independent life. As a group, disabled people are segregated and immobilized by pervasive architectural barriers. They are also poor, without necessary assistance or assistive devices, discriminated against, and lack sufficient information or governmental support to improve their situation. They suffer from massive unemployment and social, political, and economic exclusion. . . . Throughout the region, treatment of people with disabilities is also still dominated by the medical model and outmoded concepts of charity, pity and non-productivity.

One of the important facts about this part of the world is that people with disabilities are largely hidden from public view. Factors that contribute to this situation are widely held myths and prejudices that saturate the culture about disability as tragedy. These beliefs together with inadequate family supports for people with disabilities—families that often lack knowledge about disabilities and that are trapped in similar debasing ideas—form some of the core problems facing disabled people in these countries. The DRA (2001) explains this detrimental situation in the following manner: "In the past, disabled people were hidden by their family members and there is still considerable stigma attached to having a disabled child. . . . One result is the frequent institutionalization of the severely physically disabled, as well as developmentally disabled children and adults." Furthermore, it is said that "the medical model for disabled people is still the dominant paradigm. The communist concept of the ideal citizen—a healthy manual worker—reinforced this negative image and labeled disabled people as misfits."

The report also identifies prevalent myths about people with disabilities—myths that define common approaches toward this group. The first myth is that persons with disability cannot lead a productive life. This belief is identified as the "helplessness myth" and promotes ideas of extreme dependency as well as overall incapacity to contribute to society. The second myth, known as the "charity myth," claims that philanthropy rather than organized institutional structures should deal with the "problem" of disabled people. The third myth (recognized in first contacts with policy makers in Serbia and other countries of the region) is the "costs myth." According to this approach, disability costs too much and these countries cannot afford to spend their beleaguered budgets on the repair of disability issues.

The Association of Students with Disabilities of Serbia and Montenegro (ADS; 2004a) gives additional statements with regard to regional characteristics. These statements are mostly built from the valuable experiences of people with disabilities in the region, and therefore they have not yet attained the status of formal research insights:

Lack of political activities—It is very rare that one finds persons with disability as members of any national or local governments.

Architectural barriers—In most countries of the region, architectural barriers represent an impediment for people with disabilities. Lately, some regulations of accessibility for wheelchair users have been

coming into use. Accessibility regulations for blind and other visually impaired people as well as people with hearing problems are extremely rare. Ineffective laws are the main reason for such situations, because such policies provide only mild sanctions at best against institutions that do not respect general accessibility regulations.

Inaccessibility of means of transportation—In the countries of Southeast Europe, regionally accessible public transportation usually does not exist. In big cities and capitals of the region, there are special means of transport for people with disabilities but these are often limited.

Employment—In Serbia and Montenegro, young people with disabilities are most frequently only fictively employed in a company and retire after only six months to two years, with the aim to gain a right to pensions. A pension thus acquired is very low and people with disabilities are once again dependent on the government and their families. When a vacancy exists, employers will invariably employ able-bodied workers in almost 100 percent of the cases. Such practices continue regardless of the qualifications that applicants with disability might have. An additional problem exists because few data on qualified young people with disabilities have been published. Companies willing to offer employment are, as a rule, inaccessible to persons with disabilities (due to a failure to implement accessible construction regulations). There is no legal obligation or stimulation by the government for solving this problem. This description is for the most part applicable to all countries in the region.

Personal assistant programs—A personal assistant initiative has been introduced in Hungary. The program is organized and carried out by a nongovernmental organization (NGO) motivated by a cooperative arrangement with the government. One of the ways this problem might be addressed in the region is civil service as an alternative to military service, and a number of organizations and individuals support this initiative. Currently, military service in the region is compulsory so that the introduction of a civil service requirement has yet to be adopted by most countries in the region.

Because Serbia is a small country, its politics have been greatly influenced through intersecting histories with neighboring countries. Consequently, the development of disability rights in Serbia could be studied from a regional perspective.

HISTORICAL PERSPECTIVE

What was the situation of disability rights in Serbia through history? Few written documents are available for study and thus analyses of disability in Serbian history are rare.

In a recent World Bank document titled *Poverty Reduction Strategy Paper for Serbia* (2004), a general history of Serbian social protection services is presented. It draws links between poverty and people with disabilities while also challenging the common practice of institutionalizing people with disabilities throughout Serbian history.

A first Serbian law for the protection of human rights for poor people was implemented in the thirteenth century by Saint Sava.

> In close cooperation with the civil authorities, the church was in charge of the creation of "honorable homes" for: the elderly, the poor, children deprived of parental care, foreigners etc. These homes had their administrative and managerial staff, as well as real estate and other assets that were bestowed upon them. The operation of these charitable institutions was closely monitored by the overseers, who were in charge of advocating for the poor, comforting the mourners, defending the abused etc. Among the vulnerable were also those with physical disabilities: the blind, deaf, mute, lame, etc. (World Bank 2004)

In the fourteenth century another piece of legislation was introduced:

> It is characteristic of the Law of Saint Sava that, apart from the material aspects of poverty, equal attention was paid to the legal protection and equality of all before the courts, regardless of their material status. This principle of universal legal equity was also included in the Law book of Tsar Dusan from the 14th century, which states: "Every washerwoman must be as free as the priest"; "a poor soul, who cannot represent herself at court, may send a representative to speak in her name." (World Bank 2004)

Such laws suggest an uneven history of the treatment of disabled people in the region. They also present possibilities for the existence of more humane efforts than recent history may present.

Yugoslavia after World War II

The filmmaker and disability rights activist Victor Pineda, in his research, *Disabled Yugoslavia—Integration and Disability in Serbia and Montenegro* (2003), tries to illustrate the situation of human rights and people with disabilities in Yugoslavia from 1940 to 1990. In addition, Pineda also examines the situation of disabled people in the second half of the twentieth-century incarnation of Yugoslavia as Serbia and Montenegro during the past decade. Pineda is fully aware that research and data on people with disabilities in Serbia and Montenegro are nearly nonexistent. Reports like his contribute to a better understanding of the situation of people with disabilities in this area.

From the 1960s to the 1980s, Yugoslavia was lauded for being a socially advanced nonaligned nation, providing respected national health and educational institutions for all members and ethnicities in its society. Today, a very different reality prevails due to the existence of more than 1 million disabled citizens, refugees, and casualties of the recent wars. Twenty years after this progressive period, disabled people in Serbia and Montenegro are left with shattered pieces of a spent past, and hardly a glimmer of hope for a brighter tomorrow.

Disability has been primarily treated in Yugoslavia, as well as in other communist countries, as a welfare "problem." Persons with disability needed, it was widely thought, the protection of the state, as they were unable to lead productive lives. Similarly, Pineda's (2003) report starts with an overview of the situation of people with disabilities in Yugoslavia between 1960 and 1980:

> Throughout the Federal Republic of Yugoslavia (FRY), associations of disabled people are impairment specific and their approach is based largely on a medical/charity approach. As in other communist or socialist countries, the disabled person is under the protection or care of a specialized state agency. This view is still very embedded in the health and social services and it continues to influence the way in which services are delivered today.

In contrast, Pineda provides access to the unique and rare citations of Yugoslav's longtime premier, Josip Broz Tito, speaking about people with disabilities in 1948, during a debate on the budget in Federal Assembly:

> Since 1945, 13,133 disabled ex-servicemen have completed different courses, schools or learnt various trades in their servicemen's centers while 29 thousand disabled ex-servicemen have found employment through their organization. The disabled ex-servicemen have undertaken the production of various prosthetic appliances and are today covering all their needs.

Furthermore, Pineda describes the financial support for people with disabilities through an analysis of "invalid relief benefits." (*Invalid* is the term used for persons with disability. It is interesting to note that disability terminology in Yugoslavia has remained largely unchanged with time. Lately, some more politicized disability organizations suggest changing such antiquated terminology.) From there, Pineda goes on to discuss Tito's views of government support for people with disabilities:

> Tito committed 74% of the total expenditures for social welfare to "invalid relief benefits." This included free medical examination and medicine in all health institutions, and entitled 13,000 disabled ex-servicemen (between 1945–1948) to visit and undergo treatment at different spas and seaside treatment centers. These centers were very popular and thousands of sick and injured people from each of the six republics in the federation would be allowed universal and free treatment and usage, regardless of religion or ethnicity.

However, significant financial government support ended by the end of the 1980s. It was at this time that the situation for people with disabilities started to dramatically change for the worse. The contemporary wars that have decimated Yugoslavia started in 1991. Later, Serbia and Montenegro (formerly part of Yugoslavia) faced enormous poverty and increasing numbers of refugees. For instance, poverty increased from 6 to 40 percent.

In its publication *Disability and Poverty in Literature* (2002), the World Bank addresses the health care situation in Yugoslavia after 1990. It states that Yugoslavia enjoyed relatively well-developed systems for health care, health insurance, social services, and education before 1990. Yet, due to the conflicts in Yugoslavia after 1990, such advanced programs have experienced radically decreasing resources. As a result, many conditions that would normally be treated regularly ended in chronic impairments for lack of treatment.

LEGAL PERSPECTIVES

The legal analysis of this section concerns disability issues in Serbia from reports by experts Damjan Tatic and Branka Pecanac, both persons with disabilities. *The Right of Disabled Persons to Higher Education* (Tatic 2000) gives an in-depth analysis of Serbian legislation pointing out that the Constitution of FRY (Federal Republic of Yugoslavia) prescribes special protection of disabled persons in accordance with legal provisions. Tatic lists all the international documents and acts for equal opportunities and human rights for people with disabilities, which Serbia has adopted: the Universal Declaration of Human Rights and the Covenant on Economic, Social and Cultural Rights, UN Convention on Rights of Children, and UN Standard Rules for Equalization of Opportunities Provided to Disabled Persons. According to the report, "Under the auspices of United Nations, two crucial acts for regulation of legal status of disabled persons had been adopted at the beginning of the last decade of the 20th century: UN Convention on Rights of Children and UN Standard Rules for Equalization of Opportunities Provided to Disabled Persons."

Comments on the Draft of the Law against Discrimination of Persons with Disability (Pecanac 2004) explains that

> discrimination against persons with disability is a long term problem in our country, a problem in the face of which both professional public and community prefer to keep their eyes closed. The Draft of the Law against discrimination of persons with disability is a preliminary legal text treating this matter in full. The law is based on principles of sanctioning discrimination, respect of human rights and involvement in all spheres of social life on the bases of equality and also in all decision making processes about the rights and duties of persons with disability.

Pecanac recognized in the law one paragraph that is discriminatory: "organizing special forms of education for children and students with sensory and motor invalidity who cannot follow curricular activities in the usual way, as well as directing someone to special forms of education if this direction is based on categorization statement, is not to be considered discrimination." Such a provision for segregation speaks to an unchanged perspective on people with disabilities after many years of legislation in Serbia. Pecanac reminds us about this continuing praxis in special schools and the ongoing segregation of children and youths with disabilities (this entry will address these issues in more detail later). She continues with an analysis of the recent introduction of a few government bodies that oversee issues of human and civil rights for people with disabilities, and again detects discrimination in the formulation of these bodies.

EDUCATION

One of the main topics of this overview is education because this creates a foundation for the movement of people with disabilities in any country.

DRA, in its report *Invisible and Neglected* (2001), includes a description of the educational system in Central Europe, including higher education for students with disabilities:

> In education for children and young adults with disabilities, Central Europe lags far behind most Western European countries. Not only are educational levels lower for people with disabilities but there is minimal, if any, educational integration. Virtually all of the universities and graduate schools, as well as research institutes, are not accessible to wheelchairs users or people with mobility limitations.

As in the Pecanac report, Pineda (2003) also includes a brief commentary on education systems for people with disabilities in Serbia and Montenegro.

> Public education at all levels is necessary to dispel the deeply rooted prejudice against children with

Table 1 Number of Students in Special Schools in Serbia, for the School Year 2000–2001

	Total number of students	*Boys*	*%*	*Girls*	*%*
Primary	7,560	4,488	59.37	3,072	40.63
Secondary	1,269	806	63.51	463	36.49
	8,829	5,294	59.96	3,535	40.04

disabilities. Currently special schools exist for the blind, and deaf, these schools have existed for over 120 years. The newer special education schools were combined with medical treatment and rehabilitative centers in remote areas.

Likewise, the World Bank report *Poverty Reduction Strategy Paper for Serbia* (2004) includes an overview of the educational system for people with disabilities in Serbia. This document was made in cooperation with the Serbian Ministry of Social Affairs. One can notice outdated terminology such as "children with special needs" and a focus on special schools throughout the discussion:

> Children with special needs requiring long-term assistance due to irreversible disability account for approximately 7%-10% of the total student body. The majority of children with special needs are usually not covered by rehabilitation programmes until their enrolment to primary education,
>
> Pre-school education is organized in three forms:
>
> 1. Special pre-school groups in special schools;
> 2. Special development groups in regular pre-school institutions;
> 3. Pre-school education undertaken together with other children in the same pre-school group, without a special programme.
>
> Only 1% of pre-school children with special needs are covered by early childhood education and other preparatory programmes, whereas 22% of pre-school children in the general population are included in this form of education.
>
> The current education system for children with special needs is organised in three basic forms:
>
> 1. Special schools for children with mental, physical and sensory disorders and children with behavioral disorders (some 15% of children with special needs are enrolled in special schools);
> 2. Special classes in regular schools;
> 3. Classes in regular schools where children with special needs of all categories are educated together with other children, without special support.
>
> There are 85 special schools in Serbia, of which 5 are in the territory of Kosovo. Excluding Kosovo, the capacity of these institutions is 8,829 students. 61 schools are for mentally challenged children. In terms of organization and space, primary and secondary schools are normally located together. In 8 students' residences serving schools for children with visual and hearing disabilities, accommodation is provided for 480 students. The available data show that special schools do not fulfill their basic functions. They isolate children with special needs and do not prepare children for inclusion in regular life.

The document recognizes key problems in special education for children with disabilities including segregation and low-level education. The issue of low-level education is directly addressed in a later chapter of the report:

> The network of special schools and special classes in mainstream schools is not evenly distributed across the regions of Serbia. These schools are located in major cities so that rural children and children from small towns are separated from their families and placed in boarding facilities which are most often located with special schools.
>
> There are several problems related to the education of children with special needs:
>
> 1. There is no unified data concerning persons with special needs;
> 2. Only 30% of children with special needs who have completed primary school continue their education, in comparison to 79% of the total population.

Yet the editors of this document conclude in a positive way: "More efficient and greater inclusion of

children with special needs in the education system, particularly in inclusive education, is necessary."

The ADS, mentioned earlier, is a nongovernment, nonpartisan, nonprofit organization, based in Belgrade, Serbia. The organization specifically addresses improvement of the position of young people and students with disability and their inclusion in society. ADS is an active organization, both locally and in the Southeast Europe region. ADS organized many successful and internationally recognized projects, such as international conferences, Southeast European Youth Network, media campaigns, counseling centers, summer schools, scholarship programs, youth employment services, legal regulations, and special transportation projects.

The ADS document *Higher Education for People with Disabilities in Serbia and Montenegro* (2004a) reviews the situation and position of students with disabilities by students with disabilities of Serbia. The report begins with a depiction of the legacy of former communist era regimes with regard to social engineering goals:

> The former government and communist regime of Serbia and Montenegro strived to establish a "perfect society" during the last decade of their governing. In such a society there was no room for people with disabilities.

The document further explains several steps that were taken to establish a so-called perfect society: considering disability as a medical category, existence and insistence on special schools, inadequacy of existing laws and regulations, and the dominance of charity media approaches.

Description of the "promotion" of special schools is especially interesting:

> The education process of children with disabilities mostly starts with diagnosing a disability. The physician suggests a special school in which a child with disability should commence her/his education (such as schools for visually impaired children).

Detailed description of programs and perspectives in special schools is stated: Curriculums of special schools are shortened, children with mental and physical disabilities are together in the classrooms, curriculums are adjusted to pupils with the highest degree of disability, children are segregated, and special schools have increasingly become boarding schools.

From here the document goes on to introduce a description of the higher education system for students with disabilities:

> Young people with disabilities find it extremely difficult to continue education at institutions for higher education. This further contributes to their isolation, and their choice of employment is limited to jobs they were trained for at special schools.

The text goes on to discuss obstacles for students with disabilities to obtain higher education, such as inaccessible buildings and programs, lack of accessible transportation, lack of personal assistance support programs, and lack of recognition of some types of disabilities in the country in general (such as some types of learning disabilities).

Apart from technical barriers, other more important and harder to reach objectives include the following:

- Laws and other legal regulations are not dealing with students with disabilities, or if they are, then they do not use the social model approach.
- Academic community and relevant institutions (including ministries of education, rectors' offices, students without disabilities, professors, university administrators and staff) do not have enough interest in and sensitivity to the rights and problems of students with disabilities.
- Students with disabilities are not sufficiently empowered and skilled to pursue their rights.

Report on Project: Promotion of Higher Education in Southeast Europe, by ADS (2004b), represents the first descriptive research on inclusive higher education in Serbia by disabled people. This document is not in the form of a research or scientific document, but rather a collection of observations and recommendations for improvement of human rights of young people and students with disabilities. It represents a unique, insider view on the topic of education for persons with disabilities and, in this way, provides an important and previously unavailable resource on the research of higher education for students with disabilities in Serbia.

The first part of the report deals with the overview of the situation in Serbia and with the accomplishment of results from the project:

> Students with disability in Serbia seldom take part in activities relating to changing their status in society. One of the basic characteristics of stigmatized groups, such as the group of young persons with disability, is that individuals that form it are isolated from society and withdrawn, with reduced social relations. They rarely have the opportunity to develop their social and intellectual abilities and skills.

In the second part of the report, one can find results of two surveys carried out in May and June of 2004, with students with disabilities at the University of Belgrade and the University of Nis.

The document also places a special emphasis on cases of privilege and discrimination by professors and colleagues as well as attitudes and needs of the interviewees regarding support and solutions. Adaptation of teaching styles is also addressed:

> Results demonstrate that in the situations when the teaching staff is prepared to make adaptations to fit the needs of students with disability, they mostly do it through flexible approach. Even when it comes to professors who are open to specificities of students with disabilities, there is still no idea about introducing learning/teaching aids and other means that would make studying easier for this population.

The second part of the survey emphasizes students with disabilities' motivation to pursue higher education. Finally, the last part of the report focuses on the analysis of legislation and policy related to the position of students with disabilities in Serbia, followed by proposals for policy change.

This document represents a first attempt to investigate the situation of students with disabilities in Serbia. At the same time, it is part of regional Southeast Europe initiatives for inclusive education for youths with disabilities. Additional research is absolutely needed as a follow-up to these insights.

DISABILITY MOVEMENT

After World War II, the first associations and groups of people with disabilities were established. Across the board, they were uniformly founded and organized according to types of medical diagnoses. These organizations were, and continue to be, largely funded by the federal government. Weak mutual cooperation between these organizations exists.

For years, these kinds of organizations worked to create an image of people with disabilities as persons in need of compassion and assistance. From the beginning of the period of crisis in 1990, and along with destabilization of the region and warfare, activities carried out by these associations basically consisted of delivering humanitarian aid and organizing charity events. As new, younger generations have taken up leading positions in some of these associations, they have endeavored to foster new attitudes and new ways for the associations to function. However, because such kinds of leadership shifts enact changes only at a slow rate, much has not changed in terms of the emphasis on charity.

In the past decade, a number of national government organizations have been founded with the intent to alter this situation. They mainly work with cross-disability principles in mind. The organizations have helped to introduce a new approach to disability problems by emphasizing a social model of disability with the stated purpose being the full integration of disabled persons into society.

In closing, Victor Pineda offers further perspective concerning the disability rights movement in Serbia:

> The nascent disability rights movement in Yugoslavia has already initiated small and successful changes and is shaping policy and public perception in line with the social model. This analysis recognizes that the circumstances of people with disabilities and prejudice they face are socially created phenomena and have little to do with the impairments of people with disabilities. This model sees the problem not as residing in the person with a disability, but as resulting from the structures, practices, and attitudes that prevent the individual from exercising his capabilities. . . . Overall there are over 40 active disability related organizations in Serbia and Montenegro, the great majority of these are primarily organized along single disability lines, and many are quite small, having an active membership of 25 or less. Two of the most active and organized voices in Serbia are the Association of Students with Disabilities, and the Center for Independent Living in Belgrade. These

groups are claiming access and inclusion in an environment full of cultural, social and physical exclusion. In the new Democratic Serbia these proponents have passed laws, initiated media campaigns, and have been introducing a broader understanding of disability.

A new regional disability initiative, a project named Share SEE (Self-Help & Advocacy for Rights and Equal Opportunities South East Europe; http://www.share-see.org), could have outcomes not only for the Serbian disability movement but also for the whole region in general. The project promotes self-representation of people with disabilities, promotes cross-disability approaches, and advocates for changes in disability legislation in countries of the region.

Many positive signals are being transmitted that cooperation between cross-disability and social model organizations and the new government in Serbia is likely, particularly with the Ministry for Labor, Employment and Social Policy. Will this cooperation build foundations for changes in law, the inclusion of people with disabilities in civic events, and the establishment of equal opportunities for services that allow for inclusion to occur? The future for Serbian people with disabilities remains open to the possibilities for a new era of integration and access for all, but it remains to be seen how the country will ultimately respond.

CONCLUSION

Serbia, as well as other countries of the region, is in a state of transition. Laws are changing, the political situation is not stable, and minorities are at the end of legislators' priorities. This overview of the situation of people with disabilities in Serbia (and in the region of Southeast Europe) claims that future research is needed.

—Vladimir Cuk

See also Disability Law: Europe; Education, International; Employment.

Further Readings

Association of Students with Disabilities of Serbia and Montenegro. 2004a. *Problem Statement—Higher Education for People with Disabilities in Serbia and Montenegro.* Belgrade, Serbia, and Montenegro.

———. 2004b. *Report on Project: Promotion of Higher Education in Southeast Europe*. Belgrade, Serbia, and Montenegro.

Disability Rights Advocates. 2001. *Invisible and Neglected—Status of the Human Rights of People with Disabilities in Central Europe.* Internal document—report. (http://www.dralegal.org/publications/in.pdf).

Pecanac, B. 2004. *Law on Bases of Education System and Comments on the Draft of the Law against Discrimination of Persons with Disability.* Internal document—report. (http://www.hi-cis.org/sharesee/NEWSLETTERS/news%20from%20Vladimir-Serbia/ADS_january.pdf).

Pineda, V. Santiago. 2003. *Disabled Yugoslavia—Integration and Disability in Serbia and Montenegro.* (Research). San Francisco.

Tatic, D. 2000. *The Right of Disabled Persons to Higher Education: A Survey of Legislative Praxis in Other Countries.* (http://www.share-see.org/documents/Documents%20about%20serbia%20and%20Montenegro/PravoInvalidnostVisokoObrazovanjeADS[1].pdf).

World Bank. 2002. *Disability and Poverty in Literature.* (http://www.share-see.org/documents/European%20&%20International%20resources/Studies%20survey%20and%20reports/Poverty%20and%20disability.%20Ann%20Elwan.pdf).

———. 2004. *Poverty Reduction Strategy Paper for Serbia.* (http://www.siteresources.worldbank.org/INTSERBIA/Resources/279180YU-PRSP-Serbia-2-Main.pdf).

Websites

Serbian government, "Facts about Serbia, Official Web Site," http://www.srbija.sr.gov.yu/pages/intro.php?id=5

Share SEE, Internet presentation, http://www.share-see.org

EXPERIENCE OF DISABILITY: SLOVAK REPUBLIC

The Slovak Republic/Slovakia is among the "newest" nations in Europe. The former Czechoslovakia gained independence from the Soviet Union in 1989 in a nonviolent process termed "the Velvet Revolution," and the Czech and Slovak Republics subsequently separated into two independent countries in 1993 in a nonviolent political process referred to as "the Velvet Divorce." Since gaining this two-phase independence, the Slovak Republic has faced much greater economic struggle and political instability than the Czech Republic, though in 2004 both countries made a major advancement toward "rejoining Europe" when they were granted entry into the European Union.

The Slovak Republic is a small, land-locked nation of fewer than 6 million people, bordered by Austria, the Czech Republic, Poland, Ukraine, and Hungary. With the exception of Austria, all of Slovakia's neighbors are also formerly communist nations that are undergoing transition to forms of democratic governance and free-market economies at varying speeds. Slovakia possesses a beautiful and largely rural landscape of heavily forested alpine regions, rustic villages, ski and trekking resorts, and farming regions. The capital city of Bratislava was largely overrun by communist era architecture, resulting in drab city blocks with the occasional enclave of preserved historic buildings. Architectural barriers to accessibility, however, are endemic, existing throughout urban and rural regions, pervading government, private, educational, and residential structures and public transportation systems.

As in many developed Western countries and other postcommunist countries in Central and Eastern Europe, the Slovak Republic population is aging, the birth rate is declining, the nature of illness is changing, and the pressure on limited public resources is rising (Kovic 2000). Health services are poorly equipped to address disability and chronic illness, as the health care infrastructure is largely based on a biomedical, acute care model (Holland 2003). While the current political climate is encouraging a greater percentage of the gross domestic product (GDP) to be dedicated to health care (Kovic 2000), there remains an emphasis on biomedical technology over community-based services, independent living, or prevention. Indeed, health care reform in the Slovak Republic has been referred to as "a case study in social policy immobility" (Lawson and Nemec 1998). Further complicating matters is a residual health care "gray market" system in which consumers pay out-of-pocket fees to health care professionals for clinical care. This gray market system not only serves to neutralize well-intended policy changes at the national level, but it also disadvantages those citizens who do not have significant private resources. Individuals and families with disabilities are disproportionately among these disadvantaged citizens, compounding health access difficulties.

Largely in response to the biomedical and custodial nature of services for people with disabilities, as well as some instances of severe human rights violations (Mental Disability Advocacy Center [MDAC] 2003), a large number of highly innovative and resourceful grassroots nongovernmental organizations (NGOs) have emerged to address the human rights, quality-of-life, and independent living priorities of citizens with disabilities in Slovakia. These grassroots NGOs have worked to fill existing gaps in community-based and independent living services by functioning outside of the confines of the sluggish, institutional, state-sponsored medical infrastructure. Many of the disability NGOs in Slovakia, often founded and led by citizens or families with disabilities, are actively promoting the independent living model and are challenging a long history of institutionalization of disabled people (Holland 2003). They pursue this mission, however, with extremely limited resources and with varying degrees of support for civil society organizations from a highly diverse and, at times, chaotic multiparty parliament.

Many of the disability NGOs in Slovakia are, like the broader national context, undergoing change and transition, and struggling with issues of identity. While some of the grassroots disability groups focus almost exclusively on service provision addressing complex activities of daily living, others have pursued a much more politicized human rights mission, challenging specific national policies and promoting political candidates who understand and support disability issues. This diversity among the disability organizations will ultimately constitute a strength, but at this stage of civil society development, the dramatic differences in missions among the groups can at times appear like lost opportunities for coordination.

The survival and strength of the disability NGOs in Slovakia, as well as in other transitioning countries in Central and Eastern Europe, will be critical for the independent living movement. The highly biomedically oriented, institutionalized, and custodial approach to disability, as reflected by the health care infrastructure, will likely change slowly. The remarkably resourceful grassroots disability NGOs in Slovakia, however, bear tremendous hope for disabled citizens there. It will be these disability NGOs that eventually direct necessary policy changes

at the national level, while continuing their grassroots efforts to promote independent living in their communities.

—Daniel Holland and
Zuzana Ondriasova Gubrij

See also Disability Law: Europe.

Further Readings

Holland, D. 2003. "Grass Roots Promotion of Community Health and Human Rights for People with Disabilities in Post-Communist Central Europe: A Profile of the Slovak Republic." *Disability & Society* 18(2): 133–143.

Kovic, E. 2000. "Considering Changes in the Slovak Healthcare System." *Eurohealth* 6(2): 32–34.

Lawson, C. and J. Nemec. 1998. "Central European Health Reform: The Case of Slovakia 1990-1997." *Journal of European Social Policy* 8(3): 237–252.

Mental Disability Advocacy Center. 2003. "Written Comments of the Mental Disability Advocacy Center (MDAC) Concerning the Slovak Republic for Consideration by the United Nations Human Rights Committee at Its 78th Session on 14 July–8 August 2003." Unpublished manuscript.

EXPERIENCE OF DISABILITY: SUB-SAHARAN AFRICA

Disability as a category of discourse is foreign to sub-Saharan African thought. Disability is fundamentally a Western category that should be understood as a result of historical developments between people and society, in particular between people and states. In developing an idea about the experience of disability in African societies, one tries to approximate African ideas and practices that have had impacts on their existence, the individual and social lives, the development of disability services and practices during colonial times, and postcolonial developments.

How do people experience disability in Africa? Are there particular cultural practices and beliefs that inform this experience? These are important, but perhaps a more fundamental question is: Do people experience "disability"? What is the history of this experience? This entry first explores the nature of the category of disability in Africa and then looks into specific realities of disability in Africa.

DISABILITY IN AFRICAN THOUGHT

It can be said that disability as a conglomerate concept that defines people with different physical, sensory, mental, or emotional deficiencies does not exist in sub-Saharan Africa. Words referring to the concept of handicap or disability simply do not exist in African languages. This finding refers to the complicated history in Western thought that gave rise to the emergence, growth, and historical transformations of disability as a category of thought. The globalization of this thought is both part of a history of industrialization and the creation of modern society, as well as of colonization. While disability identifies "lack of," "deficiency," African thought refers more positively to a striving toward "wholeness." Indeed, "whole" and "health" have the same meaning in certain African languages, such as Swahili. While a category of disability does not exist as a repository in African languages, it should be stated that concrete translations for physical disability (lame, crippled, blind, deaf) do exist. But there are equally specific categories of deviation from the ordinary that are part of the African experience. Most notably, extra-ordinary children are identified by their assumed supernatural power. Among the Songye of Congo and many other African peoples, the birth of particular children signifies something out of the ordinary. Twins, children who are believed to hold up the rain, children born with particular characteristics (with a hand on the cheek, born with feet first, with the umbilical cord, with teeth) are given specific names and respect, and they are surrounded with ritual behavior.

In the postcolonial era, which is characterized by a decline of the state order, some children are identified with supernatural powers. With the absence of a generalized category, such as disability or handicap, it should not be assumed that there has been no historical development in the development of terminology in African languages. Yet it can be determined that some terms not only have a large time depth but also that their meanings and connotations varied over time and regionally. A contemporary example of terminology development can be found in Swahili. Here, the term *kipofu* (blind) became rejected because of its placement in the class of nouns associated with "smallness." A replacement was devised through the term

msiona (pl. *wasiona*), which literally means "the person(s) who does not see."

During the colonial period, some institutional settings, such as schools, medical centers, and vocational services, were developed. In many instances, they were merely copies of developments in the colonial center and initiatives of the colonizing country. In a few cases, there have also been initiatives during the colonial period by Africans themselves. For some, these initiatives were the result of study in the colonial center. For others, these initiatives were spurred by influences both in and out of the country. Inside some countries, the idea of self-help for Africans became prominent. The most remarkable of the latter are perhaps the initiatives of Jairos Jiri in southern Rhodesia, now Zimbabwe, because of its African initiative, aided by colonial and later international help, and its large national network of institutional development. For a long time, during the colonial period and beyond, Jairos Jiri furthered opportunities for disabled people through rehabilitation and vocational training programs.

But in general, it should be stated that disability was not an important priority during the colonial period. The postcolonial period was characterized by some attention to the plight of veterans from the liberation wars. More significant though is the growing influence of the United Nations, which culminated in the International Year of Disabled Persons in 1981. For some African countries, the international year meant the organization of a national survey as its most important activity. For the first time, disabled people were to be counted in the African context. In the following years, specialized agencies in the United Nations each developed programs in education, health, employment, and agriculture designed to affect the disability problem in Africa on both national and regional levels. In an effort to develop a concept of disability appropriate for developing countries, the World Health Organization took the lead when it launched the concept of community-based rehabilitation (CBR). Its impact was very important on the conceptualization of practices and services that were developed by other UN agencies and the work of nongovernmental organizations (NGOs). The impact in some countries was considerable, but in others it was rather limited. In many cases, these efforts were considered as generated from the outside, as postcolonial, "development," activities. In the context of the Organization of African Unity (OAU), a multilateral organization was created for the purpose of guiding the development of disability services and policy in Africa, namely, the African Rehabilitation Institute. It influence has, however, remained limited.

During the middle 1980s, self-help was being reinvented, but in the different context of global and postcolonial realities. On the global scene, human and civil rights became translated into a disability consciousness and liberation movement. It was geared against institutional development and rather toward the formation of membership organizations, although service development became also part of the agenda. The distinction between "organizations of" and "organizations for" disabled people became relevant. The development of this movement in Africa was an interesting mix between political realties, most notably the resistance to the apartheid system in South Africa, the political alignment of the so-called frontline states, and the continued global influence of UN organizations and international NGOs. Again, Zimbabwe, partly because of its lead in the frontline states movement, also showed great leadership in the development of disability-oriented membership organizations, such as the Southern African Federation of the Disabled (SAFOD). Such leadership also expanded and translated into enhanced leadership at the national scene through the representation of disabled people by disabled parliamentarians, on a more global scale, such as within the leadership of Disabled Peoples' International, and in the development of new regional initiatives, such as the African Decade of Persons with Disabilities.

The remainder of this entry explores some pertinent cultural themes relevant to the understanding of disability in African contexts.

WHY DISABLED?

Moral or religious model thinking aims at achieving an insight into the essence of phenomena. It attempts to develop links between individual, social, and religious behavior and the occurrence of disability. Traditional knowledge systems, such as taboos, sorcery and

witchcraft, and knowledge of God are instruments in grounding the very reason for not being whole, for being disabled.

These systems take away the attention from the individual into the natural, social, and religious realms in which disability is embedded. It would be correct to say that African knowledge of disability is "embedded" in its seeking for links between the occurrence of disability and several world orders. Examples are the natural order (e.g., through the observance of practices related to food and those related to contact, such as sexual and gaze taboos), the social order (as this is regulated by links between social behavior and misfortune, e.g., through sorcery and witchcraft systems of belief, and marriage regulations), and the cosmological order, in which a distant, bifacial (i.e., both good and bad) God is central.

An embedded concept of disability appears to be more powerful in addressing questions of the nature of our lives, less geared to the practical solutions. Such a concept seeks for solutions to be found outside of the disabled individual, for example, in the correction of behavior or in the taking out of evil forces. In contemporary African societies, the proliferation of religious sects supports the retaining and transformation of an embedded knowledge.

INFANTICIDE AND AFRICAN BROTHERHOOD

The killing of disabled children at birth is a practice that has been both described and denounced by colonial administrators in Africa. Such practice was seen as incompatible with the development of modern society and therefore forbidden by law. Little attention, however, went into the analysis of ritual practices and belief systems that surrounded such killing. It can be said that the occurrence of a deformed child at birth was seen as a disturbance of the order that required the intervention of an authority beyond the head of a household. In certain cases, and perhaps already under the influence of colonial practices, a fine was charged because of causing such disturbance. It is important that a higher authority (not the father) be charged with conducting the killing and observing certain rules. These rules included that such a child could not be buried because it would pollute the earth. An exception is the burial in a termite mound, because its earth is already infertile. More common was the practice of throwing such a child in the river, in accordance with the belief that people not merely die but return to a place before they are once again born. The spirit of the child was to be respected, for example, by placing a small white chicken (a symbol of purification) around the neck or ankle of the child. The person charged with the killing further would have to send the child back and admonish God to send perfect children instead. Returning from the river, this person could never look back. Such practices put into better perspective the nature of the killing and would make it difficult to maintain the colonial argument that these were cases of murder.

In some West African cultures, the killing of disabled children is mediated by beliefs that surround "children of the snake." These beliefs stress the wrongheaded impression that people can have of each other: "While one may see a child, it could be a different creature." These beliefs emphasize the permeability of borders and the possibility of transformation between different creatures. It is possible to test whether a child is of the snake by practicing ritual behavior that enables one to see whether such a child will transform itself. In some cases, it legitimates abandoning a child as a test of seeing whether it belongs to the snake.

Diametrically opposed to such practices of restoring order, the notion of African brotherhood or solidarity is a theme that emphasizes tolerance and mutual help, also toward people who are deemed to be unfortunate. The basis of brotherhood is the clan or totem. The theme has been expanded in political discourse, such as in the Kenyan concept of *harambee*. In the modern context, however, notions of brotherhood have sometimes been criticized as working opposed to capital accumulation and economic development in general. It also appears that institutional development, such as in the case of the Jairos Jiri association, became reasons to forego African brotherhood. Moreover, colonial influence created the disabled beggar who, situated in the colonial city, is entitled to its spot in the street and request alms. The disabled beggar is equally supported in countries influenced by Islam, where almsgiving is a central pillar.

AFRICAN PROVERBS

In Bantu-speaking Africa, a major theme dominates the moral imperative toward disabled people, as it is communicated in proverbs. In the first part, these proverbs admonish "Not to laugh at disabled people." The admonishment can be found in many, if not all, Bantu languages, that is, spoken by sub-Saharan African people. It is a very direct statement, without much variation. The second part of the proverb has many variations, but the message is very similar: It is unsure what will happen to your own life. This is expressed by referring to God as creator, of both good and bad things that can happen. It can also be expressed by referring to certain possibilities of things to happen, thereby referring to some trade-off between different choices: If this does not happen, then something else could still happen.

These proverbs communicate that one has no control over one's destiny and that laughing at disabled people would be the worst way of challenging that destiny, worse than, for example, laughing at poor people. These proverbs relate to an existential insecurity, essentially not knowing what the future will bring, and cultivating that knowledge.

LOCAL AND GLOBAL DIMENSIONS OF DISABILITY

In contemporary Africa, disability can be associated with contagious diseases, emerging industrialization, and traffic accidents; civil war and genocide; and terrorism. For these local conditions, there have been numerous responses, from within and outside Africa. In the aftermath of colonial initiatives, local NGOs have developed services, followed by the input of international NGOs, and from the UN specialized agencies. First, some of these services were driven by charitable and medical services, and development took place in the context of "centers for physically handicapped people." Since 1976, CBR was formalized by the World Health Organization as the more appropriate strategy for meeting the needs of rehabilitation, compared to institution-based rehabilitation. The other specialized agencies, such as UNESCO and the International Labor Organization, followed with compatible strategies in the areas of education and employment. Integrated education and income-generating projects were launched. Throughout the 1980s, many initiatives in Africa were geared toward the integration of persons with disabilities in all sectors of society. An emerging disability movement that became especially prominent in southern Africa crossed these service-oriented approaches. Influenced by international meetings, disability leaders such as Joshua Malinga became prominent in the disability movement, both in their own country and at the international level. The organizations that characterized this emerging disability movement were characterized by their membership, not services. Eventually, by the end of the 1990s, attempts were made to find a meeting place between service provision and the disability movement.

—Patrick Devlieger

See also Disability in Contemporary Africa; Infanticide; Jiri, Jairos; World Health Organization.

Further Readings

Burck, Deliane J. 1989. *Kuoma Rupandi (The Parts Are Dry): Ideas and Practices Concerning Disability and Rehabilitation in a Shona Ward*. Leiden: Afrika Studiecentrum.

Devlieger, Patrick 1995. "Why Disabled? The Cultural Understanding of Physical Disability in an African Society." Pp. 94–106 in *Disability and Culture*, edited by B. Ingstad and S. Reynolds White. Berkeley: University of California Press.

———. 1999. "Frames of Reference in African Proverbs on Disability." *International Journal of Disability, Education and Development* 46:439–451.

———. 2000. "The Logic of Killing Disabled Children: Infanticide, Songye Cosmology, and the Colonizer." Pp. 159–167 in *The Archaeology and Anthropology of Madness, Disability and Social Exclusion*, edited by J. Hubert. London: Routledge.

Gbodossou, Erick V. A. 1999. "Defining the Role of Religion and Spirituality in the Lives of Persons with Disability in the Fatick Region, Senegal, and the Mono Region, Benin." Pp. 58–77 in *Disability in Different Cultures: Reflections on Local Concepts*, edited by B. Holzer, A. Vreede, and G. Weigt. Bielefeld, Germany: Transcript Verlag.

Malinga, Joshua T. 1999. "The Pan-African Movement of People with Disabilities." Pp. 274–276 in *Disability in Different Cultures: Reflections on Local Concepts*, edited by B. Holzer, A. Vreede, and G. Weigt. Bielefeld, Germany: Transcript Verlag.

Miles, Susie. 1996. "Engaging with the Disability Rights Movement: The Experience of Community-Based Rehabilitation in Southern Africa." *Disability & Society* 11:501–517.

EXPERIENCE OF DISABILITY: TAIWAN

PRESENT SITUATION

Dignity has always been a major concern for disabled people in Taiwan. Most of them feel that they have been ignored and dishonored in every aspect of their lives, including the right to receive an education, to get a job, to have easy access to public places, and most of all, to live an independent life. In Taiwan, it was not until June 2, 1980, that the entire 26-article text of the Physically and Mentally Disabled Citizens Protection Law was promulgated, which was then completely modified to 65 articles in 1997. This law was passed to protect "the legal rights, interests, and livelihood of the disabled, secure their opportunity to participate in the social life fairly, consolidate the government and private resources, [and] plan and implement all measures of assistance and welfare." The law guarantees legal rights for the disabled and has significantly improved their welfare. The disabled persons referred to in the law are

> the people whose functions of participating in the society and engaging in the production activities are restricted or cannot be brought into full play due to physical or mental factors and who, after the process of examination and determination, are regarded as suffering one of [the] malfunctions which are in conformity with the grades regulated by the central competent authorities in charge of health and have received the handicap manuals.

The Ministry of Interior, Department (Bureau) of Social Affairs in the provincial government and the local governments are supposed to be in charge of all related affairs, such as welfare, nursery, services at home, medical treatment and rehabilitation, special education, vocational training, and employment services.

CULTURAL CONSTRUCT OF THE DISABLED IDENTITY

Before promulgation of the Physically and Mentally Disabled Citizens Protection Law, the disabled in Taiwan had gone through a very difficult period of time, and the disabled and their parents had to rely on themselves to take care of almost everything. The law helps solve many problems encountered by the individuals and their families. However, despite its well-intentioned plan and design, it still has limitations when put into practice, because the people who execute the regulations do not really care for the needs of the disabled. Indeed, given its 5,000-year cultural legacy, Chinese society is slow to react and care for the rights of underprivileged people. This negligence has its own history in Taiwan and speaks a lot about the human values that Chinese culture has nourished. With its long history, the Chinese should have more cultural assets that epitomize human values. However, when speaking of the rights and dignity of the disabled, Chinese society seems to head the other way.

To study and locate the source of the identity and stigmatization of the disabled in Chinese culture and to reveal old myths about disabilities, be they attitudinal, representational, or empirical, one may begin with a comprehensive understanding of the feudalist ideology, which is deeply embedded in Chinese culture. Given this ideology, the Chinese people are inculcated to respect only the privileged, the wealthy, and the powerful, and they look down on the underprivileged, who are often considered worthless and useless. Accordingly, disease is considered a taboo, a moral deficit, or a personal blemish, so the names of contagious or stigmatized diseases such as polio, cancer, and AIDS are not supposed to be mentioned directly. When a member in a family gets such a disease, the whole family will be discriminated against and considered morally inferior. In this situation, people might suspect that the family has done something evil or that their predecessors might have not accumulated enough merits to raise sound and healthy descendents.

Moreover, the Chinese people value family highly, and parents are responsible for continuing the strong lineage of a family. Children are supposed to honor their parents, so they will not be accused of disrespecting them. Thus, a family's value depends on its good genes or blood. Children are often considered extended egos of the parents, so a good and prosperous child can honor his or her parents by continuing the strong lineage of the family. Given this concept, a disabled child is therefore considered shameful and a burden to a family, as well as being a symbol of bad blood. The child is unwelcome because he or she cannot get married easily and is therefore unable to

continue the lineage of the family. Raising children, earning enough income, maintaining a decent family, and showing filial piety all become impossible for a disabled child. Unfortunately, his inability to fulfill the family obligations marks him as less of a human.

Presently, Chinese and Taiwanese societies have changed greatly in terms of their treatment to the disabled, but most people still retain the same prejudices about them. These misconceptions make it harder for the disabled to find work. To help the disabled get minimum-wage jobs, the Taiwanese government deliberately offers them the job of selling lottery tickets. The government's intention is good, but the job system is still based on the biased understanding that the disabled cannot earn a decent living by their abilities and have to rely on the public's sympathy to buy lottery tickets. Sadly enough, misery and poverty seem to be the necessary outcome of a disabling condition.

GREATNESS PERSONIFIED

Given all the disadvantages, however, a disabled person can be redeemed by academic or worldly achievements, because the Chinese people, on the basis of either a feudal concept or Confucianism, think highly of scholars, officials, and successful people. If a disabled person overcomes his limitations by achieving something valued and recognized by Chinese society, such as scholarship, he or she will be treated differently and thus gain respect. Liu Hsia, for instance, is one of them. Liu contracted rheumatoid arthritis at the age of 12 and was confined to a wheelchair. She once jokingly called herself a "walking quadriplegic fossil" since she had been suffering from the disease for almost five decades. Her disease hindered her from receiving any formal school education, but she managed to study on her own and went on to establish herself as an acclaimed author under the pen name Hsing lin tsi, with a body of work of more than 30 books of essays, novels, autobiographies, and audio books. Most of her articles are inspirational, and she won the National Literature and Art Award in 1982. Liu's writing also earned her a commendation as one of Taiwan's 10 most outstanding women in 1980, and she used the award's NT$200,000 (US$5,700) in prize money to establish the Eden Social Welfare Foundation to take care of people who have disabilities. Many people adore her and are deeply inspired by her strong sense of humor and inspirational attitude toward life. For instance, Reverend Maurice Alwyn Sween III, an American missionary who has been residing in Taiwan for the past 15 years, once said that Liu often inspired him with fresh ideas. "Reading her articles helped me calm down, think deeply and remain clear minded toward the challenges in my life," said Sween. Indeed, she had a unique perspective, which encouraged people to hope and to never give up. In 2000, she was appointed as a presidential adviser. In 2003, Liu passed away at the age of 61 as the result of an accidental but fatal assault from her Indonesian maid.

In Taiwan, there are still many outstanding disabled people whose lives can always be a source of inspiration. In addition to Liu, Wu Shu-chen is another exceptional figure who has drawn attention to the human rights and dignity of the disabled. She is the first lady of President Chen Shui-bian. In 1985, while accompanying her husband to thank voters for their support, she was seriously injured after being run over by a truck. Her life was spared after multiple operations, but she has ever since been a wheelchair user. Despite her physical impairment, she was later elected as a legislator. Wu's experience in overcoming her trials further enhances her standing as not only a spokesperson for Taiwan's battle to win international recognition but also a role model for the disabled.

In addition to these extraordinary figures, most of the disabled people in Taiwan are still struggling to earn their due respect. At any rate, the disabled people's awareness is emerging gradually and significantly in Taiwan, and they are now able to fight against the able-bodied public's ideological projections and feudalist investments, which have accorded a common set of stigmatizing social values to disability and determined the treatment and positioning of the disabled people in society. With their arduous efforts, they hope that one day they can rewrite the history of the disabled in Taiwan and redefine the meaning of disability.

—Hsiao-yu Sun

See also Confucius; Experience of Disability: China.

Further Readings

Chan, Sucheng. 2001. "You're Short, Besides!" Pp. 88–95 in *Essays from Contemporary Culture*, edited by Katherine Anne Ackley. New York: Harcourt Brace.

Hsing lin tsi (Liu, Hsia). 1982. *Another Kind of Love.* Taipei: Jiou ge.
———. 1996. *The Selected Writings of Hsing Lin Tsi.* 3 vols. Taipei: China Alliance Press.
———. 2000a. *Exploring the Deep Well of Life*. Taipei: Jiou ge.
———. 2000b. *True Love is a Lifetime's Promise*. Taipei: Yuan Shen.
———. 2002. *Broken China.* Taipei: Jiou ge.
———. 2004. *Memoir of Liu Hsia.* Taipei: Jiou ge.
———. 2005. *The Interpreter of Life*. Taipei: China Alliance Press.

EXPLANATORY LEGITIMACY THEORY

Explanatory legitimacy theory builds on historical and current diversity analyses and debates. Within this framework, disability is defined as a contextually embedded, dynamic grand category of human diversity. Thus, who belongs and what responses are afforded to category members are based on differential, changing, and sometimes conflicting judgments about the value of explanations for diverse human phenomena. This approach to defining disability differs from previous schemes in which disability was determined by the presence of a medical condition that caused permanent limitations in one's daily function. For example, consider three individuals who use a three-wheeled cycle. The first is a child learning to ride a bike. The second is a woman who, because of balance challenges, uses a tricycle. The third is a man who delivers groceries in an urban neighborhood. Each individual engages in cycling activity using a tricycle but the explanation differs. According to explanatory legitimacy, none, one, two, or all may fit the category of disability or not and may engender different responses. Let us see how.

BACKGROUND AND THEORETICAL FOUNDATION

Looking back in history to civilizations that predated the emergence of industrialization, medical knowledge, and technological sophistication, the grand category of disability did not exist. Rather, the identification of, worth of, and community response to those who acted and appeared in ways that were considered to be atypical were inferred on the basis of context-embedded value judgments about attributed explanations for why individuals did not fit within conceptualizations of typical. And while definitions and responses have changed over time, contextually embedded values still form the basis for defining and analyzing disability. Thus, the influence of multiple factors (including but not limited to natural, chronological, spiritual, and intellectual trends) on value judgments is the key to understanding categorization, the legitimacy of individuals and groups who fit within a category, and the responses that are deemed legitimate for members.

In the twentieth and twenty-first centuries, three contextual factors—(a) economic productivity; (b) medical knowledge, technology, and professional authority; and (c) diversity—have had significant roles in definitions of what is typical, how phenomena that fall outside of the typical are explained, and the differential and complex determination of these explanations as legitimate disability status and response.

These factors have intersected to produce two overarching and hotly debated views of disability in the current literature: medical-diagnostic and constructed. Medical-diagnostic definitions locate disability within humans and define it as an anomalous medical condition of long-term or permanent duration. Thus, within this conceptualization, the domain of disability definition and response remains within the medical community. In opposition, however, to what was perceived as a pejorative, the constructed school of disability emerged. Within this broad theoretical category, disability is defined as a set of limitations imposed on individuals (with or even without diagnosed medical conditions) from external factors such as social, cultural, and other environmental influences. Both categories of thinking provide a forum for rich debate and intellectual dialogue. However, as the discourse expands and is applied to increasingly more fields of study and application, analysis of what disability is and is not calls for theoretical specificity that can address the complexity of disability within the larger context of human diversity.

THREE ELEMENTS OF EXPLANATORY LEGITIMACY

Explanatory legitimacy theory makes the distinctions among descriptive, explanatory, and the axiological or the legitimacy dimensions of the categorization of

human diversity and identifies the relationships among these elements. Thus, similar to legitimacy-based analyses of other areas of human diversity, disability, defined and analyzed through the lens of explanatory legitimacy, is composed of the three interactive elements: description, explanation, and legitimacy.

Description

Description encompasses the full range of human activity (what people do and do not do and how they do what they do), appearance, and experience. Of particular importance to description is the statistical concept of the "norm." Developed by Belgian statistician Adolphe Quetelet in the late 1800s, "the normal man" was both *physically and morally normal.* Based on probability, the concept of normal translates into the most frequently occurring phenomena. Extremes are the "abnormal" and minimally occurring. Thus, common and frequent phenomena formed the basis for what we consider as normal and are the foundation of many theories and practices today regarding the acceptable limits of human description. Observation therefore turned to prescription and anyone exhibiting difference in activity, appearance, and/or experience was considered abnormal.

Because understanding and naming of what is normal are value based, use of terms such as *normal* does not provide the conceptual clarity sufficient for distinguishing description from axiology. Thus, in applying explanatory legitimacy to disability, the terms *typical* and *atypical* are used. They refer to magnitude rather than desirables.

Thus, description is conceptualized as two intersecting dimensions (typical/atypical and observable/reportable). Typical involves activity, appearance, and experience as most frequently occurring and expected in a specified context. Atypical refers to activity, appearance, and experience outside of what is considered to be typical.

Observable phenomena are activities and appearance that fall under the rubric of those that can be sensed and agreed on. Reportable phenomena are experiences that can be known through inference only.

Explanation

The second element of explanatory legitimacy is explanation. Applied to disability, explanation is the set of reasons for atypical doing, appearance, and experience. For example, what are described immediately above as the medical-diagnostic and constructed approaches are in our definitional taxonomy, explanations of doing, appearance, and experience across the lifespan. What is important to highlight with regard to the link between description and explanation is that explanation is always an inference. Because of the interpretative nature of explanation, this definitional element lends itself to debate and differential value judgment.

Legitimacy

The third and most important definitional element of explanatory legitimacy is legitimacy, which we suggest is composed of two subelements: judgment and response. Judgment refers to value assessments of competing groups on whether or not what one does throughout life (and thus what one does not do), how one looks, and the degree to which one's experiences fit within what is typical and are valid and acceptable explanations that are consistent with an all-too-often unspoken value set. Responses are the actions (both negative and positive) that are deemed appropriate by those rendering the value judgments. We have selected the term *legitimacy* to explicate the primacy of judgment about acceptability and worth in shaping differential definitions of disability and in determining individual, community, social group, and policy responses to those who fit within diverse disability classifications.

APPLICATION

Consider the following two examples.

Example 1

On the first day of their physics class, John and Jane both bring tape recorders for note taking. Dr. Joseph asks John and Jane to turn off the tape recorders, letting them both know that she does not allow students to tape her lectures. After class, John talks with Dr. Joseph indicating that he uses the tape recorder as an assistive device for a learning disability as recommended by disabled student services. Jane, however, tapes the lectures because she lives over an hour from the university and has a new infant who

distracts her from reading at home. By taping lectures she is able to study in the car. In both cases, the observable atypical activity is tape recording a lecture when all other students are taking notes. John has a medical-diagnostic explanation and Jane has a social explanation for the atypical activity. For Dr. Joseph, only John's explanation legitimates him as a disability category member worthy of special response.

Example 2

Two women present in the emergency room with broken noses and bruises (description). Because Sue was injured in a fall after tripping on the shoes that her husband left on the floor (explanation), she is not considered to be a victim (illegitimacy as a victim). Heidi, who was assaulted by her partner (explanation), qualifies for legitimate victim status and is afforded the services and supports of the domestic violence system (legitimacy response). Knowing that Sue has very poor balance (explanation), her husband left the shoes on the floor purposively with intent to harm. On the basis of disability membership (disability legitimacy determination), Sue is tacitly and perhaps unintentionally denied credibility as a victim (victim illegitimacy determination) and thus is not met with access responses to services that may prevent further injury or even death (illegitimacy response).

Explanatory legitimacy is a theoretical framework that not only addresses a full range of analytic complexity but also provides guidance for related social action. Both examples highlight the link between explanatory legitimacy theory, universal ideology, and the action steps that derive there from. If responses to both students had been considered in terms of need rather than disability category membership, it is likely that Dr. Joseph would have expanded tape-recorded note taking as an option for all students. To the contrary, if the victim identification protocol had been universal in scope and focused on harm rather than inferred explanations for harm, disability membership would not have been met with exclusion.

In summary, explanatory legitimacy theory builds on a rich history of intellectual examination and debate. As a pluralistic theoretical framework, it locates disability within multiple discourses and provides theoretical clarity to pave the way for informed social action.

—Stephen French Gilson and Elizabeth DePoy

See also Diversity; Models; Normality.

Further Readings

Armstrong, David. 2002. *A New History of Identity: A Sociology of Medical Knowledge*. New York: Palgrave.

Barnes, Colin, Geoffrey Mercer, and Tom Shakespeare. 1999. *Exploring Disability: A Sociological Introduction*. Cambridge, UK: Polity.

Center for Universal Design, College of Design. 1997. "What Is Universal Design?" Raleigh: North Carolina State University, Center for Universal Design. Retrieved March 15, 2004 (http://www.design.ncsu.edu/cud/univ_design/udhistory.htm).

DePoy, Elizabeth. 2004. "Modular Long-Term Care Modules." Orono: University of Maine, Center for Community Inclusion and Disability Studies. Funded by the Health Resources and Services Administration. Retrieved March 15, 2004 (http://www.ume.maine.edu/cci/hrsaltc).

DePoy, Elizabeth and Stephen French Gilson. 2004. *Rethinking Disability: Principles for Professional and Social Change*. Belmont, CA: Wadsworth.

DePoy, Elizabeth and Heather MacDuffie. 2004. *History of Long Term Care*. (http://www.ume.maine.edu/cci/hrsaltc/).

Gilson, Stephen French and Elizabeth DePoy. 2002. "Multiculturalism and Disability: A Critical Perspective." *Disability & Society* 15:207–218.

Jost, John. T. and Brenda Major. 2002. *The Psychology of Legitimacy: Emerging Perspectives on Ideology, Justice and Intergroup Relations*. Cambridge, UK: Cambridge University Press.

Linton, Simi. 1998. *Claiming Disability: Knowledge and Identity*. New York: New York University Press.

Longmore, Paul and Lauri Umansky, eds. 2001. *The New Disability History: American Perspectives*. History of Disability. New York: New York University Press.

Preiser, W. E. and Elaine Ostroff, eds. 2001. *Universal Design Handbook*. New York: McGraw-Hill.

Websites

Center for Applied Special Technology, "Universal Design for Learning," http://www.cast.org

Web Access Subcommittee, University of Maine, "Creating Accessible Websites," http://www.umaine.edu/insider/accessibility

F

FACILITATED COMMUNICATION

Facilitated communication training (FCT) is a strategy for teaching individuals with severe communication impairments to use communication aids with their hands.

> In facilitated communication training a communication partner (facilitator) helps the communication aid user overcome physical problems and develop functional movement patterns. The immediate aim in facilitated communication training is to allow the aid user to make choices and to communicate in a way that has been impossible previously. Practice using a communication aid such as a picture board, speech synthesizer, or keyboard in a functional manner is encouraged, to increase the user's physical skills and self-confidence and reduce dependency. As the student's skills and confidence increase the amount of facilitation is reduced. The ultimate goal is for students to be able to use the communication aid(s) of their choice independently.
>
> Facilitated communication training is a teaching strategy of particular relevance to individuals with severe speech impairments who can walk but have had difficulty acquiring handwriting and manual signing skills. Many such people are diagnosed as intellectually impaired and/or autistic. Through facilitated communication training numbers of these people have achieved functional communication, often revealing unexpected understanding and academic potential. (Crossley 1994)

Practices very much like facilitated communication had emerged from time to time around the world with particular people (e.g., Oppenheim 1973), but its development as a technique of general application dates from its rediscovery in Australia in 1975 by Rosemary Crossley and Anne McDonald and its adoption in the United States by Douglas Biklen. Crossley and Biklen also suggested that the high proportion of people previously regarded as intellectually impaired who had been enabled to communicate through facilitation cast considerable doubt on traditional views on the nature of the condition.

From the outset, FCT was surrounded by controversy. Many people continued to assert that the communications said to be coming from the person with communication impairment were in fact simply unconscious projections by the facilitator. An extensive bibliography deals with the conflicting studies on the validation of these communications. Two books of essays dealing with the controversy are Shane (1994) and Biklen and Cardinal (1997). Arguments became particularly pointed in the 1990s when many allegations of sexual abuse were made though facilitated communication. The method was condemned by the American Psychological Association in 1994 as a "controversial and unproved communicative procedure" and was described by one critic as "an unacceptable challenge to professional belief systems" (Shane 1993). Evidence of clients successfully achieving communication was condemned as anecdotal.

The debate continues, but differing epistemologies and presuppositions make it unlikely that any professional consensus will emerge. FCT continues to be used by a number of people around the world, assisted by the emerging evidence of increasing numbers of facilitated communication users who have graduated to independence. In the section on facilitated communication in the 1998 edition of their widely used textbook on augmentative and alternative communication, for example, Beukelman and Mirenda describe one long-term user:

> Sharisa Kochmeister is a person with autism who at one time had a measured IQ score somewhere between 10 and 15. . . . She does not speak. When she first began using facilitated communication (FC) several years ago to type on a keyboard, she required an FC facilitator to hold her hand or arm as she hunted for letters on a keyboard. No one thought she could read, write, or spell. She can now type independently (i.e., with no physical support) on a computer or type-writer.
>
> Sharisa joins a small group of people around the world who began communicating through FC and are now able to type either independently or with minimal, hand-on-shoulder support. There can be no doubt that, for them, FC "worked," in that it opened the door to communication for the first time. . . . We include FC here because of Sharisa . . . and others who now communicate fluently and independently, thanks to FC. For them, the controversy has ended. (p. 327)

—Chris Borthwick

See also Autism; Communication.

Further Readings

Beukelman, D. and P. Mirenda. 1998. *Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults*, 2d ed. Baltimore: Paul H. Brookes.

Biklen, D. and D. Cardinal, eds. 1997. *Contested Words, Contested Science*. New York: Teachers College Press.

Crossley, R. 1994. *Facilitated Communication Training*. New York: Teachers College Press.

Oppenheim, R. 1973. *Effective Teaching Methods for Autistic Children*. Springfield, IL: Charles C Thomas.

Shane, H. 1993. "The Dark Side of Facilitated Communication." *Topics in Language Disorders* 13(4): ix–xv.

———, ed. 1994. *Facilitated Communication: The Clinical and Social Phenomenon*. San Diego, CA: Singular.

FAIR HOUSING ACT AMENDMENTS OF 1988 (UNITED STATES)

Although not as well known as the Americans with Disabilities Act (ADA), the 1988 Fair Housing Amendments to the Civil Rights Act of 1968 (Fair Housing Act) guarantee civil rights of people with disabilities in the residential setting. The amendments extended coverage of the fair housing laws to people with disabilities and established accessible design and construction standards for all new multifamily housing built for first occupancy on or after March 13, 1991.

The Fair Housing Act, U.S. federal law that includes provisions for making all newly constructed multifamily housing accessible to a limited degree, covers the sale, rental, and financing of dwellings and other housing-related transactions. It prohibits discrimination based on color, national origin, religion, sex, familial status, and disability. Civil rights organizations are active in advocacy to promote the goals of the act and ensure its compliance. This includes monitoring and documenting cases of discrimination as well as legal action to obtain compliance.

By mandating adaptability (such that features of buildings that are not initially accessible can be made fully accessible with little effort and expense) and minimum accessibility in all new multifamily projects, this law was a major step toward achieving universal design in housing in the United States. But the amendments also ensured that residents with disabilities have a right to make accommodations to multifamily dwellings. Prior to the enactment of the law, the owners of buildings could prevent a tenant from adding a grab bar, widening a doorway, installing a ramp, or lowering cabinets, even if the tenant was willing to pay for the renovations. Not only did the amendments provide the legal means by which they could make modifications that they needed for accessibility, but they also require landlords to allow tenants to make changes to public parts of facilities, such as installing an automatic door opener at the entrance to a building or a ramp on the site. However, landlords can require the tenant not only to pay for the modifications but also to restore the areas modified back to their original condition when the tenant leaves.

Perhaps the most important feature of the Fair Housing Act amendments is the requirement that all new construction of multifamily buildings comply, unless covered by specific exceptions. *Multifamily* is defined as any building that has more than three dwelling units (although not including row houses). The act applies to housing finance both privately and publicly. Prior to the enactment of the act, only a few states had laws that required accessibility to dwelling units constructed with private funding. All dwelling units covered by the act must be accessible. Prior to the enactment of the act, accessible housing was generally provided by a small percentage of designated units. Thus, for new construction, the Fair Housing Act amendments introduced universal access to the multifamily housing industry.

To ensure compliance with the provisions of the act in new construction, the U.S. Department of Housing and Urban Development issued the Fair Housing Act Accessibility Guidelines (FHAAG). There are seven requirements in the guidelines:

1. An accessible building entrance on an accessible route
2. Accessible and usable public and common-use areas
3. Usable doors
4. An accessible route into and through the dwelling unit
5. Environmental controls in accessible locations
6. Reinforced walls for grab bars
7. Usable kitchens and bathrooms

Each of the seven requirements has specific technical design criteria that provide a basic level of accessibility. It is important to note that, as minimum design criteria, the FHAAG does not serve all the needs of people with severe disabilities, particularly inside the dwelling unit. The guidelines are also not as comprehensive and detailed as the ADA Accessibility Guidelines, but the latter do not have requirements specifically for dwelling units.

There are three important exceptions to Requirement 1. First, only the first-floor units in buildings that do not have elevators in housing built on steeply sloping sites are covered by the act. Second, there are exceptions for sites where accessibility is impractical due to the topography of the site (steep slopes). Third, another set of exceptions is allowed for unusual site characteristics such as location on a flood plain or coastal high-hazard area where building codes require floor levels of living areas to be a certain distance above grade.

Requirement 2 basically treats the shared areas of multifamily buildings and facilities like public buildings. This includes laundries, playgrounds, swimming pools, mailrooms, and other shared spaces. The FHAAG specifies the scope of accessibility to these spaces and references the ICC/ANSI A117.1 Standard, the model standard used to define minimum accessibility in the United States (American National Standards Institute 1998), for technical criteria. Only one entry to the dwelling unit is required to be accessible. And only one accessible path of travel is required. So, for example, a first-floor dwelling unit may have an accessible entrance to the front of the unit, but there may be stairs leading to a rear door.

Requirements 3 and 4 ensure that the circulation spaces inside the dwelling unit are accessible. The requirements do not preclude lowered or raised areas of rooms, but they do require that all rooms be on an accessible path. A major difference between other accessibility provisions in the United States and the FHAAG is that doors inside dwelling units are not required to have latch side clearances. This restricts usability for people who have limited reaching ability or large wheelchairs.

Requirements 5, 6, and 7 require a basic level of accessibility to the fixtures and equipment in the dwelling unit. This includes electrical switches and outlets, appliances, and plumbing fixtures. There are detailed requirements for access to bathrooms, ensuring privacy and independence. However, the requirements for the kitchen do not include knee clearances and lowered cabinets and counters. Bathroom requirements are also less generous than those required by the ADA, especially due to the lack of latch side requirements at doors and shorter grab bar allowances at toilets. Finally, the FHAAG does not require grab bars to be installed in any unit.

The guidelines produce dwelling units that are accessible at a basic level. The authors of the act and the regulations that support it consciously traded off the extent of accessibility required to obtain political support to cover a wider number of dwelling units. The guidelines, however, do incorporate features that allow the units to be easily adapted to an individual's specific needs. For example, Requirement 6 specifies that reinforcing must be installed in the walls of bathrooms to allow grab bars to be installed easily in the future, should they be needed by the current resident of a dwelling or some future resident. Furthermore, although the FHAAG does not specifically require it, there is an incentive for vanities to be removable or adaptable to allow the provision of knee space under a sink in the kitchen or bath. Both these measures save money by reducing expensive modification costs, and they provide added value to the design of the home.

The FHAAG does not substitute for other accessibility requirements in housing. For example, other federal accessibility laws still require 5 percent of dwelling units in federally financed housing projects to comply with the more stringent requirements of ICC/ANSI A117.1.

Housing designed to the guidelines is attractive to a wide variety of people, including people with chronic pain, temporary disabilities, visitors with a disability, and older people. Incorporating adaptability into the design also reduces the cost of making expensive modifications to accommodate an individual with a disability. This type of change is not limited to a new tenant moving in. Older people often need modifications to their dwellings to maintain independence. Disability can also occur to otherwise "healthy" people as a result of accident or disease.

Compliance with the Fair Housing Law, like the ADA, is a complaint-driven process. Initially, there was no local method of implementation in regulations. This situation is changing as the United States moves toward more uniformity in building codes. The 1999 version of the ICC/ANSI A117.1 Standard incorporated optional requirements for design of dwelling units that are essentially the same as the FHAAG. These requirements are now referenced in model construction codes that are adopted by the states and, increasingly, are being incorporated in state accessibility codes as they adopt the new model codes. In states that had more stringent requirements for housing, there is a concern that these modifications will reduce the level of accessibility provided.

While the guidelines are generally easy to implement, in comparison with the far more extensive ADA Accessibility Guidelines, information about the Fair Housing Law and its impact on new construction has not been nearly as easy to obtain as information about the ADA requirements. In fact, there is evidence that architects and builders are not very knowledgeable about the Fair Housing requirements. Builders, who prefer to construct the same design as much as possible, have made few changes in their designs to address compliance. The result has been the beginning of a wave of litigation by the U.S. Department of Justice to raise the profile of the law and ensure that the building industry understands that it must comply. Several cases have been either settled or are in the process of litigation. Settlements can include requirements to renovate common facilities, renovate units already constructed, provide opportunities for owners of condominiums to renovate their apartments if desired, and provide funding for other home modifications in the community if renovating the noncomplying units is infeasible.

—Edward Steinfeld

See also Accessibility Codes and Standards; Home Modification; Housing: Law and Policy.

Further Readings

American National Standards Institute. 1998. *ICC/ANSI A117.1 Accessible and Usable Buildings and Facilities*. New York: American National Standards Institute.

Davies, T. D. and K. A. Beasley. 1992. *Fair Housing Design Guide.* Washington, DC: Paralyzed Veterans of America.

"Fair Housing Accessibility Guidelines." 1991. *Federal Register* 56(44): 9772–9515. Washington, DC: U.S. Government Printing Office.

Steven Winter Associates. 1993. *An Analysis of the Estimated Cost of Compliance with the Fair Housing Accessibility Guidelines and ANSI A117.1.* Washington, DC: U.S. Department of Housing and Urban Development.

———. 2001. *A Basic Guide to Fair Housing Accessibility: Everything Architects and Builders Need to Know about the Fair Housing Act Accessibility Guidelines.* New York: John Wiley.

Websites

U.S. Department of Housing and Urban Development, Fair Housing Accessibility Guidelines, www.hud.gov/library/bookshelf09/fhefhag.cfm

U.S. Department of Justice, Fair Housing Act, www.usdoj.gov/crt/housing/housing_coverage.htm

FAMILY

In a rapidly changing world, there is no longer an easy answer to the question "Who is the family?" Yet it is a profoundly important question for people with disabilities and their families. Governments around the world are committed to policies that support citizens with disabilities and their families, often under the banner of community care. But we know that most care in the community is care by the family, and that families "who care" save governments billions of dollars. Support and care between family members are the product of many forces—love, duty, obligation, reciprocity, altruism, custom—but it is a vital form of support that is primarily unpaid. As far as is known, it is also the norm in all societies. Who, then, is the family that takes on these responsibilities? How do families organize support of disabled relatives? How is this experienced? And what should families expect from governments to assist them in their endeavors?

WHO IS THE FAMILY?

Governments come and go but, taking a traditional view, the family as an institution is supposed to be a constant, even a stabilizing influence on society. In countries where major economic, political, and social changes have taken place, the family as an institution has endured but family structures, family forms, and the boundaries of families are being reshaped (Silva and Smart 1999). In many postindustrial societies, people are marrying later, having fewer children, and becoming parents later in life. Women are realizing improved educational opportunities, control over their fertility, and greater participation in paid employment. Changing demographics such as these will continue to affect the supply of people within families who are theoretically available to undertake caregiving responsibilities, but government policies can foster or restrain conditions that make this possible.

More significant than banner statistics about the family is the growing consensus that diverse patterns of family life exist. Perhaps the most major change in the concept of the family is that it can be represented in terms of the subjective meanings of intimate connections as well as formal, objective blood or marriage ties. This means that it is subjective experiences that can create ties between people living in separate households for part or all of the time, as well as people who choose to belong as a family.

What a family is can be closely linked to what it does, including, for example, support of disabled relatives, child care, sharing of resources and skills, and the meeting of demands and responsibilities. Within this context of changing definitions of *family*, there is little evidence to suggest an abandonment of commitment or obligation, much as those with more conservative views might argue. Newer family forms generate their own rules and norms to regulate exchanges and responsibilities so as to address the same commitments as other, more traditional, families. Though some of these arrangements are recognizable—families of choice, parenting across households, parenting by people with disabilities, single-parent families, and stepfamilies—many do not yet have names. Gene therapy and sperm donorship are making sure of that. Hence, there exists not solely one kind of family capable of producing moral, autonomous, caring citizens or of supporting in a sensitive manner family members with disabilities.

Values and beliefs that are culturally rooted, and long established, have a powerful influence in the setting of hierarchies of responsibility within families. Who ends up caring for whom therefore is likely to be a direct or indirect product of this. This may also affect who is defined as being part of the family and how help-seeking is negotiated. Currently, little is known about relationships between disabled people and their families from different ethnic and racial groups, especially outside of North America. Constructs of "the family" in developing countries, and how they organize their affairs, are likely to provide important lessons about effective ways of supporting disabled relatives, and how disabled people in

turn can make valued contributions within the family and the community.

It is self-evident that "the family" is more than the sum of those individuals who live in the same home. Steady improvements in health and survival together with social and geographic mobility lead inevitably to the dispersal of families, though not necessarily to their fragmentation. More recent technologies such as the Internet, e-mail, and cell phones are means by which physical barriers to communication between family members can easily be accommodated, and responses to demands and crises dealt with. Indeed, these technologies represent one way in which care and support "from a distance" can be brought into play. By definition, they cannot replace requirements for more hands-on support and care where direct contact, intimacy, or constancy is necessary. This illustrates one of the fundamental divisions in how families fulfill their caregiving responsibilities toward those with disabilities or high support needs, that is, by accommodating responsibilities toward "caring for" persons while maintaining a commitment to "care about" them.

FAMILIES SUPPORTING DISABLED RELATIVES

Many ways of describing how families "do their caregiving" have been discussed in the literature. One of the more enduring approaches is to distinguish "caring for" from "caring about" responsibilities. Early social policy research tended to focus on caring-for responsibilities depicted largely in terms of highly personal care (e.g., helping someone with bathing, toileting, dressing) or homemaking (e.g., assisting with laundry, ironing, gardening). These activities can be regarded as task-based or *instrumental* in character, and clearly important as such. This is sometimes referred to as direct work. At the same time, families express how they care about their disabled children and relatives in other ways. These are rather less tangible, but no less important, and include things such as planning and anticipating, negotiating, problem solving, and case managing, all of which can be regarded as kinds of indirect care. With both direct and indirect care (caring for and caring about), there is typically an integral affective or emotional dimension reflecting the strength of ties that bind family members together.

Such ways of mapping how families express their support and care of children and relatives with disabilities dominate in the literature. They typically show that mothers are responsible for most direct care, with male partners playing a more secondary or even discretionary role. Indeed, it is the mothers who continue to occupy the role of what might be termed *primary caregivers*. In these regards, their commitments parallel those of mothers of nondisabled children. There is further evidence to suggest that when caregiving needs are most intensive or prolonged it is mothers who will be on the front line. At lower levels of caregiving intensity, contributions from male partners are more apparent. Gender divisions are not quite so clear-cut in relation to indirect care, not least because responsibilities do not fall so readily into the hands of any one person.

In relation to disabled children, grandparent support has been tacit but only recently formally studied in a systematic way. Maternal grandparents have been found to provide more support than paternal grandparents, grandmothers typically provide more support than grandfathers, and grandparents living closer to the family of the child with a disability seem to provide more support than those living farther away. Current research is exploring whether such support truly complements parent support and how it ameliorates or contributes to parental stress and adaptation. Support from siblings of the child with disabilities can similarly complement that of parents and may be particularly important at times when parents are under pressure. The impacts of such obligations on younger siblings, especially those of school age, require special attention given the formative stage of their own development.

Support and care within families are generally presumed to be positive in their effects, but this is not always so. The intent is one thing; the experience may be another. This makes it imperative to draw distinctions between motivations for caregiving, delivery of care, and the actual experience and outcomes of that care from the perspectives both of family members and disabled people in the family. Through careful

and ethically sensitive research, representations of the views and experiences of disabled children about aspects of personal and family life are now emerging that will shed further light on supportive arrangements within families.

Family caregiving has also been studied with reference to its intended purposes with a focus on motivations and outcomes rather than tasks. Such research highlights caregiving that is anticipatory, preventive, and protective as well as supervisory and instrumental. Indeed, there is evidence to suggest that family caregivers tend to think more readily along these lines. This has the advantage of sensitizing those with responsibilities for supporting families to the goals to which families aspire, to what families achieve, or to what frustrates them along the way. It therefore shifts the focus from a purely process-based orientation to one that embraces both processes and outcomes.

A linked conceptualization sees disability and its consequences for families constructed from four dimensions: onset, course, outcome, and incapacity. The *onset* of a disability may be immediate or gradual, expected or unexpected, with the particular circumstances creating challenges and demands for families. The *course* of a disability may be progressive, constant, or relapsing/episodic. The character of the course therefore affects the ability to predict when and how supports need to be put in place. The *outcome* of a condition relates primarily to the expectation of death or shortened life expectancy, which may lead to the tendency to overprotection by families. *Incapacity* is the final dimension, characterized in five areas: cognitive, sensory, mobility, energy, and stigma. Different types of incapacity are seen as requiring differing responses from individuals and families, mediated in turn by values, expectations, and available coping resources. The four dimensions within this model are united by what has been called a "meta-characteristic," namely, predictability. Evidence suggests that families find it more difficult to deal with things when conditions remain less predictable. To some degree, this can be overcome by having access to good information about the onset, course, outcomes, and incapacities likely to be encountered.

These are examples of medical model thinking that views the person's disability as *the* challenge to be addressed or overcome. They do not fully explain oppressive forces that people with disabilities and their families face on a day-to-day basis. On the other hand, the social model redefines disability as the product of how the institutions of civil society exclude, disadvantage, or oppress people, rather than viewing impairment as a personal tragedy with the individual as victim. It addresses the lived experiences of people with disabilities and their families. Potentially, then, the social model has the capacity to see the interests of disabled people and their families as being united in a struggle to overcome the environmental roots of disadvantages that bar people from participating in community life on an equal footing with others. A critique of the social model is that impairment per se cannot and should not be marginalized on the grounds that it does in fact play an important part in their everyday experiences as disabled people.

EXPERIENCES OF FAMILY CARE

After many years of research about how families experience disability, most of the accounts are from the primary caregivers—principally, mothers of disabled children, spouses or partners of disabled adults, or children of older people with disabilities. Multiple accounts from different family members within studies are still rare, so controlled comparisons of the roles, reciprocities, experiences, and outcomes of supporting disabled relatives remain a priority for prospective research.

Family caregiving of children and relatives with disabilities is frequently portrayed as a stressful experience. Images of burdened or even burned-out family members who need respite from their caregiving roles continue to dominate the professional and academic literature. These perspectives depict family carers as being physically and emotionally stressed, with limitations placed on fulfilling social relationships, employment prospects, and quality of life. This view is based on a deficit model, which presumes that supporting someone with a disability must be burdensome or unduly challenging and that burden and challenge lead inevitably to negative experiences within the family. Nevertheless, there is a lot of evidence showing that perception of potential stressors

and how these are appraised in relation to available personal coping resources are important keys to understanding how family members adapt to the pileup of demands they face.

Recent studies of parents with children with intellectual disabilities show that mothers tend to be more stressed than fathers by the behavior problems of the child, possibly because they are more involved in everyday direct caregiving, but that fathers can be more troubled by external factors such as other people's responses to or acceptance of the child. Many mediating factors have been identified in explaining such gender differences, but there is a general acknowledgment of the need for much further carefully designed research here.

Stereotypes are sometimes used to maintain an underlying pathological view of families. For example, it is still common within professional discourses to hear families being talked about as if they were responsible for the difficulties faced by their disabled relative. This is perhaps most prevalent in connection with parents of disabled children where the language of overprotection is commonly used. Similarly, the stress and burden families are presumed to face are sometimes linked to the idea that families are rather passive, unresourceful, and lacking in agency. Alternatively, in other accounts of family caregiving there is a tendency to view families as having agendas and needs that stand in opposition to those for whom they care, this perhaps being more common where disabled family members have reached adulthood with distinctive rights and claims of their own. Then there are families who are depicted as being frozen in time as a result of wanting to remember earlier times before they were engulfed by caregiving demands.

This type of imagery identifies caregiving, most of it undertaken by women, as a part of their oppression or marginalization, the proposed solutions to which appear to be a return to forms of residential or collective group home living by disabled people. This position has been criticized by disabled feminists for assuming that disability equates with dependency, and for also overlooking the voice and subjective experience of disabled people themselves, and what they contribute to collective well-being within the family and beyond.

More recently, there has been growing recognition of the wider complexities of family caregiving, including a fuller appreciation of its associated transformations and rewards. This, in turn, has been leading to a more positive view of how families accomplish their caregiving and of the capacity of families to learn, adapt, and overcome. In families with children and adults with intellectual disabilities, for example, there is undeniable evidence showing how the coping repertoires of families expand through experience. This evidence also shows how mastery increases though the growth of self-confidence and skills. As family members ascribe meaningfulness to their caregiving, the role and position of caregiving are often reevaluated in a positive way. Strengthened ties between the caregiver and the cared-for person are commonly reported arising from a fuller acknowledgment of the layers of reciprocities that bind people together. Love, coupled with the moralities of duty and obligation, is important here.

There is also experience suggesting that rewards and satisfactions accrue from overcoming everyday challenges. These can emerge from dealing successfully with matters that might seem mundane to third parties—helping to lift someone more efficiently, receiving a smile of acknowledgment from someone with a severe cognitive impairment—but they can also occur when families make breakthroughs, especially when their caregiving efforts give rise to a reevaluation of prognoses by doctors, as has happened quite frequently in families with disabled children.

Hence, despite what might at first appear to be multiple limitations in their daily lives as a result of caregiving, many families share hopeful visions and experiences, or what some have called profound personal growth, because of this experience. This "embrace of paradox" as it has been called is a perspective that acknowledges the frustrations, the sometimes dashed hopes, and the emotional troughs of caregiving experiences, but it also suggests the existence of a capacity to bounce back as a result of something more resilient that makes families what they are.

Identifying all the factors that appear to make some families, or some family members, more resilient than others when facing similar challenges remains an important topic for continuing research. Different

theoretical starting points are assumed: some searching for personal qualities that make some individuals more resilient than others, while there is an alternative view that resilience should be viewed as a family-level construct. A number of different starting points have been suggested for further investigation here.

First, there is the theme of identifying capacity rather than incapacity within families. Families are often reminded by outsiders of their deficits rather than their competencies and expertise. Like disabled people, families are often reminded of their dependency status by formal organizations that continually check their eligibility for health or social care services. Newer service models are placing an emphasis on devolved systems of funding and decision making, including the introduction of direct-payment systems.

Second, there is growing evidence of the importance of the search for meaningfulness as a key to understanding successful coping and management. Families can be presented with many unexpected demands or find themselves doing their caregiving under nonnormative circumstances, for example, continuing to look after a disabled child for years beyond what they had predicted. Hence, they typically reframe the meaning of what they are doing, often by adapting their values and beliefs as they proceed. Such evidence can be found within the accounts of many older family caregivers.

Third, the ability of families to maintain a sense of control in difficult situations is a recurrent theme. Problems arise when matters that need control are beyond the direction of the family. This can implicate services as a prime culprit, for services that are designed to support families are often not available, are not synchronized with family routines and structures, are insensitive to family norms and rules, or else fail to involve families as partners when important decisions have to be made. These remain serious challenges for services in many countries.

Fourth, resilient family members need to be able to reaffirm their own sense of identity not only as caregivers but also as persons with important duties and obligations to themselves and to others. These families balance competing claims on their time and energy, giving rise to successful "boundary maintenance" or "border crossing" between their different identities. The role of culture and ethnicity in cementing, if not underpinning, the resilient qualities of families is not clear. Indeed, features of the "holding environment," that is, the social and cultural context in which families do their caregiving, are still being mapped. It is important to understand not only how these environments mold the dispositions and values that family members bring to their caregiving but also how the social networks to which they give rise shape the giving and receiving of care.

An important dimension of the family caregiving experience is the life course of the family. For family members, the life course sets the context for considering tensions around the uncertainties about future caregiving scenarios, maintaining a sense of control of environmental demands, and keeping a balance between the use of private and public time.

Particular tensions arise when individuals have to spend too much of their private time in caregiving when in fact they would prefer to use their time in other ways, private or public. The classic example is the conflict many families of working age face in balancing caregiving demands with employment. These opposing demands are less likely to clash if families can realize tax breaks, welfare payments, flexible working conditions, and job satisfaction, and disabled people can access inclusive education, suitable employment opportunities, or, as necessary, day care. Difficulties can arise for families when they become aware of growing discontinuities between the biological and psychological development of the disabled person. This is perhaps more typical when the disabled person has a cognitive impairment. It is often a signal that caregiving will have to take place "out of time," that is, beyond the point at which other families would normally end their caregiving. This perception of being out of sync with the rest of society represents another conflict for families, here between private time and social time.

While this is happening, families and disabled people have to manage their time and their activities within the calendars set by services and other institutions of society. With increasing plurality in the supply of services, for example, people with disabilities and their families are likely to encounter many transition

points as they move between health, education, social care, employment, housing, and independent sector services during the course of their lives. Each transition is potentially very stressful since it usually heralds fresh ambiguities and a requirement to adapt to new service philosophies along with their accompanying rules and obligations.

Over the life course, families then are faced with an array of time demands generated by different personal and public calendars. How families manage such competing demands relates to their resilience and capacity, the "family-centeredness" of services, and the degree of continuity and predictability over the life course. How far this is possible given the destandardization and increasing individualization of the life course in postmodern societies remains to be seen.

ROLE RELATIONSHIPS WITH SERVICES

Families supporting either children or adults with disabilities have been described as having an ambiguous role relationship with services designed to help them. This ambivalence seems to be tied to the stereotypes of families described earlier that introduced family members as potential competitors for health and social care services, as well as allies of the disabled people they support. Four tacit models for understanding this ambivalence have been put forward: viewed by services as "resources," families would be maintained in their role as caregivers; viewed as "co-workers," they would attract greater recognition of their role from services; viewed as "co-clients," their needs are likely to be difficult to disentangle from those of their disabled relative; and finally, in the case of the "superseded" family caregiver, services would aim to replace or substitute them.

These are not fixed categories, and it is likely that over the life course family carers may well move between these roles as circumstances change, reflecting the accumulation of expertise, a preparedness to continue caregiving, and the emergence of the family caregiver's own needs. The implications of perceiving family caregivers in these contrasting ways are quite profound, for each category is associated with different sets of assumptions about what carers bring to their caregiving as well as what they might expect by way of support from services.

Service systems tend to view families largely as resources, and by various means seek to maintain them in their caregiving roles. This commitment seems to predominate over other functions, for example, those tied to enabling families to enhance caregiving enrichment, or supporting efforts by families to abrogate caregiving responsibilities without feelings of guilt when demands become too onerous. The agendas of services and families can therefore be dissimilar in significant respects.

For many years, there has been talk of professionals and services working in partnership with families, but often the rhetoric has not been matched by funding to plug gaps in family support services, by addressing imbalances in power relations, or by providing incentives for families to engage service systems in a more positive way. More recent policy initiatives in a number of countries are at last beginning to tackle these issues. System change at a number of levels is occurring to help make partnership work with families a reality. This change has entailed the following:

- A reorientation of professional activity from individualized casework to family systems approaches where reciprocities and individual autonomy within the family are respected
- A shift from the professional as expert to the family and disabled person as expert and potential case manager
- Adoption of a competency (or *salutogenic*) view of the family rather than a pathological view of the family
- An approach to assessment of family support needs that is committed to enabling families and disabled people to articulate their dreams and strengths
- Recognition that the solution to people's needs and problems is likely to be found by tapping the natural resources of the family and community with services acting as enabler, rather than by a reliance on services as the solution to everything
- Decision making that adopts a "non-zero-sum" approach, that is, where, as a result of consultation, there is the prospect of multiplying support, expertise, and knowledge that benefits all parties
- Delegation of decision-making responsibility and control of resources to people with disabilities and

families where this is feasible and, where not, to the point closest to them as possible
- A long-term view so that families can realize the kind of transitions that will occur over the lifespan and can plan for these
- New organizational forms that are more responsive, organic, and network driven rather than formal and bureaucratic
- Autobiographies and narratives based on the lives of people with disabilities and their families that act as testimonies to the values and principles to be respected in how they should be supported

—Gordon Grant

See also Caregiving; Child Care; Family, International; Social Networks.

Further Readings

Boss, Pauline with Carol Mulligan, eds. 2003. *Family Stress: Classic and Contemporary Readings.* Thousand Oaks, CA: Sage.

Bowers, B. J. 1987. "Inter-generational Caregiving: Adult Caregivers and Their Ageing Parents." *Advances in Nursing Science* 9(2): 20–31.

Connors, Clare and Kirsten Stalker. 2003. *The Views and Experiences of Disabled Children and Their Siblings: A Positive Outlook.* London: Jessica Kingsley.

Edelson, Miriam. 2000. *My Journey with Jake: A Memoir of Parenting and Disability.* Toronto: Between the Lines.

Hastings, Richard, P. 2002. "Grandparent Support for Families of Children with Down's Syndrome." *Journal of Applied Research in Intellectual Disabilities* 15:97–104.

Hawley, D. R. and L. DeHaan. 1996. "Toward a Definition of Family Resilience: Integrating Lifespan and Family Perspectives." *Family Process* 35:283–298.

Heinz, Walter R. and Helga Kruger. 2001. "Life Course: Innovations and Challenges for Research." *Current Sociology* 49:29–45.

Nolan, Mike, Gordon Grant, and John Keady. 1996. *Understanding Family Care: A Multidimensional Model of Caring and Coping.* Buckingham, UK: Open University Press.

Nolan, Mike, Ulla Lundh, Gordon Grant, and John Keady, eds. 2003. *Partnerships in Family Care: Understanding the Caregiving Career.* Maidenhead, UK: Open University Press/ McGraw-Hill.

Oliver, Michael. 1996. *Understanding Disability: From Theory to Practice*. London: Macmillan.

Parker, Gillian and Dot Lawton. 1994. *Different Types of Care, Different Types of Carer.* London: HMSO.

Rolland, John S. 1988. *Families, Illness and Disability*. New York: Basic Books.

Silva, Elizabeth B. and Carol Smart, eds. 1999. *The New Family?* London: Sage.

Stalker, Kirsten, ed. 2003. *Reconceptualising Work with "Carers": New Directions for Policy and Practice*. London: Jessica Kingsley.

Twigg, Julia and Karl Atkin. 1994. *Carers Perceived: Policy and Practice in Informal Care.* Buckingham, UK: Open University Press.

FAMILY, INTERNATIONAL

Internationally, the great majority of families caring for a disabled member live in the developing world. Life is hard for everyone, but these families often have a poorer quality of life due to the persisting stigma of disability in most cultures and the extra care demands that are placed particularly on the women of the family.

In the past two decades, three strategies have been effective in supporting these families: parent associations, home-based support, and income generation. Nonetheless, the obstacles to providing a better quality of life are formidable and their removal is dependent on a much larger agenda of political and economic advancement within and across nation-states. The primary lesson from the twentieth century is that it can be done. The challenge for this century is to make this a reality for most families with a disabled member.

WOMEN'S WORK

In all societies of the world, the task of child rearing and child caring falls mainly on women, usually mothers but also grandmothers and daughters. Mothers fulfill four main roles in relation to the disabled child or dependent adult: survival, intellectual development, socialization, and emotional support. (For convenience, the term *mother* is used throughout this entry.)

For many families in developing countries, their immediate need for survival is for food, clean water, sanitation, and basic health services. Unlike rich countries, the major causes of disability in these countries are childhood illnesses such as measles and cerebral malaria. Mothers have to keep the family fed and healthy.

Mothers and siblings promote intellectual development through the one-to-one attention in tasks such as feeding and dressing or through family games and activities. Often it is mothers who seek out nursery and school placements and assist with homework. With the disabled child, it is mothers who attend clinic appointments and who are expected to carry out recommended therapies at home.

In many cultures, it falls to mothers to socialize the child into the wider community, by bringing the child to family and community events such as religious ceremonies and celebrations and also by encouraging friendships with peers and relatives. Implicit in this is an inculcation of moral values and conduct.

Emotional support, in the form of close, sensitive, and loving relationships between mothers and children, will do much to foster their self-confidence and self-esteem, providing the child with a much needed sense of security and safety.

Mothers have to fulfill these roles alongside the other demands placed on them: working in farms or factories, coping with household chores, caring for aging parents, and being a wife. Most mothers manage all these roles despite the famines, wars, and poverty that beset many lives. A child with a disability may be the least of their worries and can even be a solace amid their woes.

The fact that most mothers and families cope is not to imply that it is natural or easy. The sacrifices are many, not least in terms of self-fulfillment and the poorer physical and mental health of these mothers, which has been evidenced in many different countries.

Yet despite attempts at finding other ways of bringing up a disabled child, the best alternative for families who are unable to care for a disabled member is undoubtedly to find another family. In Western countries, fostering and adoption rather than placement in children's homes and residential schools—no matter how well these institutions are staffed and resourced—has become a much sought after alternative. Professional workers are limited in their expertise and influence in the lives of children. Their essential role is to support families in their child-rearing and child-caring responsibilities. In the case of persons with disabilities, this may extend far into their adult years.

Yet research suggests that support from professionals is secondary to the support mothers receive from their partners and extended families. A disturbing trend internationally is the rise in the number of single parents caring for a disabled family member and the breakdown of extended family networks.

Support from neighbors and friends is more forthcoming too when the disabled person is accepted socially within the community. Particular emphasis is now placed on creating inclusive schools that are prepared to enroll all children, no matter their impairments.

PARENT ASSOCIATIONS

The perceived shame and disgrace of having a child with a disability are often keenly felt by families. Common explanations for the disability revolve around old superstitions and punishments for misdeeds, usually by the mother. Parents, individually and collectively, have been to the fore in challenging these beliefs. The pioneering parents tended to be better educated, articulate, affluent, and well connected in society. And although motivated to get the best for their child, they argued for a better deal for similarly affected families. Invariably, they came together with others to share experiences and to join forces in making their views known, and so parent associations were born. Although varying in size and sophistication, these associations commonly fulfill four main functions: providing parents with solidarity, information, advocacy, and services.

Solidarity

The heartache that comes from feeling alone with a problem can be assuaged by meeting others who have been through or are going through similar experiences. Membership can also boost parental self-confidence and help to create a sense of pride in having a child with a disability. This appears to be best fostered at a local level; hence, national associations work hard to instigate and sustain a network of branches throughout the country. Likewise, solidarity can also be nurtured internationally through worldwide organizations such as Inclusion International, which claims links with 20,000 associations of families and self-advocates.

Information

Parents bemoan the lack of information available to them even when they have access to a range of professionals. They need information that is tailored to their needs and concerns and presented in readily accessible ways. Parent associations often produce newsletters for their members; most organize meetings, conferences, and training events with invited speakers; some have telephone helplines; and other employ "parent advisers" or development workers to provide information and training for their members. The Internet is becoming a major information resource for parents in more affluent countries.

Advocacy

National associations play a vital role in speaking up for the rights of people with disabilities. They often organize events to profile issues of concern and to gain media interest. Delegations from the association may also meet government officials to press their case. Likewise, national association may support individual members as they confront local discrimination, such as school enrollment. Parent members can be trained to act as advocates and trainers of others.

The advocacy role is more effective if alliances are made with other organizations that share a common interest, most notably organizations of people with disabilities. In many countries, there is now some form of national disability council or forum that brings together all the disability organizations with a primary goal of advising and lobbying government.

Services

Parent associations through co-operative endeavors can offer services to their members. For example, parents may take turns in staffing a day care center so that other mothers can have time for other duties. Many associations have opened resource centers for their members where they can meet visiting specialists, obtain information, borrow toys and equipment, and attend income-generating activities. In more affluent countries, parent associations have started special schools, training workshops, and residential homes. These service initiatives are open to criticism, mainly on the grounds that it absolves communities and governments from investing in service provision and perpetuates a charitable ethos rather than a rights-based approach.

HOME-BASED SUPPORT

In Western countries, one of the success stories of modern disability services has been the advent of home-visiting programs in which a trained worker regularly visits the family to advise on ways of promoting the child's development. With experience, their role has widened considerably, often providing emotional support to mothers, giving advice on other family matters as well as acting as an advocate for the family. Among the best-known programs are those based on a model originating in the United States in Portage, Wisconsin, but now used in many other countries.

Around the same time, the World Health Organization started to promote the concept of community-based rehabilitation (CBR) as a means of helping people with disabilities in the developing world. Here too, a trained worker, who may be paid or unpaid, visits the person with a disability at home to show the families what they can do to help their disabled member and to offer the family support and encouragement. Although the evidence remains equivocal as to the impact such home-based programs have on the development of the person with disabilities, there is widespread agreement that they are valued highly by families. James Gallagher attributed this to "a new spirit of optimism and encouragement within the family," replacing the despair and feelings of hopelessness that usually flow from disability.

Home visitors are not a new concept. The extended family or "tribe" has often provided an adviser or confidante to new mothers with whom they can discuss their concerns. The home-visiting concept builds on this tradition by introducing the family to a person who has particular expertise or interest in the disability. However, cultures vary in their tolerance of an outsider becoming involved in family issues, and services must be sensitive to this when recruiting staff to act as home visitors.

Recruiting Home Visitors

Home visitors can be recruited from at least three different sources, and around the world, projects

invariably use some combination of these. First, existing personnel are redeployed to act as home visitors. Teachers, therapists, and health workers have adopted this new style of working rather than solely seeing people in hospital clinics or disability centers.

Second, home visitors are paid employees who have been recruited and trained specifically for this role. Although the original idea was to recruit people from the community, in later years an increasing number of people with disabilities or parents of children with disabilities have successfully been employed as home visitors. This strategy not only gives much needed employment opportunities, but these individuals come with personal insights and motivation that can make them more effective and acceptable to families.

Volunteer workers form a third option. Some community services use family members as their primary workers, whereas other community programs have successfully recruited teachers and health workers, among others, to act as voluntary supporters for families. This is best exemplified in Brian O'Toole's work in Guyana.

However, the qualities that home visitors bring to the job, rather than the background from which they come, ultimately appear to contribute more to their effectiveness. In particular, it is important that home visitors do the following:

Empathize with the culture of the family. Families are then more accepting and trusting of them.

Respond practically to the family's needs. Parents should experience some immediate benefits from having a home visitor.

Try to involve all family members. Grandparents, siblings, and cousins can all be recruited to assist with the child who has a disability.

Empower families to be decision makers. They should share information and expertise freely with families so that they are empowered to make decisions and solve their problems.

Although the options for finding effective home visitors are available in most communities around the world, a great deal of effort needs to be expended on recruiting suitable persons because of the inevitable turnover that occurs with poorly paid or volunteer workers.

This approach of providing personal supports to families and people with disabilities is now widely accepted in developed countries as a means of giving carers extra help at home or short breaks from caring as well as enabling people with disabilities to live independently in what has become known as *supported living.*

RESPONDING TO POVERTY

All over the world, disabled people are more prevalent among poorer families. In more affluent countries, state pensions and social payments help to offset some of the consequences for families of having a disabled member, but this is not so in developing countries. Indeed, many of the so-called developing countries are in fact becoming poorer as they are beset with trade barriers, famine, civil wars, and diseases such as AIDS.

Malnutrition among mothers and infants is endemic in many developing countries. The economies of developing countries will never be able to sustain the levels of health care needed by persons with biological impairments. Infant mortality and increased morbidity will long continue to be featured in third world statistics.

The growth of industrialization and the drift to the cities has split families as fathers have sought employment away from the rural areas. Moreover, people with disabilities are more likely to be discriminated against by employers, or they risk exploitation with poor wages and substandard working conditions.

In many developing countries but especially in Africa, AIDS is taking a heavy toll on families, leaving many children orphaned and in the care of aging grandparents and relatives. Among these are teenagers and adults with disabilities who will require lifelong care but have no one to provide it. The full impact of this tragedy has yet to be felt and may never be fully known.

The option of moving away from the family home into other forms of care situations is an option for few people with disabilities in the developing world. Nursing homes, shared housing, or supported tenancies may be available but only for a few and for those families that can afford it. As medical advances have

an impact on developing nations, increased longevity will surely result. Yet there are few provisions for the care of adults with disabilities who outlive their carers.

This depressing analysis had led some to question the wisdom of focusing intervention efforts solely on people with disabilities and family supports while ignoring the wider social context in which the recipients live. Rather, the solution they espouse is to empower communities to manage and direct their own development and in so doing to help all their members. This is new and radical thinking and for which Western style disability specialists have little experience.

Income Generation

Foremost is the need to instigate and sustain income generation initiatives for families and persons with disabilities because any member of the family who is not productive is then a drain on family resources. At a minimum, children with disabilities need to become self-reliant in their personal care and be able to undertake jobs around the home such as water fetching so that the family workload is shared and others are freed to earn an income.

It is better still if the young people can play a part in income generation perhaps by assisting on the family farm or business or by holding down a job with local employers. The latter option is becoming more of a reality in developed countries with the advent of supported employment programs in which a support worker trains the person with a disability on the job and remains available to offer support and guidance to employers and co-workers should problems arise. It is possible that similar programs could operate in developing countries, especially in urban areas and as industrialization advances.

Likewise, co-operatives have been established for disabled people or for mothers in which they generate the goods and services that will find a ready market in local communities, for example, the production of school uniforms and leather goods, basketry, and raising chickens.

Revolving loan and micro-credit programs have been used to provide the necessary capital to individuals and communities. The payments on the loans are used to help fund others to start similar schemes.

Community Development

Three basic tenets must underpin these and similar initiatives. First, change has to come from within families and communities. If imposed from outside these systems, it is unlikely to be sustained or to flourish.

Second, the leaders who will instigate and nurture new developments are already present in every community, but they need to be equipped with the skills and knowledge needed to function as effective leaders and given a vision of how things could improve for their community.

Third, development has to start with the present reality within communities and be shaped according to their needs; hence, there is no one universal "treatment" or approach that can be immediately applied across a nation.

Finally, these approaches will become fully successful only when society's attitude to disability is transformed from primarily a medical problem to a social issue, from a specialist concern to a community focus, and from a charitable ethos to an issue of human rights. This is starting to happen through government policies stimulated by the United Nations Standard Rules, but the transformation has to grow also at the grassroots level, and that is the bigger challenge.

Throughout human history, families have nurtured, supported, and loved their weaker members. This still remains the most cost-effective means of responding to the needs of disabled persons the world over.

—Roy McConkey

See also Caregiving; Child Care; Community-Based Rehabilitation; Developing World; Family; Global Inequities; Home Support; Poverty.

Further Readings

Bornstein, M. H. 1991. *Cultural Approaches to Parenting.* Hillsdale, NJ: Lawrence Erlbaum.

Coleridge, Peter. 1993. *Disability, Liberation and Development.* Oxford, UK: Oxfam.

Dunst, Carl J., C. M. Trivette, and A. G. Deal. 1988. *Enabling and Empowering Families: Principles and Guidelines for Practice.* Cambridge, MA: Brookline.

Gartner, Alan, D. K. Lipsky, and A. Turnbull. 1991. *Supporting Families with a Child with a Disability: An International Outlook.* Baltimore: Paul H. Brookes.

Gallagher, James J. 1992. "Longitudinal Interventions: Virtues and Limitations." In *Saving Children at Risk: Poverty and*

Disabilities, edited by T. Thompson and S. C. Hupp. Newbury Park, CA: Sage.

Helander, Einer. 1993. *Prejudice and Dignity: An Introduction to Community-Based Rehabilitation.* New York: United Nations Development Programme.

Ingstad, B. 1997. *Community-Based Rehabilitation in Botswana: The Myth of the Hidden Disabled.* Lewiston, NY: Edwin Mellen.

O'Toole, Brian. 1995. "Mobilising Communities in Guyana." In *Innovations in Developing Countries for People with Disabilities* edited by B. O'Toole and R. McConkey. Chorley, UK: Lisieux Hall. (http://www.eenet.org.uk).

Turnbull, Ann P., I. Brown, and H. R. Turnbull. 2004. *Families and People with Mental Retardation and Quality of Life: An International Perspective.* Washington, DC: American Association on Mental Retardation.

UNICEF. 1989. *Facts for Life: A Communication Challenge.* Geneva: United Nations. (http://www.unicef.org).

Websites

Enabling Education Network (EENET), http://www.eenet.org.uk

Inclusion International, http://www.inclusion-international.org/

UN Enable, the United Nations Focal Point on Persons with Disabilities, http://www.un.org/esa/socdev/enable/

FAMILY: LAW AND POLICY

The historical norm for individuals with disabilities was isolation and segregation from the rest of society. Due to the work of disability advocates, however, attitudes toward people with disabilities started changing from one of exclusion to one of integration. In the 1970s, the United Nations passed declarations that argued that people with disabilities have the right to full participation and nondiscrimination in their communities. By the end of the twentieth century, many nations created laws that protect individuals with disabilities by making discrimination illegal and protecting their right to full participation and integration in society.

This entry focuses on the relationship between the law and families that have children with disabilities. Two topics are pertinent. First is how the law can serve as a tool for families to protect their children's right to "live in the world" with the same rights and benefits as nondisabled children. What follows is a brief overview of nondiscriminatory laws, educational laws, and entitlement services that provide support and legal protection for families and their children with disabilities. After examining how the law protects a disabled child's right to integration and nondiscrimination, the second topic addressed is the controversial issue of whether a disabled infant has any right to live at all. In particular, the issue takes the form of a question of whether the law provides a right for parents to refuse necessary life-sustaining medical treatment and intervention.

NONDISCRIMINATION AND INCLUSION

Antidiscrimination legislation is a powerful tool for parents to prevent their child from social exclusion and isolation as a result of her or his disability. The earliest and most comprehensive antidiscrimination legislation emerged in the United States through Section 504 of the Rehabilitation Act (29 U.S.C. § 794) and the Americans with Disabilities Act (ADA) (42 U.S.C. § 12101–12213), which prohibit discrimination on the basis of disability. The statutes forbid discrimination based on invidious affirmative animus, and discrimination based on thoughtlessness, apathy, and stereotypes about disabled persons. The U.S. Congress found that individuals with disabilities are a "discrete and insular minority" who face restrictions and limitations "resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society" (42 U.S.C.A. § 12101(a)(7)). By prohibiting discrimination on the basis of disability, these two statutes were designed to ensure that disabled individuals have the same access to education, employment, goods, and services as the nondisabled.

Section 504 became law in 1973, and it was the first major nationwide antidiscriminatory legislation designed to protect disabled Americans. The purpose of Section 504 was to "firmly establish the right of . . . [disabled] Americans to dignity and self-respect as equal and contributing members of society, and to end the virtual isolation of millions of children and adults from society" (118 Cong. Rec. 32,310 (1972) (statement of Sen. Williams)). Section 504, however, was not the panacea to eliminate societal discrimination against disabled persons because its

scope was limited to prohibiting discrimination by the U.S. government or any program or activity that receives federal financial assistance.

The ADA, which became effective on July 26, 1990, expanded Section 504's mandate to eliminate discrimination by prohibiting discrimination in employment, housing, public accommodations, education, and public services. It requires that

> 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 person who owns, leases, (or leases to), or operates a place of public accommodation. (42 U.S.C. § 12182(a))

The ADA's purpose is "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities" (42 U.S.C. § 12101(b)(1)).

The ADA and Section 504 provide a framework that is designed to differentiate discriminatory from nondiscriminatory behavior toward individuals with disabilities. This legislation requires places of work, education, or transportation to make "reasonable accommodations" for individuals with disabilities that enable them to enjoy the same opportunities as the nondisabled. Reasonable accommodation essentially means that business and places that provide public services must make modifications in their programs and services that would provide disabled individuals the same benefits and privileges as the nondisabled. Failure to make a reasonable accommodation constitutes discrimination unless there is no way to accommodate the difference or it is an "undue hardship" to provide such accommodation. An undue hardship means that providing reasonable accommodations would require extreme difficulty or expense, which has to be proven on a case-by-case basis.

Similar antidiscrimination legislation emerged in other countries throughout the 1990s. Specifically, Australia's Disability Discrimination Act, New Zealand's Human Rights Act, the United Kingdom's Disability Discrimination Act, Israel's Disabled Persons Act, Canada's Human Rights Act, and India's Disabled Person's Act all prohibit discrimination against disabilities. In addition to nondiscriminatory legislation, there are other critically important legal tools for families to guarantee their disabled child's ability for full participation and integration in society, especially the Individuals with Disabilities Education Act (IDEA), which is designed to protect disabled children's right to education.

Education

In 1975, the IDEA was enacted to meet the educational needs of children with disabilities (20 U.S.C. §§ 1400–1485). The U.S. Congress found that more than 1 million children with disabilities were being excluded from public education, and 50 percent of all children with disabilities were not receiving appropriate education (42 U.S.C. § 1400(c)(2)). The purpose of the IDEA is to

> ensure that all children with disabilities have available . . . a free appropriate public education which emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living, to assure that the rights of children with disabilities and their parents or guardians are protected, to assist States and localities to provide for the education of all children with disabilities, and to assess and assure the effectiveness of efforts to educate children with disabilities. (42 U.S.C. § 1400(d)(1)–(3))

Protecting and improving disabled children's educational experience is necessary to "ensure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities" (id.).

The purpose of the IDEA is to provide disabled children with an individualized education. Specifically, each disabled child must be educated in the least restrictive environment (LRE) appropriate to her or his needs. This means that a disabled child may be removed from the regular educational settings only when "the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (34 C.F.R. § 300.550(b)(2)). Thus, the LRE then creates a presumption of integrating disabled children in their school environment.

The cornerstone of the IDEA is an individualized education program (IEP), which is a joint document between the disabled child's parents or guardians and school authorities. The IEP describes the child's abilities and needs and prescribes services to meet the individual needs of the child. An IEP must be formalized in a written program that contains information about the child's current level of educational performance, annual educational goals, specific services that the child will receive, and details concerning the extent of the child's involvement with regular educational programs.

In addition to protective laws for children with disabilities, many nations also have entitlement programs that provide services to families and their children with disabilities, which will be addressed next.

Entitlement Programs

The United States, as do many other countries, provides entitlement programs for families with disabilities. Entitlement programs can cover a wide range of different services from subsistence income, educational grants, and training for disabled individuals or their families. In the United States, for example, families that have disabled children may qualify (based on income and resources) for Supplemental Security Income, which entitles families to monetary assistance, and Medicaid health care coverage for their disabled child. Moreover, federal grants provide training for disabled individuals and their families. For example, under IDEA, grants provide support and information centers for parents of children with disabilities.

In the next section, this entry moves from discussing antidiscrimination protection and social support to examining whether parents have the right to refuse necessary life-sustaining medical treatment for their newborn.

DISABLED NEWBORNS

In the early 1980s, families, lawyers, bioethicists, and the courts were involved in a legal and moral battle over whether the parents of disabled children had the right to refuse medical treatment for their children. The legal question was whether parents or medical authorities could choose to let a disabled infant die rather than provide the child with necessary medical treatment or nourishment essential to sustain life. The following is a brief overview of this dispute, explaining how U.S. courts and the federal government tried to resolve this controversial issue.

In 1982, the debate started when the parents in a Bloomington, Indiana, family wanted to let their baby, who had Down syndrome and an esophageal blockage, die rather than receive lifesaving medical treatment after their doctor told them what their child's life would be like with his disabilities. The parents' decision, however, was challenged in the now famous *In re Infant Doe* case (commonly known as the Baby Doe case). The child's parents and doctors argued against corrective surgery because they believed a child with Down syndrome would have diminished quality of life—in essence, it would be better for the child to die than live with his specific disabilities. The court held that that the parents had a right to withhold treatment and ordered the hospital to comply with the parents' decision. A few days later, Baby Doe died from starvation.

Advocates of letting parents have the right to refuse medical treatment for disabled children had several rationales, which, generally, focused on sparing a life that they believed would suffer an exceptionally low quality of life. Adrienne Asch (2001) summarized the reasons for withholding treatment in the following:

> Rationales for withholding treatment focused on the physical suffering and pain of the potential treatments as well as the impairments themselves; the conviction that technology was being used to sustain children who would have short, painful, and miserable lives regardless of what was done for them; the anguish for parents who had to watch a child die slowly after enduring fruitless medical procedures; disappointment for parents who would not have the healthy child they expected and desired and might instead have to raise one who would always have disabling conditions; and believe that the millions of dollars spent for such treatments were better spent in other ways. (Pp. 303–304)

Disability rights advocates who opposed allowing parents to let disabled children die rejected arguments

that disabled children have a low quality of life. A 1989 study by the U.S. Commission on Civil Rights supported disability rights advocates' arguments when it found that a majority of disabled Americans do not see themselves as having a poor quality of life and would not choose death over life (pp. 32–33). Disability advocates argued that disabled individuals had the right to receive treatment, and refusal constituted unlawful discrimination.

In response to *In re Infant Doe* and similar cases, the U.S. Department of Health and Human Services (DHHS) created a rule maintaining it unlawful for any federally funded hospital to withhold medical treatment from disabled infants. Hospitals and doctors challenged the DHHS decision in U.S. federal court. The issue of whether the federal government could require hospitals to treat disabled children despite the wishes of parents and medical providers finally made it to the U.S. Supreme Court in *Bowen v. American Hospital Association.* In 1986, the Supreme Court held that denying treatment to disabled infants did not constitute legally protected discrimination under Section 504 of the Rehabilitation Act. The Court argued that the hospital and physicians do not make treatment decisions for disabled newborns. Instead, hospitals and doctors implement the decision of the parents. If the parents do not want treatment for their child, then the hospital is not discriminating against the child. In essence, the Court held that for a hospital or doctor to discriminate against a disabled child, parents of the disabled infant would have to want medical treatment but the hospital and doctors would have to refuse treatment because the child is disabled.

Although the *Bowen* decision held that federally funded hospitals and doctors do not discriminate against disabled children when they refuse medical treatment in accordance with the parents' decisions, the U.S. Congress enacted the Child Abuse Amendments of 1984, which called for the medical treatment of newborns with disabilities unless the child would die even with medical intervention (42 U.S.C. §§ 5101–5106, 5111–5113, 5116 [1990]). Specifically, the amendment only allows medical treatment to be withheld if it would be "futile" or "merely prolong dying" (id.). The only remedy for violations under the statute, however, is loss of federal funds, which limits the statute's effectiveness.

Currently, the vast majority of disabled infants receive necessary medical support and care. Asch (2001) states that as of the year 2000, most newborns with Down syndrome and spina bifida and infants born with premature and low birth weight in the United States receive medical intervention (p. 305). Thus, she argues that the Child Abuse Amendments, presidential commission writings, and disability advocates "have all combined to ensure that most babies who can benefit from medical interventions do receive them" (p. 305).

CONCLUSION

The challenges in the legal relationships of families that have children with disabilities are ongoing. Antidiscrimination laws, educational laws, and entitlement services provide important tools for families to protect their disabled child's right to full participation in society. U.S. Supreme Court decisions, such as *Bowen v. American Hospital Association,* show how U.S. courts and the federal government have tried to resolve the controversial issue of whether parents have a legal right to withhold necessary life-sustaining medical treatment from their disabled newborns.

—Jeffrey M. Brown

See also Americans with Disabilities Act of 1990 (United States); Antidiscrimination Law, Judicial Interpretations; Bioethics; Children with Disabilities, Rights of; Down Syndrome; Individualized Education Program; Individuals with Disabilities Education Act of 1990 (United States).

Further Readings

Asch, Adrienne. 2001. "Disability, Bioethics, and Human Rights." Pp. 297–326 in *Handbook of Disability Studies,* edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury. Thousand Oaks, CA: Sage.

Braddock, David L. and Susan L. Parish. 2001. "An Institutional History of Disability." Pp 11–68 in *Handbook of Disability Studies,* edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury. Thousand Oaks, CA: Sage.

LaPlante, Mitchell P., Dawn Carlson, H. Stephen Kay, and Julia E. Bradsher. 1996, September. "Disability Statistics Report: Families with Disabilities in the United States." National Institute on Disability and Rehabilitation Research, U.S. Department of Education. Washington, DC: U.S. Government Printing Office.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavior Research. 1983. *Deciding to Forgo Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions.* Washington, DC: U.S. Government Printing Office.

U.S. Commission on Civil Rights. 1989, September. *Medical Discrimination against Children with Disabilities*. Washington, DC: U.S. Government Printing Office.

Websites

Disability Rights Education and Defense Fund, http://www.dredf.org/

FindLaw, www.findlaw.com

National Counsel on Disability, http://www.ncd.gov

FEEBLEMINDEDNESS

By the early 1900s, *feebleminded* was widely used by eugenic social reformers and mental health professionals in England and the United States as an umbrella term referring to all degrees and types of "congenital defect." Upon its inception, this term attempted to replace earlier, more offensive categories such as moral and intellectual idiocy, but by uniting discrete social, medical, behavioral, and economic stigma under one name, the category provided dangerous interpretive flexibility. By 1915, the American Association for the Study of the Feeble-Minded defined the category broadly to include any person deemed "incapable of performing his duties as a member of society in the position of life to which he is born." Similarly, in England, the Royal Commission on the Care and Control of the Feebleminded defined a feebleminded person as incapable of competing on equal terms or of managing his or her affairs with "ordinary prudence."

Such wide-ranging classifications allowed eugenicists to conflate myriad social problems such as poverty, growing immigrant and nonwhite populations, unemployment, and criminality with purported medical and scientific diagnoses of cognitive impairment. In effect, influential eugenicists reductively explained complex cultural issues as part of a crisis brought on by a menacing and ever-expanding army of "subnormal" classes. As examples, Walter Fernald applied feeblemindedness to groups as diverse as the blind or cognitively impaired to those with poor social conduct. Harry Laughlin, an active proponent of sterilization and eradication policies, built on Henry Goddard's model to define "social inadequates" as those who failed chronically in maintaining themselves as "useful" citizens. Laughlin's inadequate classification brought together the criminal, poor, vagrant, physically and cognitively impaired, chronically ill, and visually and hearing impaired with the leprous, tuberculous, syphilitic, orphaned, and alcoholic. In this way, the process of diagnosing feeblemindedness became a simple project of locating disability, disease, moral impropriety, or economic dependency, and using these traits as evidence of mental deviance.

In an effort to further refine taxonomies of feeblemindedness, eugenicists designated specific subcategories such as the *idiot*, *imbecile*, and *moron* to reflect the range from lower to higher grades of mental defect. The introduction, maturation, and proliferation of mental testing during this period allowed eugenicists to attach particular mental ages to these categories. By 1920, these designations were solidified: Idiocy indicated a mental age up to two years; imbecility from three to seven years; and the moron category referred to those graded from 7 to 12 years. Goddard invented the term *moron* to designate those individuals most difficult to identify as mentally deficient because of their seeming normalcy. Many eugenicists considered such "borderline" individuals the greatest threat to social progress and reform.

The process of naming, labeling, and classifying individuals is inevitably a process of differentiation, and in the case of identifying feeblemindedness, it also provided eugenicists with a troubling rationale for treating people with coercion, disrespect, and profound inhumanity. Using ungrounded hereditarian arguments and misplaced medical diagnostics, anyone designated within these categories of subnormality became particularly vulnerable to state-sanctioned segregation, institutional confinement, and enforced sterilization. Once someone was *diagnosed* as feebleminded, this person was rhetorically constructed as a social menace or economic burden and represented by eugenicists as part of an urgent problem in need of eradication.

—Michelle Jarman

See also Biological Determinism; Eugenics; Walter Fernald; Henry Herbert Goddard; IQ; Mental Illness; Sterilization.

Further Readings

Fernald, Walter. 1912. "The Burden of Feeble-Mindedness." *Rptd. Medical Communications of the Massachusetts Medical Society Vol XXIII.* Delivered as the Annual Discourse before the Massachusetts Medical Society, June 12.

Goddard, Henry H. 1914. *Feeblemindedness: Its Causes and Consequences.* New York: Macmillan.

Laughlin, Harry. 1922. *Eugenical Sterilization in the United States*. Chicago: Psychopathic Laboratory of the Municipal Court of Chicago.

FEMINISM

Feminism can be defined as a movement to achieve equality between men and women and to end male domination of society. It has its origins in the late eighteenth century when Enlightenment ideals of equality and individual freedom supported an emerging campaign to extend education, professional employment, and the vote to women. "Second wave" feminism, which dates from the late 1960s (by which time women's suffrage was well established in most industrialized countries), has sought to broaden the focus of attention to include women's position within the private sphere of domestic and family life. Fundamental to its approach is the distinction between *sex,* which is regarded as a biological characteristic rooted in nature, and *gender,* which is viewed as a social characteristic deriving from the meanings given to sexual differences by society. It is these socially assigned meanings that are seen as at the heart of women's subordinate position in society, and it is the transformation of society in relation to these meanings that is seen as liberating women from oppression and exploitation.

Feminism (or the women's movement) has much in common with the disability movement in terms of both its analytical position and its political activism. It has therefore been a source of some frustration to those who have links with both movements—most notably, disabled women and mothers of disabled children—that stronger alliances have not been forged between them. Indeed, it appears that neither movement has paid serious attention to the concerns of the other. Feminism, while increasingly recognizing difference and diversity among women, has largely overlooked disability with the result that it has at times argued in ways that have been detrimental to disabled women. The disability movement, traditionally dominated by men, has largely neglected gender and adopted an agenda predominantly concerned with participation in the public sphere. It has been left primarily to disabled women feminists, marginalized by both movements, to challenge their analyses and to work toward a more inclusive model that recognizes a common cause among all oppressed groups.

A number of very different strands have developed within feminism over the past 40 years, and while none has incorporated a disability perspective, proponents of many have offered their own analyses of disability. Liberal feminists, for example, have focused on inequality of rights and opportunities and have emphasized the need for legislation and education to challenge stereotypes and open up opportunities to all disadvantaged groups including women and disabled people. The latter group includes disabled women who are regarded as bearing a "double disadvantage." Marxist and socialist feminists have focused on women's class position within capitalism and their subordinate position within the family. They argue that equality of opportunity is not enough and call for a transformation of society to challenge the structures that create and perpetuate sexism, disability, and other forms of oppression. Radical feminists explain women's subordinate position in society as the product of patriarchy, a mode of social organization in which men have dominance and control over women, and advocate radical changes ranging from separate communities for men and women to androgeny. Radical feminism is also associated with standpoint epistemology, which recognizes women as having a particular position from which to speak. A similar standpoint positioning has been proposed with regard to disability, which would include the body of knowledge built up by disabled women and a recognition of the interdependence of disabled women's experiences, consciousness, and actions.

Feminists within the disability movement have also tried to take forward the analysis of disability by

extending the social model of disability to incorporate impairment. The social model of disability views disability as a problem within society rather than within individuals with impairments. Drawing on the feminist principle that "the personal is political," feminists within the disability movement argue that by focusing exclusively on disabling barriers in the external environment, the social model of disability denies an important aspect of their experience. They stress the need for an analysis that encompasses all aspects of disability, including the experience of impairments and the problems to which they give rise that cannot be solved by social manipulation. These developments are highly contentious within the disability movement where an emphasis on impairments and the *differences* between disabled people is seen as potentially divisive and threatening to the movement as a whole.

While feminist analyses of disability have largely been welcomed by disabled women (and men), disabled women themselves rarely feature in mainstream feminist analyses. As a result, disabled women have argued that much of feminist analysis is of little relevance to, or even in conflict with, their interests and concerns *as women.* This is perhaps best illustrated in relation to two issues of central concern to women: reproductive rights and care in the community. With regard to the first, disabled women feminists point out that mainstream feminism has done much to liberate able-bodied women from the constraints of their roles as wives and mothers but has largely overlooked the way in which disabled women have been denied the possibility of ever fulfilling these roles. Within mainstream feminism, reproductive rights have been seen largely in terms of access to methods of birth control that enable women to make choices about and within motherhood. For disabled women, however, reproductive rights mean something quite different: in the context of discriminatory assumptions about the legitimacy of their desire for children and about their capacity to bear and raise them, reproductive rights mean acknowledgment of their right to have children should they wish to and provision of practical help to enable them to bring them up. Perhaps most contentious of all aspects of reproductive rights has been that of abortion. Feminists have traditionally argued for a woman's absolute right to choose to terminate a pregnancy when the fetus has an "abnormality" and have welcomed antenatal screening as a means through which women can gain further control over their own reproduction. Disabled women, by contrast, have been critical of prenatal screening and selective abortion, arguing that they devalue people with disabilities and that they are potentially a new form of eugenics.

Another key point of debate between mainstream feminism and disabled women has been in relation to community care. Those in the disability movement have welcomed the move away from residential care to care in the community for people with disabilities as a major advance toward greater social inclusion. Mainstream feminists, however, have challenged the development of community care, arguing that it depends largely on women's unpaid labor in the home. By increasing this burden, community care policies further exploit women and perpetuate their dependent role within the family. Disabled women feminists have criticized this analysis, pointing out that it is made exclusively from the point of view of the caregiver and casts the recipient of care as passive and dependent. It also fails to recognize that most recipients of care are themselves women and many have caring responsibilities of their own. It is because they have failed to integrate a disability perspective into their analysis, disabled women feminists argue, that their nondisabled sisters have argued in support of institutional forms of care, which disabled people oppose. It also explains their failure to recognize that the family could be the site of oppression for disabled people as well as women and to join with disabled people in seeking alternative ways of supporting them so they do not have to depend on unpaid care by their family. Feminist philosophers of the ethics of care offer an alternative to both these analyses, challenging the stress each places on autonomy and individualistic independence as aspirational ideals and emphasizing instead the values of caring solidarity and interdependence.

With the turn of the twenty-first century, both feminism and the disability movement have faced new challenges from the growing influence of postmodernism. Postmodernism has the potential to undermine both movements through challenging the

principle of universal rights based on citizenship entitlements and through denying that either "women" or "disabled people" constitute a unitary or stable subject on which to base political actions. Despite this, postmodern feminism has developed as an influential strand within feminism, criticizing both the "grand narrative" of feminism and the extreme relativism of postmodernism. Ironically, perhaps, the emphasis that postmodern feminism places on the deconstruction of accepted categories (such as disabled), multiple identities, and the politics of difference may provide fertile ground for a more insightful—though local, contested, and provisional—understanding of disability issues than that provided by previous strands of feminist thinking.

—Mary Boulton

See also Gender; Gender, International; Reproductive Rights.

Further Readings

Corker, Marion and Sally French, eds. 1999. *Disability Discourse.* Buckingham, UK: Open University Press.

Fawcett, Barbara. 2000. *Feminist Perspectives on Disability.* Harlow, UK: Pearson Education Limited.

Lloyd, Margaret. 2001. "The Politics of Disability and Feminism: Discord or Synthesis?" *Sociology* 35(3): 715–728.

Morris, Jenny. 1996. *Encounters with Strangers: Feminism and Disability.* London: Women's Press.

Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability.* London: Routledge.

FERAL CHILDREN

Before the seventeenth century, outside of myth and legend, only scattered and fragmented stories of feral or wild children appear in European history. Suddenly, during the 1600s, several accounts emerge; there are descriptions of a wolf boy in Germany and children abducted by bears in Poland; and, in 1644, the first story appears in English of John of Liège, a boy lost by his parents in the woods who took on animal-like behaviors to survive on his own for years. Early descriptions of such children detailed their nonhuman qualities: running on all fours, foraging and hunting for food, exceptional hearing, and absence of language. As several such children were rescued from the wild and brought back into human society, their continued animalistic behavior coupled with a seeming inability to master language fascinated philosophers, who began to wonder if such children actually belonged to a different species than the human family.

This question was taken up with great seriousness in the eighteenth and nineteenth centuries as science attempted to name, classify, and understand the intricacies of the natural world and human development. The most widely known feral child of the early eighteenth century was a boy found in Hanover in 1724. Peter the Wild Boy—as the famous Dr. Arbuthnot named him—became a fascination of the English royalty, living for the next few years both with King George I and the Prince of Wales. Like earlier children found in the wilderness, however, Peter's unbreakable silence and unique ability to survive much as an animal would compelled scientists to address this animal-human divide. Within a decade of Peter's discovery, Carl Linnæus, the hugely influential natural historian, actually included feral man, *homo ferens,* as one of six distinct human species. Notably, *ferens* is the only classification listing individuals—rather than whole races—as examples.

In the 1792 translation of Linnæus's *Natural Systems* into English, however, a note was added that such children were probably "idiots" who had been abandoned or had strayed from their families. It was this conflation of feral nature and disability that was taken up by Jean Marc Gaspard Itard in his project of civilizing one of the most famous cases in Europe, Victor of Aveyron, a wild boy caught in 1800 in the forests near Lacaune. Philippe Pinel, the foremost physician in France, dismissed Victor as an "idiot," but to Itard, the boy was a living artifact—an atavistic body on which to test Rousseau's notions of original perfection against a belief in language as the only means through which human identity could be forged. After several years of training, however, Victor was still unable to use language, a failure that further solidified an understanding of feral children as mentally "infantile" and "inferior."

In many ways, the systematic education, training, and confinement of cognitively disabled people in the nineteenth and early twentieth centuries drew on the legacy of "civilizing" projects taken up by teachers of

feral children. Building on the techniques of Itard, for example, Eduoard Séguin promoted repetitious physical and mental training processes for "feeble-minded" children—training systems that were further developed by eugenicists in Europe and the United States. During the twentieth century, as psychologists endeavored to distinguish between behaviorism and biological nature, wild children—a designation including children in isolation as well as those who survived among animals—again seemed to provide a key to the puzzle. A pervasive assumption that such children are abandoned or confined by their parents because of apparent cognitive impairments remained entrenched until the later decades of the century.

Presently, most psychologists attribute the inability of such children to master language to their unique histories of survival outside of human society—as a behavioral mechanism specifically adapted to their environment and circumstances rather than a biological inability. Fascination with wild children, however, remains, and the fates of such children become deeply tied to the doctors, teachers, and caregivers, who, through measurement, diagnosis, training, and compassion, inevitably attempt to resocialize these children and return them to the fold of human interaction.

—Michelle Jarman

See also Jean Marc Gaspard Itard; Philippe Pinel; Eduoard Onesimus Séguin; Victor of Aveyron.

Further Readings

Malson, Lucien. 1972. *Wolf Children and the Problem of Human Nature.* New York: Monthly Review Press.

Newton, Michael. 2002. *Savage Girls and Wild Boys: A History of Feral Children.* London: Faber and Faber.

Shattuck, Roger. 1980. *The Forbidden Experiment.* London: Quartet Books.

FERNALD, WALTER (1859–1924)

American institution administrator

From the time of his appointment in 1887 to his death in 1924, Walter Fernald served as superintendent of what was then known as the Massachusetts School for the Feeble-Minded (now known as the Fernald Center). In this role as head of the first public asylum in America specifically created to house intellectually disabled people (started by Samuel Gridley Howe in 1848), Fernald became one of the most prominent institutional professionals in the United States, associated with a strong advocacy of institutional care of people with intellectual disabilities. He served two terms as president of the main professional organization in the area of intellectual disability (now called the American Association on Mental Retardation). For many years, Fernald wrote in aggressive terms about the "burden of the feeble-minded" on the rest of society, and he was an active proponent of involuntary sterilization just as eugenics laws were being passed by state legislatures throughout the country.

Unlike most of his colleagues, Fernald moderated some of his more extreme views by the end of his life. He became a supporter of community placement for many of those he previously characterized as part of a "parasitic, predatory class," eventually developing one of the country's largest "parole" systems for moving institutional residents back into smaller, community-based residences.

—Philip M. Ferguson

See also Biological Determinism; Eugenics; *Feeblemindedness*; IQ; Sterilization.

Further Readings

Fernald, W. E. 1912. "The Burden of Feeble-Mindedness." *Journal of Psycho-Asthenics* 17:87–111.

Scheerenberger, R. C. 1983. *A History of Mental Retardation.* Baltimore: Paul H. Brookes.

FETAL ALCOHOL SYNDROME

Fetal alcohol syndrome (FAS) comprises a recognizable pattern of birth defects attributable to the adverse effects of maternal alcohol abuse during pregnancy. The condition was initially described independently by Paul Lemoine in France in 1967, and Kenneth Jones and David Smith in the United States in 1973. The observations of these investigators, later confirmed through animal model and human epidemiological research, constituted the first recognition that alcohol is a teratogen (a substance causing birth defects).

The full-blown disorder encompasses prenatal growth deficiency (persistent after birth), neurodevelopmental deficits, microcephaly (small head size), and a specific facial appearance, including small eye openings and an underdeveloped midface. Cardiac, renal, and skeletal anomalies may also be observed. Subsequently, a spectrum of disability was delineated accompanying prenatal alcohol exposure. Most accurately termed fetal alcohol spectrum disorders (FASD), the gamut of disability ranges from full FAS to neurodevelopmental deficits absent the other features of the syndrome. FASD is the most common environmentally induced cause of mental retardation in the world. Although the prevalence in the United States is generally quoted as 0.5–2.0 cases per thousand births, in some children in the Western Cape province of South Africa rates as high as 48 per thousand have been documented.

—Kenneth Warrens

See also Substance Abuse.

Further Readings

Institute of Medicine. 1996. *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment.* Washington, DC: National Academy Press.

National Institute on Alcohol Abuse and Alcoholism. 1997. "Prenatal Exposure to Alcohol." Pp. 283–338 in *Ninth Special Report to the U.S. Congress on Alcohol and Health.* NIH Publication No. 97–4017. Bethesda, MD: National Institute on Alcohol Abuse and Alcoholism (http://www.niaaa.nih.gov/publications/10report/chap05.pdf).

———. 2001. "Alcohol-Related Birth Defects: An Update." *Alcohol Research & Health* 25(3): 149–240. (http://www.niaaa.nih.gov/publications/arh25–3/toc25–3.htm).

FIBROMYALGIA

Fibromyalgia is a medical syndrome (constellation of symptoms) that is characterized by chronic widespread pain of at least six months' duration. In 1990, the American College of Rheumatology proposed criteria for diagnosis:

- Pain in the axial skeleton (pain in the region of the cervical or thoracic spine, anterior chest, or lower back)
- Pain above and below the waist
- Pain upon palpation in at least 11 or 18 paired tender points throughout the body. (Palpation is performed over the tender points with just enough pressure to just blanch the fingertip of the examining physician.)

SYMPTOMS

The most common symptoms that people with fibromyalgia experience are widespread pain, fatigue, sleep disturbance, and myalgias (muscle aches). There are several other syndromes that are commonly associated with fibromyalgia. These include migraine headaches, irritable bowel syndrome, interstitial cystitis (pain of the bladder region), depression, anxiety, and temporomandibular dysfunction (pain in the region of the jaw).

PHYSICAL EXAMINATION

The treating physician should perform a thorough general medical and neurological examination, which is generally normal. In addition, a complete examination of the musculoskeletal system should be done to evaluate for local overuse pain problems such as bursitis (inflammation of the bursa or fluid sac between bone and muscle), tendinitis, radiculopathy ("pinched nerve" or sciatica), and myofascial trigger points (areas of "muscle knots").

The examining physician should palpate the 18 paired tender points with approximately 4kg of pressure. This is just enough pressure to blanch the fingernail of the examiner. The patient will experience pain at these locations.

TREATMENT

Initial treatment includes patient education, pharmacologic treatment (medications), gentle exercise, and relaxation training. Pharmacologic management aims to normalize sleep patterns and diminish pain. Low doses of sedating antidepressants at bedtime (e.g., 10–25 milligrams of amitriptyline) can be helpful for sleep and pain. In addition, small doses of more stimulating antidepressants (e.g., fluoxetine) can be given in the morning to reduce pain and fatigue. The combination works better than either medication taken alone.

Pain may be relieved with simple analgesics such as acetominophen or ibuprofen. Tramadol is the next-line agent. Opioids (e.g., morphine) are rarely necessary. Adjunctive nonpharmacologic pain control methods include acupuncture, massage, and biofeedback.

REHABILITATION

Physical therapy is used to educate the patient on a stretching, gentle strengthening, and cardiovascular (aerobic) fitness program. This can improve fitness and function and decrease pain. Occupational therapy is incorporated to review ergonomics (efficient ways of performing tasks) of daily household and worksite activities. Task simplification, pacing, and maximization of function are emphasized.

Mental health professionals can be helpful in the rehabilitative phase to educate the patients in a mind-body stress reduction program. This provides the patient with positive coping strategies for living with chronic pain. Associated depression and anxiety may require evaluation and treatment by a psychiatrist.

FUNCTIONAL LIMITATIONS AND DISABILITY

Patients may be limited by both pain and fatigue. Patients also report cognitive dysfunction with difficulty in concentration, organization, and motivation. This has been termed "fibro fog." Approximately 25 percent of patients with fibromyalgia report themselves as disabled and are collecting some form of disability payments. Individuals are more likely to become disabled if they report higher pain scores, work at a job that requires heavy physical labor, have poor coping strategies and feel helpless, or are involved in litigation.

—Joanne Borg-Stein

See also Acupuncture; Myofascial Pain.

Further Readings

Bennett, R. M. 1996. "Multidisciplinary Group Programs to Treat Fibromyalgia Patients." *Rheumatic Disease Clinics of North America* 22(2): 351–367.

Berman, B. M., J. Exxo, et al. March 1999. "Is Acupuncture Effective in the Treatment of Fibromyalgia?" *Journal of Family Practice* 48(3): 213–218.

Borg-Stein, J. 2001. "Fibromyalgia." Pp. 559–562 in *Essentials of Physical Medicine and Rehabilitation,* edited by W. F. Frontera and J. S. Silver. Philadelphia: Hanley & Belfus.

———. 2002. "Management of Peripheral Pain Generators in Fibromyalgia." *Rheumatic Disease Clinics of North America* 28(2): 305–317.

Goldenberg, D. L. 1999. "Fibromyalgia Syndrome a Decade Later: What Have We Learned?" *Archives of Internal Medicine* 159:777–785.

Goldenberg, D. L., C. J. Mossey, et al. 1995. "A Model to Assess Severity and Impact of Fibromyalgia." *Journal of Rheumatology* 22(12): 2313–2318.

Kaplan, K. H., D. L. Goldenberg, et al. 1993. "The Impact of a Meditation-Based Stress Reduction Program on Fibromyalgia." *General Hospital Psychiatry* 15:284–289.

Rosen, N. B. 1994. "Physical Medicine and Rehabilitation Approaches to the Management of Myofascial Pain and Fibromyalgia Syndromes." *Bailliere's Clinical Rheumatology* 8(4): 881–916.

Websites

Oregon Fibromyalgia Foundation, http://www.myalgia.com. This website is hosted by the Oregon Fibromyalgia Foundation, which was started in 1995 by Robert Bennett and Sharon Clark. It is a nonprofit academic organization that provides reliable and unbiased information to fibromyalgia patients and others.

FILM

The portrayal of disability on film shares traits with that of literature and drama. Disability in film has been disproportionately underrepresented at the same time that it has been excessively displayed. For the most part, disabled characters onscreen are minor figures, whose less-than-perfect bodies serve as a foil for the protagonist. In this way, characters portrayed as disabled perform the dual purpose of signifying a "lack" or character flaw to which more primary characters (and presumed-to-be-able-bodied audience members) might succumb, while at the same time disabled characters reestablish the wholesomeness and integrity of those key characters (and supposedly normative audience members).

In such films, disability figures as metaphorical emphasis for any moral impact in the films that directors wish to impart. Some notable examples include the unconscious character of Alicia (Leonor Watling)

in Spanish filmmaker Pedro Almodóvar's *Hable con Ella* (*Talk to Her* [2001]) whose coma enables her nurse and suitor, Benigno (Javier Cámara), to sexually violate her body, or the title character of the independent U.S. film *Pumpkin* (2002), a young man (Hank Harris) with developmental and physical disabilities who comes to represent the undesirable "other" to sorority girl Carolyn (Christina Ricci). The mainstream Hollywood movie *At First Sight* (1998) features a blind character, Virgil (Val Kilmer), who struggles to adjust once he has *regained* his lost vision. This film ironically presents its character as doubly "challenged": first as a character who must relearn how to negotiate his changed environment and second as a living metaphor for the ills of the world that other characters "choose" not to see.

Alternatively, Dogme 95 (a Danish-based collective of film directors) member Lars von Trier's film *The Idiots* (1998) depicts characters who embody the physically normative, yet who perform as if they have cognitive disabilities in order to disrupt and disturb their conventional world. Independent Canadian filmmakers Shawna Dempsey and Lorri Millan, in their short video *The Headless Woman* (1998), display the circus freak not only as metaphoric of the contemporary status of women and especially lesbians but also to reveal the haven that the sideshow world has traditionally offered to people whose bodies and bodily desires did not always fit into societal ideals of "the norm." A small number of mainstream films embrace disabled characters as central to the plot, but that plot usually depends on a narrative of triumph, wherein the protagonist must "overcome" a physical impairment to fit into the normative nondisabled world. In such narratives, the protagonist strives for a victory of personal achievement and attitude, rather than one of making the world more disability-accessible or disability-centered. Examples include Susie Hendrix (Audrey Hepburn) in *Wait Until Dark* (1967), a character who has gone blind and must summon her limited resources to battle the crooks who threaten her, and Alice Culhane (Mary McDonnell) in *Passion Fish* (1992), whose accident has left her a wheelchair user and has also deprived her of her job as television soap opera star.

DISABILITY STUDIES FILM SCHOLARSHIP

Film scholarship on disability representation has followed the stages named by critics David Mitchell and Sharon Snyder in *Narrative Prosthesis: Disability and the Dependencies of Discourse.* Tom Shakespeare, Paul Longmore, and Paul Darke helped to initiate the field with articulations of what Mitchell and Snyder call the "negative imagery" school of disability film criticism. Martin Norden's *The Cinema of Isolation: A History of Physical Disability in the Movies* clarifies such disability critique in its categorization of such disability stereotypes. Norden's categories include the "Civilian Superstar," the "Comic Misadventurer," the "Elderly Dupe," the "High-Tech Guru," the "Noble Warrior," the "Obsessive Avenger," "Saintly Sage," the "Sweet Innocent," the "Techno Marvel," and the "Tragic Victim." He emphasizes the placement of these stereotypes in a number of films, especially those not predominantly focusing on disability.

The first collection of essays to explore the "fusion" of disability and film studies, 2001's *Screening Disability: Essays on Cinema and Disability,* edited by Anthony Enns and Christopher R. Smit, moves to what Mitchell and Snyder call the "social realist" school in an attempt to contextualize and confront the negative images that dominate cinematic representation. Mitchell and Snyder's own work in *Narrative Prosthesis* participates in a stage of disability criticism they have labeled "transgressive reappropriation," which demonstrates how disability representation can work against dominant modes of understanding power and can undermine typical portrayals of social dynamics. For example, in Atom Egoyan's *The Sweet Hereafter* (1997), the character of Nicole (Sarah Polley) openly plays on the effects of her disability to emphasize her newfound power over her sexually abusive father—rather than showcasing her recently acquired disability as an outward sign of a shameful secret. More recently, the Korean film *Oasis* (2002) depicts the "severely" disabled central character Gong-ju (Moon So-ri) forging an intimate link with a male character, Jong-du (Seol Kyeong-gu), who has sexually assaulted her. The characters' outcast status allows them a transgressive space in which to call

into question societal assumptions about their personal lives.

SILENT ERA FILMS

With Charlie Chaplin's *His New Profession* (1915) and Tod Browning's *The Unknown* (1927) as perhaps the most prominent and famous examples, the silent era of film introduced a number of disability themes and patterns that continue to this day. For example, *Stella Maris* (1918) features Mary Pickford as a disabled avenger. Though this pattern continues throughout film history, it is important to note that the female avenger is less common than the male. D. W. Griffith's last successful film, *Orphans of the Storm* (1921), portrays a blind sister Louise (Dorothy Gish) dependent on her sighted sister Henrietta (Lillian Gish). The two sisters set out for Paris to seek a cure for Louise's condition and are both kidnapped in the process. King Vidor's *The Big Parade* (1925) introduces a visual standard for the portrayal of veterans who acquire disabilities in battle. *The Hunchback of Notre Dame* (1923) began a long tradition of adapting the novel for the screen and also marked Lon Chaney as a key actor in early disability roles, particularly in the horror genre.

HORROR FILMS

For many filmmakers and viewers, the image of disability and the horror genre are closely intertwined. In Hollywood, movies such as *Darkman I, II, and III* (1990, 1994, and 1996), the various versions of *Frankenstein* (1931, 1970, 1973, 1984, and 1992, among others), *Night of the Living Dead* (1931, 1994), *Terror in the Wax Museum* (1973), and the first of many *Halloween* films (beginning in 1978) exploit viewers' unease about screened versions of crippled, disfigured, or mentally disabled characters. Filmgoers' long association of disabled characters with evil (or at least as living within the realm of evil) reaches from the silent film era's *Hunchback of Notre Dame* (1919), *The Shock* (1923), and *Phantom of the Opera* (1925) to the new millennium's *X-Men* I and II (2000 and 2003), and *Hannibal* (2001). An influential film for directors, actors, and disability activists, the early "talkie" *Freaks* (1932) blasted into cinemas by presenting actual disabled actors as their disabled character counterparts. Both praised and reviled, *Freaks* director Tod Browning reinvented the horror genre at the same time that the ending of his film reinforces a horror-disability correlation.

A subcategory of the horror genre is the science fiction film, many of which began to surface in the late 1930s and return with significant consequences in the late 1980s and early 1990s. Set in a time markedly different from the present, sci-fi narratives invariably propose "alternative" bodily categories as abundant examples of the "norm" gone deviant. Some examples include the Mariner (Kevin Costner) in *Waterworld* (1995), where the proliferation of ocean miraculously encourages evolutionary changes onto the body, such as the main character's gills and webbed feet. Less "neutral" bodily transformations include the clichéd chemical and biological mutants that sci-fi films continue to offer. Examples range from *The Island of Dr. Moreau* (1933) to the tedious genetic-experiment-gone-amok of Ang Lee's *Hulk* (2003). In David Cronenberg's film *Dead Ringers* (1988), twin gynecologists Beverly and Elliot Mantle (both played by Jeremy Irons) liken themselves to the famous conjoined twins Chang and Eng. The twins indulge in sexual exploration while studying the genetically "mutant" body of medical patient Claire Niveau (Geneviève Bujold) at the same time as their attempts to claim individual lives descend into a medical nightmare.

WAR AND WAR VETERAN FILMS

Beginning with Thomas Edison's newsreels featuring war coverage (first projected in 1897), war veterans and characters who have been affected and impaired by war have played a large role in film history. Such documentary spots soon gave way to narrative features, beginning with *The Empty Sleeve* (also released as *Memories of Bygone Days* [1909]). This film participates in a long-standing tradition wherein disabled war veterans gain social value only when they can display triumph in a homecoming celebration of their geographically distant nationalist triumphs. U.S. war films made during or immediately following prominent international conflicts tend to valorize the positive

symbolic potential of brave wounds. This pattern has resulted in waves of patriotic World War I films such as *For Valour* (1914), *I'm Glad My Boy Grew Up to Be a Soldier* (1915), and *Womanhood: The Glory of Nation* (1917). U.S. patriotism continued in post–World War II films such as *Thirty Seconds over Tokyo* (1944), *The Enchanted Cottage* (1944), and *Since You Went Away* (1944).

In part because of the large role played by television representation, making the horrors of war immediately available in American living rooms, the Korean, Vietnam, and Iraq (1991) conflicts have yielded many filmic depictions of veteran postwar experiences. Examples include *Coming Home* (1978), *Deer Hunter* (1978), and *Courage under Fire* (1996). A main concern for largely male disabled veterans featured prominently in such films is the type of sexual life they will be able to pursue, and, as a result, their subsequent (masculine) virility comes into question, a patent example being *Born on the Fourth of July* (1989).

Films made following major conflicts are more likely to question the cost of war, with *The Big Parade* (1925) providing an early example. After the glow of World War II conquest began to fade, U.S. filmmakers initiated film plots that questioned the ease of readjustment to ableist home environments. Prominent examples include *The Best Years of Our Lives* (1946), *The Men* (1950), and *Bright Victory* (1952). A film about life subsequent to World War II that contrasts such patriotism is Akira Kurosawa's *Hachigatsu no Kyoshikyoku* (*Rhapsody in August* [1990]), which depicts a character who survived the Nagasaki bombings. She retells (and relives) those days to her grandchildren, for whom the war is simply a long-ago ghost story.

CHILDREN'S FILMS

An often overlooked medium, films directed at children present an especially high number of disabled (or "afflicted") characters. Whether child audiences actually demand physically distinct characters, or whether filmmakers simply find such characters a convenient route through which to navigate the film's narrative and moral conclusions, a plethora of films reproduce disability stereotypes in the visual depictions of secondary characters. Even in a film such as *Toy Story* (1995) that offers a fantastical depiction of childhood imagination, the unavoidable "real world" invades owing to the minor character of the boy next door who destroys the toy-characters and then reconstructs them as "mutant" beings.

As is true of their literary counterparts, disabled characters appear on children's screen as either diabolical (e.g., Captain Hook in *Peter Pan* [most recently 2003] and *Hook* [1991] or Governor John Ratcliffe in *Pocahontas* [1995]) or delightfully benevolent and determined (e.g., the tin man in *The Wizard of Oz* [first made in 1939] or the beast in *Beauty and the Beast* [1946, 1991]). Quite often in children's movies, characters are represented as *both.* For example, in the *Harry Potter* (2001–2005) films, Harry has been injured and scarred for life, which is admirable, yet his nasty cousin, Dudley, is obese and constantly gorging himself. As well, a character such as the grinch (in *The Grinch* [2002]) is visually obvious as the villain, yet the very visual "difference" that sets such a character apart as evil indicates to the audience that such a character can be morally redeemed.

Children's movies also frequently feature the disability as a plot device that enables the action. For example, in *Mulan* (1998), the main character (voice-over by Ming-Na Wen) not only hides her gender in order to go to war to fight for her people, she also steals her father's papers in order to fake his identity. Had she not done this, the film implies, his disability injury from the previous war would have led to his likely death in battle.

CONCLUSION

Too frequently, written narratives and narrative films (especially but not exclusively dominant Hollywood productions) portray disabled characters as either pathetic victims (some examples include Blanche Hudson [Joan Crawford] in *Whatever Happened to Baby Jane?* [1962] and Tiny Tim in *Christmas Carol* [adapted for the screen several times between 1938 and now]), courageous heroes (Christy Brown [Daniel Day-Lewis] in *My Left Foot* [1989]), avenging villains (Quasimodo [Lon Chaney initiated the film role] in

Hunchback of Notre Dame [repeatedly adapted for film between 1923 and 2002]), or minor metaphorical glosses to a more important ableist central narrative (e.g., Warren Jensen Matthews [W. Earl Brown] and Tucker [Lee Evans] in *There's Something About Mary* [1998] and Ronny [Nicholas Cage] in *Moonstruck* [1987]). However, the history of cinematic depiction of disability both in Hollywood and elsewhere differs from that of literature and other representational arts in part because of techniques such as lighting, framing, and editing that control the gaze of the film audience. In addition, the film industry and its domination by Hollywood renders film a unique example of visually imposed normativity. Disability roles can be the focus of a movie (e.g., Sam, played by Sean Penn in *I Am Sam* [2002] or Helen Keller, played by Patty Duke in *The Miracle Worker* [1962]) or can be tangential to the main plot (e.g., a character who happens to be deaf, such as the brother character, David [played by David Bower], in *Four Weddings and a Funeral* [1994]).

Frequently, filmmakers use disability to portray a character as essentially evil, the character's disability serving as bodily signifier to inherently "flawed" human characteristic (e.g., Elijah Price [Samuel L. Jackson] in *Unbreakable* [2000] or Arliss Loveless [Kenneth Branagh] in *Wild, Wild West* [1999]). As Robert Bogdan (1988) says about the depiction of such characters (quoting his young son) in *Freak Show: Presenting Human Oddities for Amusement and Profit,* "If they look bad, then they are bad" (p. 6). Almost as frequently, filmmakers portray the opposite; rather than presenting villains whose disabilities display their essential evil, many films depict "ordinary heroes" whose disabilities—in and of themselves—transform them into noble and dignified "better than average" characters (e.g., Ben Affleck's blind and therefore extremely physically adept do-gooder lawyer, Matt Murdoch, in *Daredevil* [2003] or the tormented yet dignified John Merrick [John Hurt] in *The Elephant Man* [1980]).

Recently, independent and documentary films have begun to explore a more rounded or complex representation of disability onscreen. *What's Eating Gilbert Grape?* (1994), although still predominantly focused on main character Gilbert (Johnny Depp), depicts his brother (Leonardo DiCaprio), who has a developmental disability, and their extremely overweight and reclusive mother (Darlene Cates) as major players in the film's narrative. The documentary narrative *When Billy Broke His Head . . . And Other Tales of Wonder* (1994) humorously adopts a road-trip format while portraying Billy Golfus's attempts to rejoin the workforce with a brain injury; as well, David Mitchell and Sharon Snyder's short film *Vital Signs* (1995) situates disability as a provocative site of culture and performance. The two documentaries *Forbidden Maternity* (2002) and *Face to Face: The Schappell Twins* (1996) portray "Othered" lives from the point of view of the subjects'—rather than the expected viewers'—point of view. More and more, such films work to undermine clichéd presentations of disabled characters at the same time as they achieve grounds for further filmic narrative explorations.

—Sally Chivers and Nicole Markotic

See also Charles Albert "Tod" Browning; Documentary Film, Normality; Representations of Disability, History of.

Further Readings

Bogdan, Robert. 1988. *Freak Show: Presenting Human Oddities for Amusement and Profit.* Chicago: University of Chicago Press.

Enns, Anthony and Christopher Smit, eds. 2001. *Screening Disability: Essays on Cinema and Disability.* Lanham, MD: University Press of America.

Klobas, Lauri E. 1988. *Disability Drama in Television and Film.* Jefferson, NC: McFarland.

Longmore, Paul. 1985. "Screening Stereotypes: Images of Disabled People in Television and Motion Pictures." *Social Policy* 16(1): 31–38.

Mitchell, David and Sharon Snyder, eds. 1997. *The Body and Physical Difference: Discourses of Disability.* Ann Arbor: University of Michigan Press.

Mitchell, David T. and Sharon L. Snyder. 2000. *Narrative Prosthesis: Disability and the Dependencies of Discourse.* Ann Arbor: University of Michigan Press.

Norden, Martin. 1994. *Cinema of Isolation: A History of Physical Disability in the Movies.* New Brunswick, NJ: Rutgers University Press.

———. 1997. "Hollywood's Disabled Vietnam Vet Revisited." Pp. 179–190 in *The Eye of the Beholder: Critical Perspectives in Popular Film and Television,* edited by G. Edgerton, M. Marsden, and J. Nachbar. Bowling Green, OH: Bowling Green State University Popular Press.

Pointon, Ann with Chris Davies. 1997. *Framed: Interrogating Disability in the Media.* London: British Film Institute.

FINANCIAL COSTS OF DISABILITY

Examining financial costs of disabilities from a number of different perspectives having to do with actual and opportunity costs, presented by the disability, is the focus of this entry. Analysis of who pays the costs for the treatment of the disability must also be understood. This entry also looks at factors involved when a decision is made to no longer pay the financial costs associated with disability and the impact on the society in which the person with a disability lives. Consideration of the factors involved in conceptualizing the extent and impact of the financial costs of disabilities is a useful exercise in promoting an understanding of the impact of disabilities on the individual and society.

Understanding the financial costs of disability requires examination of actual and indirect costs. This is a complex task, since the term *disability* means different things in different cultures and countries, and sometimes means different things within a culture and country.

DISABILITY DEFINED

In the United States, for example, the term *disability* is defined in a variety of ways in different pieces of federal legislation. Disability, as defined in the Ticket to Work and Work Incentives Improvement Act (TWIIA), relates to functional limitations that determine a person's eligibility for national vocational rehabilitation services (TWIIA 2001). Under the Americans with Disabilities Act (ADA), a disability implies real or perceived impairment, which may result in some discriminatory activity (ADA 2001). Disability under the Social Security Act means the inability to engage in substantial gainful activity because of a medically diagnosable impairment (Social Security Act 2001).

Similar legal and cultural discrepancies exist in the way the term *disability* is defined or treated within and among other cultures. The dialogue about disability centers around the concept that an individual has a disability when he or she has diminished physical, mental, or emotional capacity(ies) when compared with the population in which he or she lives. For example, the World Health Organization (WHO) defines disability as the functional limitation(s) secondary to a mental, physical, or emotional impairment (WHO 1980). Although cultural norms vary, the standardized approach to defining this diminished functional capacity would be a standard deviation or more below the mean of that culture on that functional limitation. In many cases, cutoff points are defined by formalized testing to justify qualification for programming or services.

From a societal perspective, existence of diminished capacities associated with disabilities threatens the decision-making abilities of those who have them. Therefore, persons with disabilities, whether they are children, adolescents, or adults, (often) have a diminished capacity to make binding decisions in regard to their lives (financial or otherwise), which is consistent with their non-disability-related state of life.

ACTUAL COST

Because people with disabilities, by definition, have a limitation in physical, mental, or neurological capacity, an accommodation to that diminished capacity needs to be made. For example, the societal burden of accommodating and treating mental illness was estimated to be more than $170 billion in the United States alone in 1990 (Rupp, Gause, and Regier 1998). In the U.S. Social Security system, total maintenance support income for consumers with disabilities (both Supplemental Security Income [SSI] and Social Security Disability Insurance [SSDI]) is estimated at $7.3 billion of the $70 billion Social Security Administration budget, or roughly 10 percent of the U.S. taxpayers' contribution to the Social Security system (Garske, Williams, and Schiro-Geist 1999).

Substituting, replacing, or adding to the usual and customary way things are done in order to accommodate a person with a disability also has cost. Often, the real cost of accommodation is not monetary. Rather, the cost is in the thinking and planning process associated with creation of an appropriate appliance, therapy, or program that makes the accommodation functional. Application of the thought process can often be done with little cost. In returning a person with a disability to work, 90 percent of the accommodations required end up costing $500 or less (Geist and Calzaretta

1982). This cost can be borne by the employer or the potential employee or by some external benefactor such as the state/federal system of vocational rehabilitation in the United States.

Medical costs and therapeutic interventions are also borne by the person with a disability, his or her family, or society. In countries without national health care, this can become an overwhelming burden on the family system. To respond to this burden, persons with disabilities are often emancipated from their family situation to allow the shift in therapeutic intervention from the individual/family to societal responsibility.

In the United States, for example, the SSDI program evolved to an income maintenance program from the original concept of holding benefits consistent from the point of disability to the usual retirement age of 65+. SSI evolved in the 1970s as a general welfare program for adults. Benefits from this program have since been extended to include children with disabilities who have not contributed to the pension system to earn the benefits of this insurance-based system. The amount of maintenance provided for SSI recipients is subject to the generosity of the U.S. Congress.

In other countries, reliance on government support rarely guarantees an amount consistent with even a substandard level of gainful support. The expectation exists that some other part of society, usually the family, will help support the person with a disability who is not working. In some countries, persons with disabilities are considered "lucky" to have any kind of regular income maintenance, and the income maintenance payment itself becomes a disincentive to competitive employment.

Examination of disability cost extends beyond medical services. Persons with disabilities in many cultures and countries receive special vocational support and administrative services (Schiro-Geist 1992). Service delivery systems vary from centralized or decentralized depending on the size and structure of the country. The costs also vary greatly depending on the availability of other benefits such as free or low-cost educational services, attendant care, housing, and administrative costs. Analysis of international costs of nonmedical expenditures is hampered by inconsistent availability of data.

In addition to the more obvious physical disabilities, mental disabilities financially tax society. Individuals with mental disorders make up the largest single disability group in the United States. Services for this group absorb one-quarter of all federal disability funding. Provision of direct services for this population accounts for more than $69 billion in annual costs in the United States. Indirect costs such as social disruption and loss of productivity were estimated to account for an additional $78.5 billion annually. These direct and indirect costs include income maintenance, disability-related costs such as case management, rehabilitation service costs, and work-related cost containment. Although advances in treatment for mental health problems are being made, the amount spent on mental health research is disproportionately low when compared to other research in the life sciences (Rupp et al. 1998).

In Western countries, which will soon see the full effect of the aging baby boomer generation, the fear of disability-related costs looms large. There is limited discussion about the reality that this increased cost to society will also result in increased production of goods and services consistent with the increased need of the majority aging population.

When totaling the cost of disability, one should attend to the profit accrued by components of disability-based industries. The population of persons with disabilities requires a variety of drugs, appliances, therapies, and support to function. Producing these products and services is done at a profit. Vendors of products as well as service providers live and run their businesses based on the needs of people with disabilities, borne by themselves, their families, and society. This often overlooked contribution to the gross national product, created by the disabled community, is one to be reckoned within any national economy. Many people with disabilities report only limited income for fear of losing their maintenance payment. They contribute to the national economy of a country with the goods and services produced through their "shadow economy" of work products and services rendered but not reported and taxed. Economists can only estimate the value of this disability shadow economy related to disability for a country and assume it to be a major contribution. Removal of the costs and benefits connected with people who have disabilities would undoubtedly affect the productivity of the country.

OPPORTUNITY COST

In addition to the actual costs accrued for goods, services, and income maintenance, there are costs to the person with a disability, his or her family, and society. These include lost opportunity, time, status, and often diminished return on benefits. People with disabilities are prohibited from doing things that they want to do and families and society assume the responsibility to provide for (whether or not they want to) the functional limitations created by disabling conditions.

The perception exists that people with disabilities are a negative financial influence on society or weigh society down. This creates stigmatizing values. These values lead to the conclusion that the person with a disability creates a huge financial drain on society because things have to be done for them or to them and these costs would otherwise not accrue to society as a whole. This misperception may come from the lower socioeconomic position of many people with disabilities. If people with unlimited financial resources have someone do their laundry, clean their house, do their shopping, and even dress them, there is less stigmatization. The wealthy person commands respect in spite of being dependent on a host of people to maintain his or her status. When a person with a disability of lower means requires or uses the same services, however, that person is seen as a burden on society even if the person is paying for the services.

TERMINATION OF PAYMENT OF COST

Society, to contain the ever rising and inflating costs, often puts caps on direct and indirect costs. In countries with national health care policies, there are age limitations on treatment offered to persons with potentially terminal disabilities. Medicare, the major insurer for retired persons in the United States, has caps on the amount of payments made for a variety of medical problems. Some states in the United States are moving toward limitations on all but palliative care for persons over age 80. Persons with private insurance or unlimited personal resources can continue to access treatment and services that are limited in the public domain. This highlights the inequity of disability support for persons based on their socioeconomic status.

SUMMARY

Just as the term *disability* varies in definition across and within countries, so does an estimate of the financial cost of the disability vary depending on the perspective of the analyst. The costs of the disability can be seen as a negative drain on a society, especially if the society or culture views disability in a negative way. However, the financial costs connected to disability can also be perceived as a positive influence from the perspective of the disability industry as an active economy within the larger gross economy of a country.

—Chrisann Schiro-Geist and Emer Dean Broadbent

See also Economic Analysis of Disability; Health Management Systems; Quality of Life.

Further Readings

Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq. (2001).

Garske, G., B. Williams, and C. Schiro-Geist. 1999. "The Financial Costs of Mental Illness." *Journal of Rehabilitation* 65(4): 39–44.

Geist, C. and W. Calzaretta. 1982. *Placement Handbook for Counseling Disabled Persons.* Springfield, IL: Charles C Thomas.

Rupp, A., E. M. Gause, and D. A. Regier. 1998. "Research Policy Implications of Cost-of-Illness Studies for Mental Disorders." *British Journal of Psychiatry* 123(Suppl. 36): 19–25.

Schiro-Geist, Chrisann. 1992. *Vocational Counseling for Special Populations*. Springfield, IL: Charles C Thomas.

Social Security Act, 42 U.S.C. § 301 et seq. (2001).

Ticket to Work and Work Incentives Improvement Act of 1999, 42 U.S.C. § 301 et seq. (2001).

World Health Organization. 1980. *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease.* Geneva: World Health Organization.

FINANCIAL PLANNING

See Economic Decision Making by the Disabled

FLEURY, VICTOR (1800–1856)

French author and school administrator

Victor Fleury was born in France and moved to St. Petersburg in 1817. He began as a teacher of the deaf

and then became director of St. Petersburg School for the Deaf (1838–1856). He authored the book *Deaf-mutes* (1835), which described methods of instruction and analyzed sign language of the deaf.

—Anna Komarova

FOLK BELIEF

Folk beliefs are often cautionary tales that locate misfortune, accidents, and unexpected events in human causes, and people who seem different from others appear most frequently as these causes. Fairy tales and folklore recount the adventures of human beings with creatures who seem less or more than human: witches, nature spirits, fools, trolls, dead ancestors, speaking and singing animals, shape-shifters, zombies, ogres, giants, and dwarfs. Superstition holds that people with the evil eye harm with a glance, that hunchbacks bring good luck, and that diseased or deformed children are changelings substituted for a human child. Some figures of folk belief, of course, are neither less nor more than human. They are simply human beings who present some form of mental or physical disability. The creatures of folk belief include the seeing and hearing impaired; twins; people with achondroplasia, epilepsy, birthmarks, or birth defects; and those simply deemed more ugly than others by social convention.

Folk belief represents disability as a curse or punishment, a symbol of sin and disgrace in the family, or a sign of impending disaster, and people with disabilities are said to have malignant influence over other people or to possess magical powers. The world of folk belief is a world of human difference often explained to the detriment of disabled people.

The reliance of folk belief on disability is at once obvious and little discussed. Gods, cultural heroes, magical beings, and their adversaries bear marks of bodily and mental impairment that echo or exaggerate common disabilities. Divinities are routinely portrayed in folklore as possessing a surplus or deficit of organs. In Hindu folklore, gods have six faces; in China, three faces; in Jewish lore, five faces. Hindu and Chinese legends tell of gods with many eyes, while Tonga folk belief describes a god with eight mouths. In India, Tahiti, Hawaii, and Russia, divinities possess many heads, but they are legless or armless in Borneo. Irish and Greek legends describe one-legged and lame gods. A cultural hero of the Maori has different-colored eyes, while Irish legend pictures a hero with seven pupils in each eye. Oedipus has a clubfoot in Greek myth, and Balor of Ireland possesses an evil third eye. When gods or cultural heroes do not have a disability, they may pretend to have one for the purpose of humble disguise. In England and Ireland, fairies have unusually long ears or hair, or they might possess hairy bodies, a long tail, half a thumb, or red eyes. Changelings are recognized by large teeth, a thick neck or skull, and congenital disorders. Ogres are blind in Iceland and one-eyed in Ireland, while other minor villains of folklore present a broad variety of disabilities and bodily differences, including being one-eyed in Jewish, Irish, and Chinese superstition; toothless in India; and left-handed among the Inuit.

The most common superstitions attribute to ordinary people exceptional powers based on unusual characteristics. The evil eye, for example, is a folk superstition evident in nearly every world culture, both archaic and modern. It expresses the belief that certain people may pass illness, do harm, or cause accidents with a look. Those accused of possessing the evil eye are often disabled or distinguished physically or mentally in obvious ways. Eye disabilities such as lesions, corneal scars, and strabismus increase the chance of being accused of possessing the evil eye, as do squinting or red eyes. Eye color may also affect the possibility of being accused. In regions where an eye color is rare—for example, green eyes in the Middle East—that color is inevitably associated with the evil eye. The idea that an evil or envious eye that disapproves of wealth or beauty causes accidents, injuries, and disabilities is seen as the products of malignant wishes or curses. Moreover, the evil eye superstition explains that certain illnesses and deformities may be passed from person to person through the medium of the eyes. The cleft palate takes its common name, harelip, not only from its resemblance to the lips of the hare but also from the belief that a pregnant mother may pass the feature to her child if she sees the animal. Folk belief explains common birth

defects as impressions passed to child from mother when she looks too intensely at her surroundings.

Many other folk beliefs are based on congenital disabilities, appearances deemed ugly, cognitive disabilities, or physical and mental characteristics uncommon to a given population. Scholars argue that people with epilepsy or catatonia provide the model for the belief in zombies in Haiti. A host of exaggerated beliefs surround the seeing impaired, often representing them as possessing magical or malignant influence. On the one hand, the blind are routinely said to possess second sight or clairvoyance, as in the case of the blind prophet Tiresias of Greek mythology. Folk beliefs also suppose the blind to be more impartial judges than other people because appearances do not deceive them. On the other hand, blindness symbolizes evil, sinfulness, ignorance, avarice, or self-delusion. Leviticus 21:18 forbids the blind from entering the temple, and Jewish legend calls Satan "the blind one." Superstition holds that the evil eye produces blindness or that the blind may transmit their impairment if they accidentally look into the eyes of a sighted person.

In general, the appearance of disability foretells evil or impending disaster. Dwarfs are universally credited with malignant powers. Their lack of growth represents ignorance in Hindu myth, and they are often described by other folk traditions as jealous or miserly hoarders. Animals offered for sacrifice in Greek and Jewish belief must be unblemished, and the lame, blemished, or disfigured are often forbidden from appearing in places of worship. The birth of monsters signals the end of the world in Jewish mythology. In soothsaying, the birth of a child without nostrils portends that a country will enter a period of affliction, while the birth of a child without fingers prophesizes mass infertility. However, the presence of disability may also herald favorable times. Rubbing the back of a hunchback is thought to promise good fortune. Touching cripples or giving them alms ensures good luck.

Folk beliefs throughout the world characterize disability or deformity as a punishment for sinful or improper behavior. Blindness is characterized as God's will or a punishment for promiscuity or immorality. In folk belief, people are often struck speechless as a punishment for misbehavior. In Ireland and Iceland, paralysis is a frequent punishment. Curses produce leprosy in India, loss of an eye in Ireland, and the head to drop off in the United States. They lead to stillbirths in India and sick children in Canada. In Ireland and the United States, monstrous births are a punishment for pride, while in China and Greece incest causes misshapen children. Folklore also attributes the forms of animals to misbehavior: The flounder was punished with a crooked mouth for discourteous speech; the crab has eyes in the back of its head and the hare a cleft lip as punishment for speaking rudely or out of turn.

Folk humor reserves a special place for disabled people. Folklore makes fun on many occasions of misunderstandings caused by deafness. It also recounts numerous stories about the blind leading the blind to ridiculous effect or about duping blind people for a good joke. The fool is a universal figure in the disability humor of folklore. Taking advantage of fools, duping them into injuring themselves, or laughing at their stupidity are recurring motifs in world mythology, showing that folk belief is preoccupied with mental as well as physical disability. Other human characteristics ridiculed by folk humor include long noses, stuttering and speech impediments, ugliness, lameness, fatness, and small stature. Folk belief provides a convincing catalogue of the human propensity to mock unusual people or to make them the butt of a joke.

People with disabilities would seem to have little in common with the creations of folk belief and superstition. The fantastic worlds of folklore are populated by mythological gods, witches, monsters, magical heroes, and supernatural villains such as the possessor of the evil eye. But the worlds of folk belief and human difference collide when the need to account for misfortune and accidents places blame on people who do not seem to fit the norms of appearance and ability dictated by society. It is a small step from the human diversity of disability to the supernatural differences of folklore, mythology, and superstition.

—Tobin Siebers

See also Changeling; Deformity; History of Disability: Medieval West; Norse Sagas.

Further Readings

Eberly, Susan Schoon. 1988. "Fairies and the Folklore of Disability: Changelings, Hybrids and the Solitary Fairy." *Folklore* 5:58–77.

Siebers, Tobin. 1979. "The Blindspot in Descartes's *La Dioptrique*." *Modern Language Notes* 94(4): 846–853.

———. [1983] 2000. *The Mirror of Medusa.* New Zealand: Cybereditions.

Thompson, Stith. 1955–1958. *Motif-Index of Folk-Literature.* 6 vols. Copenhagen: Rosenkilde and Bagger.

Wagner-Lampl, A. and G. W. Oliver. 1994. "Folklore of Blindness." *Journal of Visual Impairment and Blindness* 88:267–276.

FOLLY LITERATURE

See Literature, Folly

FOOLS

The origin of fools is uncertain. During the Middle Ages and Renaissance, fools played various roles. They were merrymakers at court, had their own "fool-societies," and particularly played their roles during the time of carnival. At the end of the Middle Ages and in the beginning of Renaissance, literature often used foolishness as a metaphor to describe the radical changes taking place in religion, economy, politics, and culture.

In late medieval times, particularly at court, fools were separated into natural and artificial fools. To the latter, merrymakers and jesters such as the German Kunz von der Rosen, the Italian Gonnellas, or the French Brusquet belonged. They were expected to act in foolish ways to make people laugh. To fulfill this aim, they performed comic and obscene productions and mimicry. Artificial fools were laughed at and laughed with. In contrast, natural fools were only laughed at. They were objects of mockery, adoration, and, in later times, pity. From the perspective of disability studies, natural fools are the more interesting topic.

Until the Enlightenment, natural folly was understood as a mental difference that was congenital. It was perceived neither as a mental disease nor as a changeable condition of human being. Instead, mentally challenged people were interpreted as a category in their own right. According to the Dominican friar and theologian Thomas Aquinas (1225/27–1274), natural folly was not a sin but a natural disposition. Natural fools belonged to the "marvelous" human beings, as the fourteenth-century encyclopedist Konrad von Megenberg (1309–1374) put it in his *Buch der Natur* (*Book of Nature*).

Marvelous human beings were divided into two different groups: marvelous people and monstrous individuals. Marvelous people were thought to live at the "end of the world." It was assumed that they were different from the European type of mankind and formed their own cultures with their own rules and customs. Monstrous individuals, showing selective physical or mental deviations, were also regarded as marvels. These individuals were seen as divine beings whose purpose was to warn mankind about forthcoming evil events.

Within this categorization, natural fools did not belong to the group of marvelous people but to the one of monstrous individuals. Courts kept natural fools and made them live in special conditions. They were treated like children and often exposed to physical violence. They could be laughed at and were allowed to say nearly anything. They did not own property nor did they get any wages, as was the case with their artificial counterparts.

Written evidence about natural fools is rare. Few records only reveal nicknames or first names. Some bills are preserved, but they simply state the cost of clothes or, in some cases, the salary for the fool's waiter. In general, natural fools had to be looked after, since they were not held responsible for any damage they did. According to various laws such as the German *Sachsenspiegel*, fools and mentally ill people could not be judged. Any cost of damage caused by them had to be paid by their guardian (*Sachsenspiegel*, III, 3: "ouer rechten doren unde sinnelose lüde en scal men oc nicht richten. wenne se auer scadet ere uormünde scal dat geldene").

Outside the courts, people designated as natural fools lived with their families at home or sometimes in special institutions. In Germany, these institutions were named *Narrenhäuser* (fools' homes) or *Torenkisten* (fools' boxes). In these asylums, fools were locked away together with the mentally ill, drunkards, or men who visited whorehouses. These inhabitants were supposed to be dangerous to themselves or society

and were therefore put away in special institutions. For admittance, a medical diagnosis was not required; therapy was not offered, either. If families could not afford to look after their temporarily or permanently mentally impaired members, they brought them to the *Narrenhaus* (fools' home). Fools from foreign towns were also kept in these asylums, but only for a short time before being sent home again. Towns even used ships to get rid of foreign fools. However, there never were any "ships of fools" aimlessly traveling around the country as the French philosopher Michel Foucault falsely described it in his book *Madness and Civilization*.

During the sixteenth century, natural fools were increasingly kept as "marvels of nature." In various courts, marvelous and miraculous objects such as precious stones, ostrich eggs, whale bones, and peculiar plants were collected. Even humans belonged to these "cabinets of curiosity." As marvelous objects they were not only thought to have material value but magic forces, too. Like the religious relics, which often were the basis of these collections, the objects represented their aristocratic possessor's power and uniqueness. At court, physically different people, such as dwarfs, giants, or people with dark or hirsute skin, were kept as living attractions. Natural fools were collected as well because of their different mental abilities. In contrast to the fifteenth century, they were no longer exclusively laughed at, but also adored, like the "folyshe Duke at Lancaster." He was the first natural fool taken by Henry VII (1457–1509) on his formal progress to Sittingbourne in 1492. Other natural fools also accompanied English kings on their formal progresses. This tradition was practiced until James I (1566–1625). The illustrated Triumph progress of the Holy Roman emperor and German king Maximilian I (1459–1519) at which artificial fools as well as natural fools were shown can serve as a further example of the fools' increasing value at the beginning of the sixteenth century. The emperor outlined his Triumph himself: He included not only pictures about his life and genealogy but also about his fools.

Natural fools were also used as presents. A natural fool named Sexton was given to Henry VIII (1491–1547) by Cardinal Wolsey in exchange for a ring. The fool was described as "for a nobleman's pleasure he is worth a thousand pounds." Details about his life are preserved because, like other fools, he was counted as part of the King's Privy Chamber. According to Cavendish's "Life and Death of Cardinal Wolsey," the fool himself did not want to be separated from his former possessor, Cardinal Wolsey. "Six tall yeomen" were needed "to conduct and convey the fool to the court."

During the sixteenth century, it was even discussed whether mocking natural fools should be prohibited. Paracelsus (1493/94–1541) among others believed that divine messages embodied by the fools could not be read if they were vexed. Fools such as the German Claus Narr were expected to show insight and prophecy. Natural fools belonging to the so-called monstrous individuals were seen as prodigies. Their behavior was interpreted as containing divine messages. However, in contrast to physically different "monstrous" individuals, it was said that the divine signs made by natural fools could not be seen from the outside. It is told that once Claus Narr divided a precious coat. His action was interpreted as a warning to the Saxon sovereigns not to divide their country. During the sixteenth century, insight and prophecy were no contradictions to mental diversity.

At the end of the eighteenth century, the exclusion of mentally impaired people from society—analyzed by Foucault in his book *Madness and Civilization*—also had an impact on natural fools. The Enlightenment saw natural folly declared a treatable mental sickness and the focus of medicine and pedagogy. Natural folly became an object of different scientific approaches and lost its marvelous characteristics.

—Ruth von Bernuth

See also Folk Belief; Literature, Folly.

Further Readings

Cavendish, George. 1961. *The Life and Death of Cardinal Wolsey*. Edited by Richard S. Sylvester. London: Oxford University Press.

Daston, Lorraine and Katharine Park. 1998. *Wonders and the Order of Nature 1150-1750*. New York: Zone Books.

Foucault, Michel. 1965. *Madness and Civilization: A History of Insanity in the Age of Reason*. New York: Pantheon.

Midelfort, H. C. Erik. 1999. *A History of Madness in Sixteenth-Century Germany*. Stanford, CA: Stanford University Press.

Southworth, John. 1998. *Fools and Jesters at the English Court*. Stroud, UK: Sutton.

Velten, Hans Rudolf. 2001. "Komische Körper. Hofnarren und die Dramaturgie des Lachens im späten Mittelalter." *Zeitschrift für Germanistik N. F. XI (N. F. = Neue Folge), S*. 292–317.

Welsford, Enid. 1935. *The Fool: His Social and Literary History*. London: Faber & Faber.

FOUCAULT, MICHEL (1926–1984)

French philosopher

Michel Foucault's work is immense, exploring extremely diverse fields, and it is read and commented on throughout the entire world. Here, only a few aspects that concern the sphere of disability will be reviewed. *The History of Madness in the Classical Age* (1961) inaugurated his major inquiries into the production of truths and bodies of knowledge but revealed less about the institutionalization of "disorders" (poverty, infirmity, madness, social marginality) than about the new relationship between reason and unreason, the creator of a radical madness and of the mad without remission. It would take a century and a half after the founding of the General Hospital by Louis XIV (1656) for madness to be considered curable (Philippe Pinel), and unreason came to be viewed as one more manifestation of the human mind. For all those concerned with the archaeology of madness and its treatments, Foucault's book remains obligatory reading and an academic *rite de passage.* In 1974–1975, Foucault (1999) devoted his classes at the Collège de France to the "abnormal" (*les anormaux*): the monster, the incorrigible, and the onanist. As concerns monstrosity, his views are consistent with those of Georges Canguilhem, but for Foucault, it is essential to show that social categories no longer function, while disability, even when upsetting the natural order, still has its place in law. Yet it may be confused with monstrosity and so be exiled from the common social space.

—Henri-Jacques Stiker

See also Body, Theories of; Georges Canguilhem; Mental Illness.

Further Readings

Foucault, Michel. 1999. *Les anormaux* (The Abnormal). Paris: Gallimard, Le Seuil.

FRAILTY

The term *frail elderly* is accepted in the medical community to refer to a physically weak older person who is susceptible to disease. Geriatricians are trying to develop a working definition of frailty so that it relates to measurable physical attributes and functionality. Although debates continue about whether it is possible to diagnose "frailty," the term serves to differentiate those older individuals who require specific care from those who appear to function without assistance and without impediment to their regular daily activities (as defined by the medical establishment). Although literary gerontologists such as Kathleen Woodward and Margaret Morganroth Gullette have argued that the elderly are mistakenly interpreted as always already weak and in decline from their youthful vibrant selves, the need within medical parlance for a distinguishing adjective indicates that "elderly" itself does not denote frailty. That is, it suggests that a robust late life is possible.

Given the diagnostic tests recently developed by Thomas M. Gill, however, the addition of the adjective *frail* also implies that physical disability in late life is a marker of weakness. Gill's tests consist of asking patients to stand up from a chair without the assistance of one's arms and to walk a measured distance at a normative pace. Of course, people with disabilities of all ages may score as frail under these tests when they do not really match the criteria geriatricians seek to measure. The attempt to measure frailty through physical function does not capture the impact of normal daily activities as desired by the geriatric community. Furthermore, while *frail elderly* is wielded selectively within the medical and gerontological communities, laypeople often assume *frail* and *old* to be interchangeable. The broader usage of the term and implications of frailty, such as referring to an older woman as a "little old lady," support the findings of age scholars in the humanities and social sciences. As demonstrated in the well-known usage "Frailty, thy name is woman," *frail* connotes delicacy, unreliability, and moral corruptibility capturing the ways in which people with "extraordinary" bodies are interpreted as socially suspect on a number of fronts. Although it has been interpreted as meaning physical fragility in contemporary contexts, frailty in this sense refers to the tendency of women to be unfaithful in love. The ascription

of frailty to older people who essentially fail to remain young, then, fits into a long-standing context of depicting people with physical disabilities and nonnormative physical functionality as though they are immoral.

—Sally Chivers

See also Aging; Aging, International.

Further Readings

Becker, G. 1994. "The Oldest Old: Autonomy in the Face of Frailty." *Journal of Aging Studies* 8(1): 59–76.

Bortz, Walter M., II. 2002. "A Conceptual Framework of Frailty: A Review." *Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 57a(5): 283–289.

Chater, Keri. 2002. "Aging: A Body of Resistance." *Nursing and Health Sciences* 4(3): 123–130.

Dowling, Colette. 2000. *The Frailty Myth: Women Approaching Physical Equality.* New York: Random House.

Ho, Laura S., Harriet G. Wells, and Emily A. W. Hardwick. 2002. "Discriminating Characteristics of Community-Dwelling Elderly at High and Low Risk for Frailty." *Journal of Aging and Physical Activity* 10(4): 413–432.

Lachs, Mark S., and Pamela Boyer. 2003. "Head Off Trouble." *Prevention* 55(4): 160–163.

Morley, John E., H. Mitchell Perry III, and Douglas K. Miller. 2002. "Something about Frailty." *Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 57a(11): 698–706.

Rockwood, Kenneth J. 2002. "Out of the Furrow and into the Fire: Where Do We Go with Delirium?" *CMAJ: Canadian Medical Association Journal* 167(7): 763–770.

Website

The Program of All-inclusive Care for the Elderly (PACE):
National PACE Association, 801 N. Fairfax Street, Suite 309, Alexandria, VA 22314.
http://www.npaonline.org/
The Program of All-inclusive Care for the Elderly (PACE) model is centered around the belief that it is better for the well-being of seniors with chronic care needs and their families to be served in the community whenever possible.

FRANCE

See Advocacy Movements: France

FREAK SHOW

The term *freak* appears to be descended from the Old English word *frician,* to dance. *Freking*, for the medievals, was a form of cavorting, sudden movement, or capricious behavior. During the craze for scientific classification of the eighteenth century, as naturalists attempted to find specific categories for all life forms, organisms that failed to match a perceived species average were often referred to as *lusus naturae,* "cavorts" or "freaks of nature." In the early nineteenth century, certain naturalists toured Europe and America with examples of exotic or unique animals, charging admission to view their "cabinets of curiosities." Humans with bodies that were perceived to deviate significantly from an understood norm were often grouped with these *lusus naturae* shows, and so developed a variety of different performance genres that became collectively known as the freak show.

"Freak show" was a very general category that could refer to nontheatrical exhibits such as fetuses in jars ("pickled punks") or exotic or deformed animals as well as exhibitions of human "curiosities." In this context, *freak* was considered a relatively odious way of referring to humans, in performance or not, and was rarely used by professional performers or promoters until close to the end of the nineteenth century, after the death of Phineas Taylor (P. T.) Barnum (Barnum was never once known to use the term himself; see below). Favored alternatives were "raree show," "pit show," "kid show," and "ten-in-one."

Freak performers were present in America as early as 1738, but these freaks were not highly professionalized, and they appeared more often in the context of scientific lectures than theatrical performance, possibly as a means of evading colonial anti-theater laws. During the middle part of the nineteenth century, freaks gained great legitimacy, respectability, and profitability by performing their acts within the context of a new form of American entertainment known as the Dime Museum.

In 1835, Joice Heth, ostensibly a 161-year-old African American woman who had been the nurse of George Washington himself, was exhibited in the hall of a hotel in Bridgeport, Connecticut. She was a tremendous success, partially because of her flamboyant promotion, partially because her tales of Washington's youth were, reportedly, told with such integrity and intimacy that a controversy over her true identity was kept alive for decades. The controversy

was resolved when an autopsy revealed she was merely 80, but Heth's fame only increased after her death. Skillful protestations of innocence on the part of her manager, P. T. Barnum, resulted in widespread publicity and interest.

Following his success with Heth, Barnum became a promoter of theatricals and the emerging variety entertainments. In 1841, Barnum purchased Scudder's American Museum on the corner of Broadway and Ann Street in downtown New York City; this moment is considered to be the beginning of the "Golden Age" of the freaks, which would persist until the 1940s. Among the human curiosities at the museum were the notorious and controversial Broadway actor Hervey Leach (also known as Hervio Nano), Mlle. Fanny (who turned out to be a perfectly normal orangutan), Native American and Chinese "families," giants such as Jane Campbell ("The largest Mountain of Human Flesh ever seen in the form of a woman"), a 220-pound four-year-old known as the Mammoth Infant, giantess Shakespearean actress and "sentimental soloist" Anna Swan, giant Captain Martin Bates, Isaac Sprague the "Living Skeleton," R. O. Wickware the "Living Phantom," a variety of dwarves, the famous "Albino Family," African Americans with vitiligo, the armless wonder S.K.G. Nellis, a cadre of sexually ambiguous persons such as bearded ladies and hermaphrodites, clairvoyants, "Lightning Calculators," and many, many others. Without question, the greatest of all the American Museum's stars was Charles Stratton, better known as General Tom Thumb. The General appeared not in the traditional "pit show" or "cabinet of curiosities" format but was celebrated around the world as a talented actor of highly theatrical, expensively produced melodramas, and appeared in performances before American presidents and industrial barons as well as the royal sovereigns of Europe and Asia.

By 1860, the human freak, appearing in the museum, on the legitimate stage, or in carnival sideshows (so named because they required a separate fee for entry from the main circus or carnival midway), had become one of the chief attractions for American audiences. A major moment in this period was the "Revolt of the Freaks" in 1898, when a collection of the 40 or so most famous freaks in the world staged a labor strike while on tour in London, demanding that the management of Barnum and Bailey's remove the term *freak* from promotional materials for their shows. A nationwide campaign to produce a new name was instigated, and the term *prodigies* was adopted by the "Council of Freaks." The intensity of this controversy reflected and magnified the popularity of freak shows, even though the whole event was probably nothing more than a publicity stunt.

In the middle of the twentieth century, the freak show began to suffer a major decline in popularity. Many factors combined to this decline; certainly the emergence of the medical model of disability, which replaced the freak show's narrative of wonder with one of pathology, made freak shows seem to be celebrations of disease, but advances in mechanical ride technology (rides were cheaper to run and more profitable than freak shows) and the rise of cinema and television were probably even more significant to ending the Golden Age of the freaks.

The use of the term *freak* did not diminish as freak shows became less prevalent in the latter part of the twentieth century, although its connotation suffered a sea change. The most common use of *freak* in modern American English refers to anything that appears in contrast to expectations, as in "a freak hailstorm," "a freak allergic reaction," or a person whose behavior is bizarre or unconventional, as in "an acid freak," or obsessive, as in "a computer freak." In the 1960s, the pejorative was appropriated by those who sought to celebrate an intentional rejection of conventional, conformist ideals by "Lettin' Your Freak Flag Fly." *Freak* entered American slang in the late 1970s with an undoubtedly positive spin: "Le Freak, C'est Chic," sang disco group Chic on a 1978 Atlantic Records hit to describe a joyful dance, while Rick James's "Superfreak" described a desirable woman in his 1981 funk album *Street Songs.* Nevertheless, *freak* continued to be applied pejoratively to disabled persons.

Freak show performance has a complicated relationship to disability; not all freaks were persons with disabilities, and activists of the disability rights movement have tended to avoid *freak* as a term of hatefulness. Eli Clare, activist and author of *Exile and Pride,*

wrote: "Unlike *queer* and *crip,* [*freak*] has not been widely embraced in my communities. For me *freak* has a hurtful, scary edge; it takes *queer* and *cripple* one step too far; it doesn't feel good or liberating."

Two of the twentieth century's most well-known professional carnival personalities, Priscilla the Monkey-Girl and Half-Girl Jeannie Tomaini, reported that they had "problems" with being referred to as *freaks.* The tension between freaks and disability rights came to a head in 1984, when disability rights activist Barbara Baskin successfully lobbied the New York State Fair to remove Sutton's Incredible Wonders of the World Sideshow, featuring the beloved performer Otis Jordan (a limbless man who performed as the "Frog Boy") from the midway.

More recently, however, activists have argued that the "Geek Love" mentality (referring to the title of the 1989 freak show novel by Katherine Dunn) is generating a desire even among "norms" to "freakify" themselves with piercings and tattoos. To the Geek Love advocates, the freak show signifies a celebration of human difference, which includes a politically motivated rejection of normality and conformity. Geek Love has, in fact, come to connote "disability pride" among certain disability activists.

In the twenty-first century, the freak show persists in America as part of the avant-garde underground circus movement. One chief practitioner is the highly regarded director and circus performer Jennifer Miller. Coney Island's "Sideshow by the Sea" maintains the classic ten-in-one freak show approach and includes many forms of bizarre entertainment. Freak show imagery and history are also increasingly used in avant-garde performance, visual art, cinema, and music, notably including the 2004 HBO television series *Carnivàle* and the popular *Jim Rose's Circus Sideshow.*

—Michael M. Chemers

See also Body, Theories of; Film.

Further Readings

Adams, Rachel. 2001. *Sideshow USA: Freaks and the American Cultural Imagination.* Chicago: University of Chicago Press.

Bogdan, Robert. 1988. *Freak Show, Presenting Human Oddity for Amusement and Profit,* Chicago: University of Chicago Press.

Dennett, Andrea Stulman. 1997. *Weird and Wonderful, the Dime Museum in America.* New York: New York University Press.

Thomson, Rosemarie Garland, ed. 1996. *Freakery, Cultural Spectacles of the Extraordinary Body.* New York: New York University Press.

Thomson, Rosemarie Garland. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature.* New York: Columbia University Press.

FREUD, SIGMUND
(1856–1939)

Austrian neurologist and psychoanalyst

Born in 1856 in a caul, an event that he believed guaranteed his future fame, Sigmund Freud invented psychoanalysis and established the direction of modern psychology. *The Interpretation of Dreams* (1900) elaborates his theories that the mind has both conscious and unconscious dimensions, that dreams seek the fulfillment of wishes, and that human beings are socialized under the pressure of an Oedipal triangle that places in conflict the desires of father, mother, and child. Freud devised the psychoanalytic session in which patients reveal the first thoughts that enter their mind as a mechanism for unlocking the unconscious basis of their mental problems. Freud's most enduring influence on the study of disability was to develop 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 actions or repressed desires. In 1914, he further connected mental and physical states with the concept of narcissism, a pathology of self-love, whose theory also explains that bodily injuries prevent neurosis but make one susceptible to more serious narcissistic disorders such as megalomania or paranoia. Freud's last theories divide the mind into the ego, id, and superego where the demands of the social world struggle with those of libido and conscience to determine the mental and physical health of the individual. Freud's death in 1939 was physician-assisted by a dose of morphine to relieve suffering caused by cancer of the mouth.

—Tobin Siebers

See also Narcissistic Personality Disorder; Neurosis; Normality; Psychiatric Disorders; Psychiatry.

Further Readings

Cubbage, Maxwell E. and Kenneth R. Thomas. 1989. "Freud and Disability." *Rehabilitation Psychology* 34(3): 161–173.

Jacobson, Edith. 1959. "The 'Exceptions': An Elaboration of Freud's Character Study." *Psychoanalytic Study of the Child* 14:518–534.

Siebers, Tobin. 2002. "Tender Organs, Narcissism, and Identity Politics." Pp. 40–55 in *Disability Studies: Enabling the Humanities,* edited by Sharon L. Snyder, Brenda Jo Brueggemann, and Rosemarie Garland Thomson. New York: Modern Language Association.

FULLER, MARGARET (1810–1850)

American journalist

Margaret Fuller was an American journalist and Transcendentalist writer. Fuller's experience with disability was both personal and familial. She had chronic severe migraines of which her friend, Ralph Waldo Emerson, said, "She read and wrote in bed, and believed that she could understand anything better when she was ill. Pain acted like a girdle, to give tension to her powers." Her youngest brother, James Lloyd Fuller (b. 1826), had mental disabilities that seemed to combine elements of intellectual disability and mental illness—at the time he was called slow, lunatic, eccentric. When she left home for her writing career, she maintained a strong interest and responsibility for Lloyd's well-being, arranging jobs, clothing, and housing for him or sharing her own rooms with him during some periods. Margaret Fuller took a professional interest in disability as well. She wrote about the salutory effects of community living, with a romantic view of caregiving and resignation to one's fate as a moral opportunity and moral example to others. She wrote glowing reports from France about advances in education for people with developmental disabilities, and she described the Bloomingdale Asylum for the Insane in articles (1845–1846) for the *New York Daily Tribune.*

—Penny L. Richards

See also Progressive Era Women in Special Education.

Further Readings

Davis, Cynthia J. 1999. "Margaret Fuller, Body and Soul." *American Literature* 71(1): 31–56.

Hudspeth, Robert N., ed. 1983–1994. *The Letters of Margaret Fuller,* 6 vols. Ithaca, NY: Cornell University Press.

FUNCTIONAL ASSESSMENT

A gerontologist in Philadelphia, M. Powell Lawton, wrote in 1971 the first definition of *functional assessment*. He said that functional assessment was any systematic attempt to objectively measure the level at which a person is functioning in a variety of domains. Functional assessment, as a scientific endeavor, was slow to develop in rehabilitation. In fact, during the 1970s, most clinicians regarded functional assessment as an effort to measure the unmeasurable.

Substantial progress has been made in the past 30 years and functional assessment, in combination with outcomes analysis, is now considered one of the "basic sciences" of rehabilitation. Measurement of function is essential to the goals of rehabilitation, particularly medical rehabilitation. These goals are to monitor, support, and facilitate human performance and behavior, while considering environmental, structural, physiological, or psychological limitations. Functional assessment is a method for describing a person's abilities and limitations.

The essence of functional assessment is the measurement of a person's use of skills included in performing tasks necessary to daily living, leisure activities, vocational pursuits, social interactions, and other required behaviors. Information obtained from functional assessment is used to help formulate judgments as to how well essential skills are being used and to gauge the degree to which tasks are accomplished and social role expectations are met. Performance-based functional assessments take into account the social and physical contexts of the person. Measurement of functional abilities and outcomes must relate to real-life situations and settings.

Commonly, the emphases of rehabilitation programs include improving the functional status of individuals through a system of interdisciplinary interventions. Outcomes are determined by periodic

reassessment of changes over time. The purposes of measurement are to make explicit the effectiveness, the efficiency, and the cost-effectiveness of the interventions. In this manner, outcomes of professional interventions of health care, rehabilitation, education, or psychological and social counseling may be described and monitored. Once outcomes become measurable, they become manageable.

The term *evidence-based practices* fits nicely with the idea of functional assessment and outcomes analysis as a basic science of rehabilitation. A scientific approach to assessing function and rehabilitation outcomes enhances national and international communications through use of a common language.

MEASURING FUNCTION AND ANALYZING OUTCOMES

Functional assessment and outcomes analysis require measurement. Measurement begins with understanding what is to be measured. This understanding must be grounded in theory and must be connected to a comprehensive model for identifying and then meeting the needs of the person being assessed. Each tool used in measurement must be designed and tested with respect to its purpose, practicality, construction, standardization, reliability, validity, responsiveness to change, feasibility for use, and meaningfulness in the clinical setting.

There are many difficulties in applying measurement principles to function and outcomes because the concepts to be evaluated relate to whole-person perceptions, attitudes, knowledge, or behaviors and are more often intangible (so-called latent traits) rather than tangible. For example, physical performance measured in terms of muscle strength, endurance, velocity of contraction, oxygen uptake, or even timed ambulation is much more tangible than measuring the ease or difficulty that a person as a whole experiences in tasks of daily living. Another example is the long-standing difficulty in measuring pain. Pain is a factor that often limits a person's ability to complete daily living activities, social interactions, and role participation.

Person variables are latent traits because they are hidden in the person; we can only infer them from observation of behaviors. These are just a sample because the person may generate a universe of behaviors, not simply mechanistic responses to external stimuli. One can infer that a person is "independent in daily life" by observing that he or she eats, dresses, or moves autonomously, but many other behaviors, if produced and observed or reported, might convey the same kind of information. This implies (a) discontinuity in the source data (we can only count discrete observations along a continuum); (b) nonlinearity of the counts (different behaviors do not represent the same amount of autonomy, despite being counted as "one more"); (c) more numerous behaviors replicate (and thus make more reliable) the observation that the variable is there, but do not necessarily reveal "more" of the variable; and (d) inhomogeneity of the error surrounding the observation (too easy or too difficult tasks for a given person provide very reproducible outcomes, whereas tasks "on target," despite being more informative, may end up in "pass" or "fail"). Thus, despite integer numbers, counts of observations represent a potentially poor surrogate of the intended measure. Recent developments of psychometrics, led by Rasch analysis (after the name of the Danish mathematician Georg Rasch), are at last shedding light on this fundamental challenge to functional assessment.

One technique for developing measures of tangible and intangible phenomena is through use of the Rasch mathematical model. Easily used software programs are now available to assist in the measurement process using the Rasch model. Rasch is described later, in the section titled "Uses of Functional Assessment."

Distinctions must be made between performance-based functional assessment, taking the social and physical contexts into account, and the conceptually simpler, more objective evaluation and measurement of functional capacity. Functional capacity assesses the person's performance under controlled circumstances, similar to judging optimal performance in laboratory conditions. These results may not reflect how the person performs in daily living activities in the "real world." Testing muscle strength and timed walking distance, as described above, are measures of functional capacity rather than of daily living activities.

There are many models for conceptualizing the attributes to be measured. Most emanate from the work of psychologist Abraham Maslow (1954), who evolved a hierarchy of needs to achieve self-actualization in

order to live a fulfilling life. He understood that life's work was to systematically overcome barriers. At the base of Maslow's hierarchy lie needs for physical survival, and at progressively higher levels are satisfaction of needs for security, social interaction, and self-esteem. One derivation considers that the concepts to be measured are challenges to quality of daily living. In this model, the goal of fulfillment is achieved through balancing one's choices, options, and expectations (functional opportunities) with one's physical, cognitive, and emotional constraints (functional demands/barriers).

When opportunities and demands are not directly measurable in quantitative terms, then the underlying factors that either support or form barriers to health and functioning are often chosen for measurement. For example, functional opportunities that are supported by good health may be described and measured by assessing physical status, mental/emotional status, social interactions, role participation, and general well-being. On the other hand, functional demands/barriers may be described and measured by assessing pathophysiology, impairment, functional limitations, disability, and societal limitations (see definitions below).

As another example, motivation is felt to be an important underlying determinant of how well a person may cope with adversity, for instance, a chronic disease or disability. While not directly measurable, inferences may be made by measuring variables related to motivation, such as self-esteem, mood, or by analyzing the steps one follows in solving a problem or in developing a plan of action.

The World Health Organization (WHO; 1980) originally proposed a series of definitions that have had a profound impact on the assessment of functional status and outcomes in rehabilitation. The original WHO framework was modified in a National Institutes of Health, National Center for Medical Rehabilitation Research report published in 1993. This report included the following definitions that are widely used within rehabilitation:

> *Pathophysiology* is any interruption of, or interference with, normal physiological and developmental processes or structures.

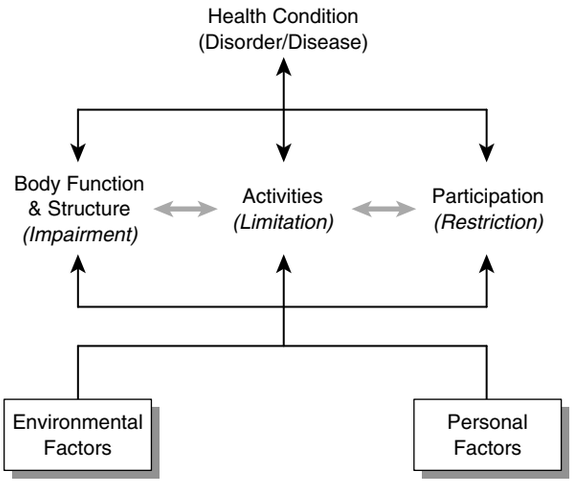

Figure 1 Interaction of Concepts
Source: World Health Organization (2001).

> *Impairment* is any loss or abnormality at the organ or organ system level of the body.
>
> *Functional limitation* is any restriction or lack of ability to perform an action in the manner or within a range consistent with the purpose of an organ or organ system.
>
> *Disability* is any limitation in performing tasks, activities, and roles to levels expected with physical and social contexts.
>
> *Societal limitation* is any restriction attributable to social policy or barriers (structural or attitudinal) that limits fulfillment of roles or denies access to services and opportunities associated with full participation in society.

Recently, the WHO (2001) proposed a revised model referred to as the International Classification of Functioning, Disability, and Health. The components of this model are presented in Figure 1.

The dynamic evolution of disablement models illustrates that measurement of functional abilities and rehabilitation outcomes is an ongoing challenge in which researchers and clinicians attempt to disentangle complex nonlinear interactions that occur in real life, across many different variables. Yet measurement of each variable, itself, must be linear, that is, proportional to the quantity it is claimed to represent. Rehabilitation outcomes are multiple rather than

singular. Assessment of "quality of life" requires use of measures that cover several aspects of functioning concurrently, yet cooperating in defining a unitary construct. This means that using a large number of instruments is not necessarily better than using a few well-chosen ones. As well, one must be vigilant that instruments are measuring accurately and succinctly. Johnston, Keith, and Hinderer (1992) have identified interdisciplinary standards and guidelines to foster improvement in development of functional assessment scales in rehabilitation. These standards and guidelines were compiled to counter the tendency to measure the "whole person" based on evaluation of severity of focal impairment alone.

The guidelines cover validity, reliability, clinical application, and program evaluation/quality improvement.

Validity includes three forms (content, predictive, and construct) and is the paramount criterion for choice and use of an instrument. Validity is regarded as the extent to which a test measures what it is intended to measure. Commonly, a "gold standard" is sought against which newer measures may be compared.

Reliability is the extent to which the data contain relevant information with a high signal-to-noise ratio versus irrelevant static and confusion, that is, sufficiently free of either random or systemic error. Repeatability indicates reliability. Agreement is the most stringent form of repeatability in which results of testing match across raters, time, or subjects. Agreement, however, may come also from the same bias affecting multiple observations (e.g., across raters or times). Internal consistency is another, perhaps even more stringent, form of reliability, demonstrating that all items are evaluating the same general construct. The more coherent the items are, the more they will be free from individual changes, independent from the shared construct, and thus, the scores will tend to be repeatable.

Clinical application means that users need to understand the scientific basis for the inferences they make from their clinical assessments and the boundaries of this knowledge.

Program evaluation/quality improvement involve application of measures to groups for purposes of ongoing review to systematically resolve identified problems and pursue opportunities to improve care and services, to accomplish accreditation, and to use evidence to support policy making. Wide variations in responses of individuals may reflect an instrument or measurement process that is not accurate or stable. Outcomes not only are dependent on the effectiveness of treatment but also depend on patterns of input, process, and conditions surrounding the treatment intervention. Good outcomes are the culmination of the combined effects of structure and process. Case-mix adjustments must be made to account for variations in severity or qualitative differences in the individuals being measured.

USES OF FUNCTIONAL ASSESSMENT

Using data from the Uniform Data System for Medical Rehabilitation, Margaret Stineman, associate professor, Rehabilitation Medicine, University of Pennsylvania, and colleagues (Stineman 1998; Stineman et al. 1994; Stineman et al. 1997) developed the FIM-FRG system to classify patients at the time of admission to inpatient rehabilitation. The FIM-FRG system was designed to facilitate prediction of length of stay and level of function that can be achieved during rehabilitation, and to compare outcomes between patients, having made case-mix adjustments. The classification system uses type of impairment, severity of disability using the FIMTM instrument (*Guide to the Uniform Data System* 1996) motor and cognitive measures, and for some groups, age. The IRF-PAI (Inpatient Rehabilitation Facility-Patient Assessment Instrument), developed for the U.S. Centers for Medicare and Medicaid Services (www.cms.hhs.gov) to use for prospective payment to rehabilitation hospitals, incorporates the FIMTM instrument, and has been used in the United States since January 2002.

In contrast to continuous linear measures (such as those for length and weight), item-response scales are most commonly used for functional assessment and outcome analysis. Scales are typically discontinuous-ordinal. The raw scores they provide are neither linear nor equal-interval, thus they should not be used in parametric statistical analyses. Interval measurement derived from raw scores through Rasch-based (Wright and Linacre 1989) transformation improves functional status analysis by providing unidimensionality and

additivity. Unidimensionality means that items cooperate with each other as they progress in difficulty across a common range of performance, with each item adding a level of difficulty for the subjects. Unidimensionality also means that the abilities of the subjects can be located along the continuum defined by the items, according to common standard units. Additivity means that adding one more unit always increases the pool by the same amount, whatever the overall level of the measure.

Together, these two concepts of item difficulty and person ability being measured on the same linear metric are referred to as conjoint additivity. Conjoint additivity is achieved only if the measure is independent of the particular sample being tested, and of the particular set of items adopted. Therefore, Rasch-transformed measures, complying with the requirement of conjoint additivity, permit statistical validity and generalizability in comparing individuals on the basis of results using an aggregate rating and in comparing changes in ratings over time. The Rasch measurement model offers opportunities for comparing standardized expected values both for aggregate ratings and item responses when persons have problems that are relevant to the latent trait being measured.

Measures of function and outcome analysis are classified according to questions that they are intended to answer: (1) discriminative, (2) evaluative, or (3) predictive. The first task in using a measure is to identify levels of severity from low to high. The second task is to identify whether the value of the measure changes with changing severity. The third is to predict another parameter that is either concurrent, such as the cost of the treatment program or the value of a variable in the future, such as the likelihood of recovery.

A challenge that remains for the medical rehabilitation field to solve is the predictable relationship between the "dose" of rehabilitative services and the "response" of the person. In fact, depending on the problem and the treatment, rehabilitation outcomes may follow teaching-learning paradigms (e.g., in therapeutic exercises), in the same way that chemical dose-response dynamics (e.g., in chemical treatments for pain or spasticity) do.

When functional assessment is performed by observation of activities, it is very important to assure accuracy or intrarater and interrater reliability. This may be accomplished through several methods that include (1) testing competence of the assessors with an examination, (2) testing the results of the assessments with standard statistical studies of variance, and (3) Rasch modeling of the data testing for separability of persons and items and the fit of item responses to expected rating patterns. Assessors who are performing ratings through observation or interview need to receive training and then be tested to ensure their knowledge of the criteria for rating.

CONCLUSION

Feedback of the results of functional assessment and outcome analysis is extremely important (1) for clinicians to know whether they are "on track" and (2) for administrators to perform program planning and program evaluation and to make policy decisions responsibly. Accrediting bodies require functional assessment and outcome analysis as evidence of quality assurance. Accreditation agencies are also increasingly sensitive to feedback from the consumers of rehabilitation services. In the effort to measure quality of daily living, it has become important to use patient-centered questionnaires that gather the person's perspective, rather than attempt to infer this perspective from objective testing of body functions. The patient-centered approach to functional assessment and the evaluation of rehabilitation outcomes is consistent with the goals of medical rehabilitation and reflected in the motto "As we function, so shall we live!"

—Carl V. Granger,
Kenneth J. Ottenbacher, and Luigi Tesio

See also Evidence-Based Medicine; International Classification of Functioning, Disability, and Health (ICF/ICIDH).

Further Readings

Clark, G. and C. Granger. 1997. "Functional Assessment for Outcome Analysis." Pp. 9–14 in *Physical Medicine and Rehabilitation Secrets,* 2d ed., edited by B. O'Young, M. Young, and S. Stiens. Philadelphia: Hanley & Belfus.

Fiedler, R. and C. Granger. 1996. "The Functional Independence Measure: A Measurement of Disability and Medical Rehabilitation." Pp. 75–92 in *Functional Evaluation of Stroke Patients*, edited by N. Chino and J. L. Melvin. Tokyo: Springer-Verlag.

Granger, C. V. and G. E. Greshman, eds. 1984. *Functional Assessment in Rehabilitation Medicine.* Baltimore: Williams & Wilkins.

Granger, C. V., M. Kelly-Hayes, M. Johnston, A. Deutsch, S. Braun, and R. Fiedler. 2000. "Quality and Outcome Measures for Medical Rehabilitation." Pp. 151–164 in *Physical Medicine and Rehabilitation.* 2d ed., edited by Randall L. Braddom. Philadelphia: W. B. Saunders.

Guide to the Uniform Data System for Medical Rehabilitation (Version 5.0). 1996. Buffalo: State University of New York at Buffalo.

Johnston, M., R. Keith, and S. Hinderer. 1992. "Measurement Standards for Interdisciplinary Medical Rehabilitation." *Archives of Physical Medicine and Rehabilitation* 73(Suppl. 12-S, S1–23).

Johnston, M. U., T. W. Findley, J. DeLura, and R. T. Katz. 1991. "Research in Physical Medicine and Rehabilitation XII: Measurement Tools with Applications to Brain Injury." *American Journal of Physical Medicine and Rehabilitation* 70(Suppl. 1): 114–120.

Lawton, M. 1971. "The Functional Assessment of Elderly People." *Journal of the American Geriatrics Society* 19(6): 465–481.

Maslow, A. 1954. *Motivation and Personality.* New York: Harper and Row.

———. 1954. *Toward a Psychology of Being,* 2d ed. Princeton, NJ: Van Nostrand.

National Institutes of Health, National Institute of Child Health and Human Development. 1993. *Plan for the National Center for Medical Rehabilitation Research.* U.S. Department of Health and Human Services, Public Health (NIH) Publication No. 93–3509. Rockville, MD: National Institutes of Health.

NIH Task Force. 1993. *Report of the Task Force on Medical Rehabilitation Research.* Hunt Valley, MD: NIH Task Force Committee.

Ottenbacher, K. J., Y. Hsu, C. V. Granger, and R. C. Fiedler. 1996. "The Reliability of the Functional Independence Measure (FIM): A Quantitative Review." *Archives of Physical Medicine and Rehabilitation* 77:1226–1232.

Stineman, M. 1998. "Function-Related Groups 101: A Primer." *Critical Reviews in Physical Rehabilitation Medicine* 10:319–358.

Stineman, M., J. Escarce, J. Goin, B. Hamilton, C. Granger, and S. Williams. 1994. "A Case-Mix Classification System for Medical Rehabilitation." *Medical Care* 32(4): 366–379.

Stineman, M., J. Shea, A. Jette, C. Tassoni, K. Ottenbacher, R. Fiedler, and C. Granger. 1996. "The Functional Independence Measure: Tests of Scaling Assumptions, Structure, and Reliability across 20 Diverse Impairment Categories." *Archives of Physical Medicine and Rehabilitation* 77:1101–1108.

Stineman, M., C. Tassoni, J. Escarce, J. Goin, C. Granger, R. Fiedler, et al. 1997. "Development of Function-Related Groups Version 2.0: A Classification System for Medical Rehabilitation." *Health Services Research* 32(4): 529–548.

Tesio, L. 2003. "Measuring Behaviours and Perceptions: Rasch Analysis as a Tool for Rehabilitation Research." *Journal of Rehabilitation Medicine* 35:105–115.

Tesio, L., C. Granger, and R. Fiedler. 1997. "A Unidimensional Pain/Disability Measure for Low-Back Pain Syndromes." *Pain* 69:269–278.

World Health Organization. 1980. *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease.* Geneva: World Health Organization.

———. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

Wright, B. and J. Linacre. 1989. "Observations Are Always Ordinal; Measurements, However, Must Be Interval." *Archives of Physical Medicine and Rehabilitation* 70:857.

Wright, B. and G. Masters. 1992. *Rating Scale Analysis.* Chicago: MESA.

Websites

U.S. Centers for Medicare and Medicaid Services, www.cms.hhs.gov

FUNCTIONAL MEASUREMENT

Functional measurement is a general term that describes the processes by which we collect information to evaluate disability and determine the need for vocational or rehabilitation services. On the surface, functional measurement may simply represent the act of determining a meaningful quantity of something. The term *functional* means purposeful or useful. Measurement refers to the process of determining a quantity or amount. However, the term takes on a special meaning in the context of disability and refers more specifically to the process of quantifying an individual's performance of particular tasks and activities in the context of specified social and physical environments. A preponderance of functional measurement is focused on the completion of tasks and activities that relate to work (specifically, to a particular job) or to caring for oneself. Thus, key tasks and environments that are most often the focus of functional measurement are *activities of daily living* (e.g., eating, dressing) completed in the home and specific job functions completed in the workplace. Another, though less emphasized, area of functional measurement involves getting around and using the community at large.

The reason for conducting functional measurements is to obtain a reliable and valid representation of how well an individual performs particular tasks or activities under certain circumstances. This task is complex, because people have a dynamic and personal relationship with the environments in which they inhabit. Therefore, the circumstances of any given performance involves many factors, including personal capabilities (knowledge, skills, abilities, and attitudes), the particular demands of the task that needs to be performed, and the setting in which the performance takes place. In practice, individual performance can be influenced by improving the person's capabilities (through accommodation or some other rehabilitation strategy), by altering the task to reduce or eliminate unnecessary demands, or by modifying the setting to remove environmental barriers. Rehabilitation and vocational specialists engaged in improving client performance and reducing disability use all of these strategies. Furthermore, the range of options is made known only through functional measurements that take into account the individual's capacities, the specific tasks to be performed, and the specific settings in which they take place.

HISTORICAL FOUNDATION

The concept of functional measurement has evolved over the past century as views toward compensation for injury and rehabilitation have become more sophisticated. In the first third of the twentieth century, disability was primarily considered a "defect with a cash value." Honored workers in the national economy (such as those in the military or civil service) were compensated for injuries that occurred on the job. At that time, assessment was limited to determination of impairment. The resulting compensation was rather crude involving a set cash payment for different types of impairments. For example, the loss of vision in one eye resulted in a different payment than did the loss of function in an arm.

Society continues to compensate workers for their injuries, although the method of calculating benefits has changed substantially. During the middle third of the twentieth century, we also began teaching injured workers to use and adapt residual capacities to work and reach their maximum vocational potential. This happened for a variety of reasons. However, the primary reason was the growing population now living with impairment due in part to the large numbers of casualties resulting from both World Wars and to increasing numbers of car accidents. Advances in medical science and technology resulted in people surviving injuries that previously resulted in death. The remarkable change in rehabilitation during this period was the acceptance of the holistic philosophy in rehabilitation. This philosophy held that the mind and body accomplish tasks in an integrated way. By implication, one cannot obtain a clear picture of the capacity to perform tasks or activities by measuring the functioning of body structures alone. Instead, the focus of assessment shifted to the "whole" person completing tasks and activities associated with daily living. According to Kessler (1970), the effective dynamic action of mind, body structure, and body function work as a single unit to complete tasks and achieve goals. During this period, there was a proliferation of functional assessment instruments that focused on the accomplishment of key activities of daily living, such as eating, dressing, and bathing.

The latter third of the twentieth century saw profound changes in rehabilitation. Advances in rehabilitation medicine led to improvements in the ability to remediate and improve patient capacity following injury or disease. However, just as important was the recognition that disability is "a form of inability or limitation in performing roles and tasks expected of an individual within a social environment" (Nagi 1977). In effect, Nagi defined disability as a distinct concept, one that is different from impairment. *Disability* is a socially derived term that refers to an individual's performance of tasks and activities related to achievement of social roles. The term *disability* was further formalized with the introduction of the World Health Organization's International Classification of Impairments, Disabilities, and Handicaps in 1980 and further refined in its International Classification of Functioning, Disability, and Health in 2001. As researchers and clinicians set about the task of "measuring" disability, the concept of functional measurement began to take shape.

PURPOSES OF FUNCTIONAL MEASUREMENT

There are two principal purposes for conducting functional measurements. One purpose is to facilitate reintegration back into one's living environment following injury, disease, or disorder. Rehabilitation or vocational specialists gather information about their client's home and work environments to discover ways to improve the individual's ability to complete important daily tasks. In this case, functional measurement refers to the collection of information to reflect the dynamic characteristics of the individual, including personal activities, capacities, environmental conditions, and needs. Together, this information is used strategically to plan for the individual's reintegration back into familiar work and living environments. Rehabilitation strategies can range from new surgery or therapy that is needed to improve the individual's personal capacity to remodeling the home to accommodate incapacity due to permanent impairment. Vocational strategies can range from retraining the individual to do a current or previous job to remodeling a previous work environment or training for a new vocational goal. All of these actions have the effect of reducing disability.

Analogous to this purpose is the concept of habilitation that concerns the integration, as opposed to reintegration, of an individual into increasingly demanding adult living situations or environments. Habilitation most often relates to the education of children and youths with disabilities. The goal is to reduce the potentially disabling effects of the increasing demands associated with adult living tasks and environmental settings through education. Functional measures provide a means for understanding educational needs.

The second purpose for conducting functional measurements is to facilitate decisions about access to relief under various laws. Functional measures provide critical information to the decision of whether a claimant meets the legal definition of disability, thereby making him or her eligible for benefits under the particular law. While the definitions are somewhat different under each law, they all require some functional measure of a claimant's ability to meet the demands of age-appropriate daily living requirements. For example, disability under the Social Security Administration (SSA) is narrowly defined and reserved only for individuals who cannot perform substantial gainful activity (i.e., SSA's term for work) now or in the foreseeable future. A determination of work disability, as it is sometimes called, leads to an award of monetary and health benefits to claimants who are disabled under the law. Given that the consequences of the decision for the individual and for society are costly, it is not surprising that disability determination under Social Security is a formal and often lengthy process involving careful assessment of a claimant's capacity for engaging in previous work or any work available in the national economy. If the impairment is severe and interferes with the completion of previous work requirements or the work requirements of any job found in the national economy, then the claimant is judged unable to engage in substantial gainful activity and is awarded benefits.

In all cases where a legal determination of disability is required, the decision is reached through a formal process of data collection and analysis. Functional measures are only a part of that process. For example, while the definition of disability is markedly different under the laws governing education and Social Security, both processes require that measures of impairment be collected before actual functional measures are collected. This makes sense, given that impairment is a prerequisite to disability.

Disability is sometimes "presumed" based on an assessment of impairment alone. In these cases, the impairment is considered so severe that it is not necessary to assess the environmental consequences of the impairment. In effect, it is already known. For example, individuals with Down syndrome who have a measured intelligence quotient in the low 50s are presumed to be disabled. This decision is based on accumulated knowledge that such persons will now (and in the future) face serious barriers to gaining control over their environment and will not be able to take on expected social roles. These individuals will largely require supervision in the conduct of daily living tasks and activities requiring higher levels of language, problem solving, and judgment.

MEASURES OF IMPAIRMENT

Functional measurement can be contrasted with measurement of impairment. Measurement of impairment is focused on a determination of the extent to which the body's structure or function deviates from that which is considered normal. In the International Classification of Functioning, Disability, and Health, examples of body structures include the nervous system (such as the brain and spinal cord), the eye, voice mechanisms (such as the nose, mouth, pharynx, and larynx), and structures related to movement (such as the head and neck, upper extremities, and lower extremities). Examples of body functions include mental functions (such as general functions of consciousness and intellect as well as specific functions such as memory and attention), sensory functions (such as taste and smell), and neuromuscular and movement-related functions (such as mobility and stability of joints and muscle power).

We may measure handgrip strength or range of motion associated with the shoulder, elbow, or wrists to determine the extent to which hand or arm function is impaired. The extent to which these measures deviate from normal measures, given age and sex, determines the existence of impairment.

Measurements for mental capacity or emotional development can be treated in a similar fashion. An individual's performance on a test of intelligence (IQ test) provides the information needed to determine the extent of mental impairment. Thus, measures such as the Stanford-Binet scale or Wechsler Adult Intelligence Scale (WAIS) yield information on the intellectual performance of an individual compared to "normal" intellectual performance. For many years, low IQ test performance was all that was necessary to "presume" disability for purposes of disability under SSA. However, these days IQ test performance is only part of the SSA disability determination process involving mental impairment. In recognition of the many skills and abilities that apply to successful work performance in one's environment, functional measures are now also required to supplement IQ testing in the determination of disability.

Functional measurement can also be contrasted with functional capacity evaluation (FCE). FCEs move a step closer to measures of a person's ability to perform daily tasks and activities. Even so, the measures remain focused on the individual as opposed to the relationship between the individual and the environment. FCEs assess individual performance on meaningful tasks, as does functional measurement. The purpose is to generalize to functional abilities that result from normal physical or mental development. Thus, FCEs require individuals to perform tasks that are specifically designed to measure limitations in physical ability (pushing/pulling, carrying, reaching, seeing, and hearing), neurobehavioral performance (walking, balance, and stamina), cognitive ability (oral or written language, memory, and problem solving), and interpersonal interaction (teamwork and responsibility). Performance on these "functional" abilities is then used to predict ability to engage in a previous job and meet daily living expectations. It is obvious that FCE is complementary to both measurement of impairment and to functional measurement. However, functional measurement is focused on the performance of actual job functions whereas measurement of impairment is focused on the extent of damage to a body structure or function, and FCE is focused on the effect of impairment on particular uses of the impaired body structure or function.

FUNCTIONAL MEASUREMENT METHODS

Functional measurement employs one or more methods of data collection. There are generally three types of methods for obtaining functional measures: (1) self-report methods, (2) structured performance rating methods, and (3) behavioral observations and situational assessment methods. Each method has its own unique use and characteristics.

Self-Report Methods

Self-report methods include checklists, rating scales, and inventories. The common characteristic among these types of instruments is that the data collection procedure involves obtaining the information directly from the individual who is the target of the assessment. They report on their own functioning. The individual affected is often considered to be the best source for information about his or her ability to

function in familiar environments. Thus, self-reports are an efficient and direct way of obtaining reliable information. In addition, they can cover a wide range of topics and content. However, they are also subject to problems of validity since they are easily influenced by the desires of reporters who wish to appear more or less disabled, depending on the circumstances and the reinforcers apparent in consequences tied to the assessment. For these reasons, self-reports form only a small part of eligibility decisions associated with legal disability determination.

Self-report methods are used mainly in health care settings and in national surveys. In the health care setting, self-reports are often supplemented with clinical evaluations and judgments. For these reasons, their potential invalidity—due to "wishful" reporting—is less of an issue. Self-report is also the primary method for obtaining information in national surveys, since this method is the most efficient and cost-effective way of finding out about an individual's situation.

In some cases, another person, called a proxy, completes the self-report because the targeted individual may not be capable of reporting his or her own behavior due to weakness or fatigue or mental incompetence, for example. Proxy reports are most useful when the questions do not address personal feelings, opinions, or hypothetical situations. These types of questions lead to results that differ from the target individual's.

Structured Performance Ratings

Structured performance ratings include checklists, rating scales, and inventories completed by a trained evaluator. The notion behind structured performance ratings is that a trained evaluator provides objective evidence of performance. Typically, such persons include a physician, therapist, nurse, vocational assessor, or other service provider. The sources of information about the target individual might include observations, interviews, case histories, and tests. However, this implies that structured performance ratings are retrospective rating scales that provide judgments about performance observed in the past. While still subjective, structured performance ratings offer a more objective method for assessing target individual performance since the trained evaluator would have less incentive to skew the ratings.

The major limitation of structured performance ratings is the common context for making ratings. Evaluators may have insufficient information to arrive at a valid rating. This result could be due to ambiguous questions or bias. One way developers of such instruments confront this problem is to accept input only from evaluators who meet specified criteria—such as knowing the targeted individual for a certain period of time, or having observed the targeted individual in specific settings.

Behavioral Observations and Situational Assessments

Behavioral observations and situational assessments include observations of target individuals performing in natural or artificial environments. Behavioral observations typically focus on performance in natural settings, such as the individual's home, community, or workplace. Situational assessments are observations of performance in artificially constructed (situations) environments. Both methods provide a rich source of information about target individual performance. However, they are also time-consuming and costly. Their major limitation is the breadth with which one can generalize performance to a broader range of environments in which the target individual may find himself or herself. Another issue is that the episodic nature of some impairments does not lend well to these types of methods unless repeated trials can cover the length of time or period needed to obtain a complete picture of performance.

—William D. Frey

See also Activities of Daily Living (ADLs); Employability; Employment; Functional Assessment; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Vocational Rehabilitation.

Further Readings

Frey, W. D. 1984. "Functional Assessment in the 80s: A Conceptual Enigma, a Technical Challenge" in *Functional Assessment in Rehabilitation,* edited by A. S. Halpern and M. J. Fuhrer. Baltimore: Paul H. Brookes.

Kessler, H. H. 1970. *Disability—Determination and Evaluation.* Philadelphia: Lea & Fibiger.

Linton, S. 1998. *Claiming Disability.* New York: New York University Press.

Mathiowetz, N. and G. S. Wunderlick. 2000. *Survey Measurement of Work Disability: Summary of a Workshop.* Washington, DC: National Academy Press, Institute on Medicine.

Nagi, S. Z. 1977. "The Disabled and Rehabilitation Services: A National Overview." *American Rehabilitation* 2(5): 26–33.

Pope, A. M. and A. R. Tarlov. 1991. *Disability in America: Toward a National Agenda for Prevention.* Washington, DC: National Academy Press, Institute on Medicine.

Wunderlich, G. S., ed. 1999. *Measuring Functional Capacity and Work Requirements.* Washington, DC: National Academy Press, Institute on Medicine.

Wunderlich, G. S., D. P. Rice, and N. L. Amado. 2002. *The Dynamics of Disability: Measuring and Monitoring Disability for Social Security Programs.* Washington, DC: National Academy Press, Institute of Medicine.

World Health Organization. 1980. *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease.* Geneva: World Health Organization.

———. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

Websites

PACER Center, Parent Advocacy Coalition for Educational Rights (Functional Assessment in Children), http://www.pacer.org/parent/function.htm

Social Security Determination Process, http://www.ssa.gov

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GAIT ANALYSIS

Twenty years ago, Gordon Rose, a pioneer in the field, suggested that the term *gait assessment* should be applied to the whole process of evaluating a patient's gait and that the term *gait analysis* be reserved for the high-tech component of gait evaluation. In the diagnostic triad of history, physical examination, and laboratory tests, gait analysis is a laboratory test. Historically, while Eadweard Muybridge (1830–1904) famously used sequential photographs to display gait in several species, gait laboratories were developed to support research into the biomechanics of human movement. The difficulty of the process limited the amount of data that could be processed and the sophistication of the models used to interpret the results. In the past few decades, gait analysis technology has improved significantly, resulting in a potential for wider clinical application. The development of powerful and inexpensive microcomputers has reduced the time and labor costs of gait analysis. Coincidentally, commercial vendors have developed standard packaged gait analysis systems that integrate the basic technologies required for gait analysis, motion capture, ground reaction force measurement, and muscle activity monitoring. Gait laboratories have developed a consistent set of parameters for describing gait and gait pathology.

At present, the most common clinical use of gait analysis is the assessment of spastic gait in patients with partial paralysis from an upper motor neuron pathology. Gait analysis allows one to understand the dynamic implications of a specific impairment, such as spasticity or weakness in a particular muscle group. Gait analysis helps the clinician determine those impairments and functional limitations that likely contribute to a walking disability. Probably no two sets of quantitative gait data from two individuals are the same, no matter how visually similar the individuals' gait disabilities appear. Logically, the optimal treatment for a given individual will be the one that addresses the impairments and functional limitations most contributory to that person's gait disability.

By defining causative impairments and functional limitations, gait analysis can focus and optimize rehabilitation treatment, including the prescription of specific exercises, electromyographic biofeedback, functional electrical stimulation, orthotics, and nerve or intramuscular blocks. In patients with upper motor neuron pathology, traditional static evaluations are not effective in measuring either functional muscle strength or spasticity. By identifying which muscle groups need strengthening (or electrical stimulation, or bracing) and which need relaxation (or stretching, or intramuscular neurolysis, or tendon lengthening), gait analysis can lead to optimal, methodical, and directed treatment.

Undoubtedly, gait analysis technology will continue to improve with developments in computer vision, artificial intelligence, computational methods, and computer power. In addition, models used to

interpret gait analysis data will be refined and standardized. Ultimately, a clinician will likely be able to input kinetics measured with current gait analysis technology into a computerized robotic model that will produce a kinematic gait pattern, or mathematical description of the person's entire gait, that is similar to the individual's actual kinematic pattern. Changing the kinetic inputs in the robotic model could simulate rehabilitation, such as strengthening a particular muscle. The resulting modeled kinematics would help predict the kinematic changes to be expected if the patient were to undergo the treatment.

—Patrick O. Riley and D. Casey Kerrigan

See also Computer Technology; Paralysis.

Further Readings

Rose, G. K. 1983. "Clinical Gait Assessment: A Personal View." *Journal of Medical Engineering & Technology* 7:273–279.

Whittle, M. W. 1996. "Clinical Gait Analysis: A Review." *Human Movement Science* 15:369–387.

GALEN (129–CA. 199/216)

Greek physician and philosopher

Galen was a physician from Asia Minor who practiced on both gladiators and rulers, serving as physician to four emperors. He was also a philosopher and author who wrote more than 350 works in Greek on subjects ranging from anatomy to deontology, from philosophy to poetry, from pathology to therapy. He was a vigorous advocate of the tradition of Hippocrates but was equally eager to display his own innovative knowledge and investigations. In particular, Galen enhanced the concept of the four humors as a system of explanation for diseases.

At once arrogant and brilliant, Galen, through his texts and ideas, had a profound influence on elite Western medicine until the nineteenth century, although observations by anatomists and physiologists starting in the sixteenth century (e.g., those of Andreas Vesalius [1514–1564]) began to undercut the power of his ideas.

Galen's descriptions of disabling conditions ranged from fractures and paralyses to visual impairments and epilepsy, while his therapeutic interventions embraced dietary changes, fractured limb reductions, and bloodletting. He helped differentiate the trachea and the larynx, thus allowing speech disorders to be pathologized. Galen publicly demonstrated the function of the recurrent laryngeal nerve, which innervates the voice box. He cut the nerve in a squealing pig and thereby "removed" its voice, thus demonstrating both a refined physiological sensitivity and the use of impairment as a marker of physiological dysfunction. Galen's influence on disability, by way of medicine, is at once distant and profound.

—Walton O. Schalick III

See also History of Disability: Ancient West; Medicine.

Further Readings

Kühn, Karl G. 1997. *Claudii Galeni opera omnia.* New York: Georg Olms.

Nutton, Vivian. 2004. *Ancient Medicine.* London: Routledge.

Rose, Martha L. 2003. *The Staff of Oedipus: Transforming Disability in Ancient Greece*. Ann Arbor: University of Michigan Press.

GALLAUDET UNIVERSITY

See Gallaudet, Edward Miner

GALLAUDET, EDWARD MINER (1837–1917)

American educator

Edward Miner Gallaudet, an influential nineteenth-century educator, was the founder of the world's first institution of higher education for deaf people. During his 46-year tenure as the head of the National Deaf-Mutes College (today known as Gallaudet University), Gallaudet was internationally renowned as the originator and chief proponent of the so-called combined method of educating deaf children, a method that stressed a combination of spoken-language training and the use of sign language in the classroom. A

native user of American Sign Language (his mother was deaf), Gallaudet maintained lifelong connections with the American Deaf community largely through "his boys," the Deaf male graduates of the college.

The youngest son of Thomas Hopkins Gallaudet, cofounder of American Deaf education, Gallaudet was born in Hartford, Connecticut, on February 5, 1837. After a stint as a teacher at the American School for the Deaf from 1855 to 1857, he was invited to establish a school for deaf children in the District of Columbia. The Columbian Institution for the Instruction of the Deaf, Dumb, and Blind was established on February 16, 1857, its college division charter signed by Abraham Lincoln on April 8, 1864. Gallaudet died in Hartford, Connecticut, on September 26, 1917, in the centennial year of the founding of American Deaf education.

—Joseph J. Murray

See also Deaf, History of the; Deaf Culture; Thomas Hopkins Gallaudet.

Further Readings

Boatner, Maxine Tull. 1959. *Voice of the Deaf: A Biography of Edward Miner Gallaudet.* Washington, DC: Public Affairs Press.

De Lorenzo, David L. 1987. "Gallaudet, Edward Miner." Pp. 439–444 in *Gallaudet Encyclopedia of Deaf People and Deafness,* edited by John V. Van Cleve. New York: McGraw-Hill.

"Dr. Edward Miner Gallaudet Papers." Gallaudet University Archives, Washington, DC.

Gallaudet, Edward Miner. 1867. "Report of the President on the Systems of Deaf-Mute Instruction Pursued in Europe." In *Tenth Annual Report of the Columbia Institution for the Deaf and Dumb.* Washington, DC: Columbia Institution for the Deaf and Dumb.

———. 1983. *History of a College for the Deaf, 1857–1907.* Washington, DC: Gallaudet University Press.

Gordon, Joseph. 1892. *Education of Deaf Children. Evidence of E. M. Gallaudet and A. G. Bell Presented to the Royal Commission of the United Kingdom on the Education of the Blind, the Deaf, and the Dumb.* Washington, DC: Volta Bureau.

"Papers of T. H. and Edward Miner Gallaudet, 1806–1958." Archival Manuscript Collection, Library of Congress, Washington, DC.

Winfield, Richard M. 1987. *Never the Twain Shall Meet: Bell, Gallaudet, and the Communications Debate.* Washington, DC: Gallaudet University Press.

GALLAUDET, THOMAS HOPKINS (1787–1851)

American educator

Thomas Hopkins Gallaudet was the cofounder of American Deaf education in 1817. A noted orator and evangelical Christian, Gallaudet used his considerable rhetorical skills to garner support from influential citizens and financial assistance from state legislatures for the then outlandish notion of educating Deaf people. Gallaudet held a lifelong interest in education and social reform, campaigning in areas as disparate as the common school movement, work with the mentally ill, and the abolition of slavery.

Gallaudet, born on December 10, 1787, became interested in the education of Deaf people after meeting Alice Cogswell, the Deaf daughter of a neighbor. With funding from Cogswell's father and other prominent Connecticut citizens, Gallaudet traveled to Europe in 1815 to learn how to teach Deaf children. Dissatisfied by what he saw in British schools for Deaf people, Gallaudet was invited to visit a school in Paris. There, he received training from Deaf teachers Jean Massieu and Laurent Clerc. The latter accompanied Gallaudet back to Hartford in 1816 and helped him establish the first permanent school for the deaf in the United States in 1817, now known as the American School for the Deaf. Gallaudet served as the institution's principal until 1830. Gallaudet and his wife, Sofia Fowler, a former pupil, had eight children, the eldest and youngest of whom continued their parents' work with Deaf people. Gallaudet died on September 10, 1851.

—Joseph J. Murray

See also Deaf, History of the; Deaf Culture; Edward Miner Gallaudet.

Further Readings

Barnard, Henry. 1859. *Tribute to Gallaudet.* New York: F. C. Brownwell.

Fernandez, James J. 1980. "The Gate to Heaven: T. H. Gallaudet and the Rhetoric of the Deaf Education Movement" Ph.D. dissertation, University of Michigan.

———. 1987. "Gallaudet, Thomas Hopkins." Pp. 444–447 in *Gallaudet Encyclopedia of Deaf People and Deafness,* edited by John V. Van Cleve. New York: McGraw-Hill.

Gallaudet, Edward Miner. 1888. *The Life of Thomas Hopkins Gallaudet, Founder of Deaf-Mute Instruction in America.* New York: Henry Holt.

Gallaudet, Thomas Hopkins. 1817. *A Sermon on the Opening of the Hartford Institution for the Deaf and Dumb.* Washington, DC: Volta Bureau.

———. 1821. *Discourse Delivered at the Dedication of the American Asylum for the Education of the Deaf and Dumb, May 22nd, 1821.* Hartford, CT: Hudson.

"Papers of T. H. and Edward Miner Gallaudet, 1806–1958." Archival Manuscript Collection, Library of Congress, Washington, DC.

GALSWORTHY, JOHN E. (1867–1933)

English novelist and dramatist

Educated at Harrow and at New College, Oxford, and recipient of the 1932 Nobel Prize in literature, John Galsworthy is best remembered for his series of novels tracing the history of the upper-middle-class Forsyte family from the 1880s to the 1920s. Appointed to Britain's War Propaganda Bureau (WPB) in 1914, Galsworthy refused to encourage public hate of Germany, instead emphasizing support of men wounded and disabled in the conflict. To this end, he worked with the Red Cross in France at the Benevole Hospital for disabled soldiers, offered his family house as a convalescent home for recovering British soldiers, and chaired the executive committee of Kitchener House, a club for wounded sailors and soldiers. Galsworthy also published successful appeals on behalf of the Star and Garter Home for Disabled Sailors and Soldiers, contributed material to the *American Journal of Care for Cripples,* among many other publications, and wrote the foreword to the proceedings of the second Inter-Allied Conference on the After-Care of Disabled Men (1918). Additionally, he served as editor of *Recalled to Life,* later *Reveille,* a Ministry of Pensions journal designed to inform the general public of the welfare of disabled sailors and soldiers. Galsworthy resigned as editor following ministry disenchantment with the public indignation sparked by the publication. Galsworthy's collections *A Sheaf* (1916) and *Another Sheaf* (1917) contain articles he wrote specifically for the WPB.

—Jeffrey S. Reznick

See also Veterans; War.

Further Readings

Cohen, Deborah. 2001. *The War Come Home: Disabled Veterans in Britain and Germany, 1914–1939.* Berkeley: University of California Press.

Fréchet, Alec. 1982. *John Galsworthy: A Reassessment.* Translated by Denis Mahaffey. Lanham, MD: Rowman & Littlefield.

Gindin, James. 1987. *John Galsworthy's Life and Art: An Alien's Fortress.* Ann Arbor: University of Michigan Press.

Reznick, Jeffrey S. 2004. *Healing the Nation: Soldiers and the Culture of Caregiving in Britain during the Great War.* Manchester, UK: Manchester University Press.

GALTON, FRANCIS (1822–1911)

English inventor, scientist, geographer, meteorologist, eugenicist

Francis Galton, inventor, scientist, explorer, and developer of eugenics, was born near Birmingham, England, on February 16, 1822. He entered medical school at King's College, London, in 1839 but subsequently left, in part owing to the urgings of his second cousin, Charles Darwin. Galton then entered Trinity College, Cambridge, to finish his medical degree; he graduated in 1844.

Inspired by Darwin's *Origin of Species,* Galton believed humankind could improve its physical and mental health through selective breeding, which he termed *eugenics.* Galton spent much of his later life conducting research on the physical and mental characteristics of Londoners in his anthropometric laboratory. He conducted studies on eminent men, twins, and adopted children to demonstrate the heritability of mental characteristics. Galton developed the idea for intelligence tests and the statistical methods of correlation and regression, which were used to verify the strength of heritable relationships.

Galton's eugenics ideas inspired many countries, including the United States, France, Sweden, and Germany to adopt racial hygiene movements, immigration restrictions, and forced sterilization laws. These activities resulted in the castration, vasectomy, salpingectomy (the tying of the fallopian tubes), and deaths of numerous individuals from diverse racial

and ethnic backgrounds who suffered from physical and mental disabilities.

—Michael J. Root

See also Eugenics; Eugenics: Germany; Racial Hygiene *(Rassenhygiene).*

Further Readings

Forrest, D. W. 1974. *Francis Galton: The Life and Work of a Victorian Genius.* New York: Taplinger.

Gillham, Nicholas R. 2001. *A Life of Sir Francis Galton: From African Exploration to the Birth of Eugenics.* New York: Oxford University Press.

GASTROINTESTINAL DISABILITIES

The gut is vital to the process of digestion and the processing of food into metabolic substrates necessary for energy, growth, and survival. In the medical model, functional failure results in disabilities ranging from mild to severe and may even be life threatening. In general, the gut comprises an entrance orifice, the mouth, and a lengthy hollow tube, the intestine; the mouth allows food to be masticated by the teeth and passed on for digestion and absorption in the intestine. The intestine includes first the esophagus (transit tube into the stomach) then the stomach (which secretes acid to kill ingested bacteria and also an enzyme, pepsin, to activate digestion), duodenum, and small bowel (jejunum and ileum), and finally the colon (cecum, right, left, and sigmoid) and rectum, which terminates at the anus for the elimination of feces. Most digestive products are absorbed into the portal venous system and thence metabolized by the liver, from where they enter the general circulation. Fats are absorbed in a similar fashion but conveyed via lymphatics and the thoracic duct directly into the circulation, bypassing the liver. The entire gut is supplied with blood by the celiac, superior, and inferior mesenteric arteries, which in turn give rise to the gastric, hepatic, and pancreatic vessels. Interference with either the arterial supply or venous drainage results in pain, bleeding, ischemia, and even bowel death. Medical evaluation of the gut is by endoscopy (upper or lower), barium studies, computerized axial tomography (CAT scan), and/or angiography; surgical evaluation is undertaken either by open operation (laparotomy) or closed visualization (laparoscopy)

Infection of the stomach with *H. Pylori* (bacteria) results in gastritis and peptic ulceration, although this can also be produced by excess acid production or agents such as alcohol and aspirin. Inflammation of the esophagus (esophagitis is caused by acid reflux) results in substantial pain and even difficulty in swallowing. Inflammation and ulcers of the esophagus, stomach, or duodenum may all result in bleeding, perforation, or stricture, with results ranging from discomfort to incapacitation and even death. The esophagus may also perforate after vomiting or during the medical procedure endoscopy. Inflammation of the small bowel (Crohn's disease) and colon (ulcerative colitis) is generically referred to as *inflammatory bowel disease;* its sequelae include bleeding, ulceration, and perforation, with symptoms ranging from pain and diarrhea to death. The cecum has a congenital diverticulum (the appendix) that often becomes infected (appendicitis) and requires surgical removal. The sigmoid colon with age develops other diverticuli that may become inflamed, bleed, or perforate, requiring either antibiotics or surgical therapy for treatment. The anus is commonly the site of dilated venous channels (hemorrhoids) that are problematic in terms of pain, prolapse, and bleeding. They may be removed by banding or surgical resection.

Cancers of the hollow viscera usually cause bleeding and block the lumen, resulting in obstruction and death if surgery is not undertaken to relieve the problem. They are most common in the colon, stomach, and esophagus but are rare in the small bowel. Surgical resection alone may not be adequate, as the tumors may spread either locally, to the liver, or elsewhere.

The accessory digestive organs, the pancreas and liver, drain their secretions (pancreatic juice and bile, respectively) into the duodenum via ducts, thus providing digestive enzymes and bile salts to facilitate absorption of carbohydrates, fats, and amino acids in the small bowel. The pancreas, in addition, secretes a hormone, insulin, into the blood from the islets of Langerhans that is necessary for glucose homeostasis. In certain conditions (chronic pancreatitis and islet cell dysfunction) lack of insulin secretion results in

diabetes mellitus. Acute pancreatitis is usually due to alcohol or gallstones and causes an often uncontrollable inflammation of the pancreas that may result in death. Tumors of the pancreas are very malignant, present late, and even if removed usually lead to early death, although tumors of the endocrine pancreas are in general far more benign. The liver is susceptible to damage by viruses (hepatitis) and by alcohol and may become cirrhotic (fibrosed) leading to malfunction, jaundice (a yellow coloration of the skin and eyes), and the accumulation of fluid in the abdominal cavity (ascites). Bile is stored in the gallbladder before secretion during digestion, and gallstones often form, causing inflammation (cholycystitis) or even blockage of the bile duct and jaundice. Tumors of the liver are generally highly malignant and despite surgery are usually incurable.

In general, the organs of the gastrointestinal system are crucial to vital functions. Impairment of those functions leads to a variety of disabilities, as noted above, and their consequent handicaps under World Health Organization definitions. While many therapies exist, an enormous amount of work remains to be done through the collaboration of researchers, clinicians, and people with these impairments to improve their quality of life.

—Irvin M. Modlin

See also Diabetes.

Further Readings

Modlin, Irvin. 2003. *A History of Gastroenterology at the Millennium.* Milan: NextHealth.

Modlin, Irvin and George Sachs. 2004. *Acid Related Diseases: Biology and Treatment.* Philadelphia: Lippincott Williams & Wilkins.

Yamada, Tadataka. 2003. *Textbook of Gastroenterology.* Philadelphia: Lippincott Williams & Wilkins.

GENDER

Globally, persons with disabilities have historically experienced stigmatization and discrimination that continues to the present day. Evidence suggests that society views and stigmatizes persons with disabilities as second-class citizens, thus placing this group at risk for isolation beyond what may be caused by the disability itself. Among the many social divisions ascribed to individuals in a society is that of gender. It has been suggested that gender may play a role in the disenfranchisement that persons with disabilities experience in everyday life. Men with disabilities are often thought to be less masculine and weaker than nondisabled men. Likewise, disabled women are viewed as being less feminine and weaker than nondisabled women. It is important to view the role of gender in disability from both of these dichotomies (disabled/nondisabled and men/women) because evidence suggests that women with disabilities are at increased risk for poor health and social outcomes that go beyond placing them in "double jeopardy" as a result of sexism and disability bias.

Gender is often regarded as synonymous with sex differentiation, which posits that biologically and physiologically there are only two sexes, male and female. According to the World Health Organization, *sex* refers to the biological and physiological characteristics of male and female animals: genitalia, reproductive organs, chromosomal complement, and hormonal environment. However, transsexual individuals and those born with congenital anomalies such as ambiguous sex organs suggest that categorization of individuals by sex is not clearly differentiated. A broader interpretation of gender suggests that it is a culturally bound interpretation of biological differences. Again according to the World Health Organization, *gender* refers to the socially constructed roles, rights, responsibilities, possibilities, and limitations that, in a given society, are assigned to men and women. In sum, *gender* refers to what it means to be considered "masculine" and "feminine" in a given time and place. In this context, *gender* refers to a set of societal norms, roles, and behaviors that can be ascribed to individuals. For example, men are viewed as being more powerful than women and as exhibiting masculine traits, such as dominance and competitiveness, whereas women are viewed as exhibiting feminine traits, such as passiveness and nurturing. However, persons who are gay or lesbian, bisexual or transsexual provide evidence to suggest that the norms, roles, and behaviors associated with a particular gender cannot be universally applied. It is useful to consider both

sex and gender concepts when addressing health and disability as a practice generally referred to as *gender awareness* or *consciousness.*

DISABILITY FRAMEWORK

Several conceptual frameworks related to the disabling process exist. Two of the most widely used disability taxonomies, those developed by Nagi (1969) and Wood (1975), suggest that there is both an individual role performance component and a social role performance component in the disabling process. In both the Nagi and Wood taxonomies, the "impairment" stage involves abnormality or loss of structure or function at the anatomical, physiological, mental, or emotional level of the individual. Such change requires medical intervention. As end points in the disabling process, Nagi views disability as limitation in the performance of socially defined roles within the larger societal environment. Similarly, Wood suggests that a handicap is a disadvantage that limits or prevents a normal role from being fulfilled. These taxonomies' "disability" and "handicap" stages both involve the notion of performance in a sociocultural context.

These distinctions are important because they parallel the two major sets of understandings of how persons with disabilities are viewed and stigmatized by society. When viewed as deviating from the "normal-bodied" norm, persons with disabilities become medicalized. When viewed as deviating from the "able-bodied" norm, persons with disabilities become second-class members of society.

In the social model of disability, disability is viewed as the discrimination against persons with disabilities that result from mainstream society's orientation toward "able-bodiedness." In this view, disability is a socially constructed phenomenon and those with disabilities find themselves socially oppressed. This is in contrast to more individually derived models in which those with disabilities must learn to cope and accept their status as having the individual and personal burden of disabilities that society views negatively.

The social model argues that two primary components reinforce the notion of disability as a societal negative: medicalization of disability and socioeconomic discrimination. Medicalization of disability can be seen as the ways in which the medical profession claims control of defining disability. Socioeconomic discrimination takes a variety of forms, including discrimination in employment and the strong relationship between poverty and disability. Ample evidence suggests that persons with disabilities worldwide experience multiple disparities in terms of social, economic, and health status compared with those who are not disabled. Specifically, these disparities are exhibited as greater rates of isolation and mental health impairments, higher rates of poverty and unemployment, and increased risk for premature mortality and morbidity.

THE GLOBAL BURDEN OF DISABILITY

According to the 1990 Global Burden of Disease project, a worldwide collaboration of researchers sponsored by WHO and the World Bank and based at the Harvard School of Public Health, several patterns may be seen in the global burden of disability:

- Disability plays a major role in influencing the overall health status of a population.
- The leading causes of death are substantially different from the leading causes of disability.
- Worldwide, almost half (49.4 percent) of all disability due to disease or injury occurs in the young adult age group (15–44 years), one-fifth (18.3 percent) occurs in the early childhood age group (0–4 years), and less than one-tenth (9.3 percent) of the disability burden is due to the incidence of disease or injury.
- The burden of psychiatric conditions has been underestimated.
- Of the 10 leading causes of disability (measured as years lived with a disability) 5 are psychiatric conditions: unipolar major depression, alcohol use, bipolar disorder, schizophrenia, and obsessive-compulsive disorder.
- There are differences by gender with regard to the leading causes of disability due to disease and injury.

Table 1 illustrates how the prevalence of disability differs by gender. The primary indicator used to analyze the burden of disease and injury by cause is years lived with disability (YLD). The 10 leading causes of

Table 1 Ten Leading Causes of Years Lived with Disability by Sex, 1990

Both Sexes			*Males*			*Females*		
Rank	*Disease or Injury*	*Cumulative %*	*Rank*	*Disease or Injury*	*Cumulative %*	*Rank*	*Disease or Injury*	*Cumulative %*
1	Unipolar major depression	10.7	1	Unipolar major depression	7.7	1	Unipolar major depression	13.8
2	Iron-deficiency anemia	15.4	2	Alcohol use	13.6	2	Iron-deficiency anemia	18.9
3	Falls	20.0	3	Falls	19.3	3	Falls	22.5
4	Alcohol use	23.4	4	Iron-deficiency anemia	23.5	4	Osteoarthritis	25.8
5	Chronic obstructive pulmonary disease	26.5	5	Chronic obstructive pulmonary disease	27.0	5	Bipolar disorder	28.8
6	Bipolar disorder	29.5	6	Bipolar disorder	30.1	6	Congenital anomalies	31.6
7	Congenital anomalies	32.3	7	Congenital anomalies	33.0	7	Chronic obstructive pulmonary disease	34.3
8	Osteoarthritis	35.1	8	Schizophrenia	35.7	8	Chlamydia	36.7
9	Schizophrenia	37.7	9	Road traffic accidents	38.2	9	Schizophrenia	39.2
10	Obsessive-compulsive disorders	39.9	10	Osteoarthritis	40.5	10	Obsessive-compulsive disorders	41.6

SOURCE: Adapted from Murray and Lopez (1996).

worldwide YLD account for nearly four-tenths (39.9 percent) of all YLD. As noted above, of these 10 causes, 5 are related to neuropsychiatric conditions (unipolar major depression, alcohol use, bipolar disorder, schizophrenia, and obsessive-compulsive disorder). Unipolar major depression accounts for 11 percent of all YLD worldwide. The other leading causes of YLD include anemia, falls, osteoarthritis, and chronic obstructive pulmonary disease (COPD).

When comparisons are made across gender, differences are also noted in YLD rank ordering and cause. For men, alcohol use (rank 2) and road traffic accidents (rank 9) are among the 10 leading causes of YLD worldwide. For women, anemia (rank 2) and chlamydia (rank 8) are leading causes of YLD globally. There are also differences in the rank ordering of the 10 leading causes of YLD by gender.

WOMEN AND DISABILITY

Most of the literature on gender and disability does not differentiate between women and men. Rather, the focus is on those with disability compared with those without disability. This is due, in part, to the societal stigma attached to those with disability as being "abnormal." This deviance from the norm has been the focus of most work in disability studies, and gender concerns have not been well investigated. Other barriers include social issues such as the feminization of poverty, abuse, violence, and sexual and reproductive rights. However, in recent years research examining the impact of gender on persons with disabilities has pointed to a relative decrease in status of women with disabilities compared with men with disabilities. Some examples:

- Disabled women are poorer than disabled men and are often heads of households.
- Disabled women have lower incomes than disabled men.
- Disabled women are at greater risk of sexual abuse than are nondisabled women.
- Women with disabilities are viewed as "asexual."
- Women with disabilities receive less education than do either nondisabled women or men with disabilities.
- Most disabled students are educated in segregation from students of the opposite sex.
- Women with disabilities have less access to "rehabilitation" services than do men with disabilities.
- There are differences between men with disabilities and women with disabilities in the rates and degrees of disability following heart attacks and strokes.

An estimated 300 million women and girls are disabled worldwide. A majority of these live in resource-poor or developing countries. Given that disability is a dynamic process, changes in gender differences among persons with disabilities can and will occur with increasing worldwide focus on women's rights. As a consequence, cultural taboos may lessen and more information will likely emerge about the disabilities resulting from such practices as female genital mutilation and domestic violence.

Although men and women with disabilities share many similarities, the literature suggests that women with disabilities are at a double disadvantage. This is manifested in a variety of ways, including disabled women's lower levels of participation in societal activities and lower levels of self-concept. In addition, the sociocultural aspects of being a disabled woman take the form of a variety of stigmas, including sexism and ableism.

Societal Participation

Compared with men with disabilities, women with disabilities are more likely to be isolated from general societal participation, including social relationships, education, and employment. This could be due to the general stigma society places on persons with disabilities. With regard to social relationships, compared with disabled and nondisabled men and nondisabled women, women with disabilities are more likely to remain single and, of those who marry, more likely to be divorced or separated. Similarly, women with disabilities are less likely to have children and to have significant relationships. These factors may result in forms of social isolation that may contribute to poorer general health among women with disabilities. Isolation may also be increased by the general lack of mobility due to disability.

With regard to education, women with disabilities are less likely to graduate from high school or to attend college for some period of time. In addition to the amount of education, differences may also exist in the content of the education received by women with disabilities. Comparison of employment rates between women with disabilities and other groups indicates that disabled women have lower rates of labor force participation, lower rates of full-time employment, and lower wage earnings.

Self-Concept

Women with disabilities generally have lower self-concepts than do men with disabilities. In particular, such women often feel the oppression of being disabled, the feeling that they cannot and should not engage in certain activities, and this is reflected in lower self-images and low levels of self-esteem. Such a poor self-concept may come from the woman's family members, who may place guilt on the disabled member as causing inconvenience or, conversely, may have an overprotective attitude toward the disabled woman.

Sociocultural Aspects

The sociocultural aspects of being a woman with a disability include stigma and discrimination. *Sexism* refers to the devalued status of women in comparison with men in society generally. Women are seen as childlike, passive, and dependent. Women with disabilities are often perceived as not being able to fulfill the variety of roles society places on women in general, such as mother, wife, and sexual partner. Likewise, society often views these women as not being physically attractive and thus as being relatively passive, nonsociable, uninteresting, and unintelligent. Needless to say, women of color who have disabilities can experience a third layer of bias. Clearly, women with disabilities bear a disproportionate share of

stigma and discrimination from both internal (self) and external (society) perspectives.

The current global approach to addressing disability includes efforts not only to reduce the incidence and prevalence of disability but also to address the personal, economic, and social consequences of disability and thereby improve the quality of life for disabled individuals, their families, and society. Whatever specific strategies are developed in the future to address the issues related to disability worldwide, the process will be much enhanced by attention to the multiple influences that gender has on persons with disabilities.

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See also Gender, International; India, Impact of Gender in; India, Marriage and Disabled Women in; Invalid Women.

Further Readings

Bagilhole, B. 1997. *Equal Opportunities and Social Policy: Issues of Gender, Race and Disability.* New York: Longman.

Blair, M., J. Holland, and S. Sheldon, eds. 1995. *Identity and Diversity: Gender and the Experience of Education.* Philadelphia: Multilingual Matters.

Bowe, F. 1984. *Disabled Women in America: A Statistical Report Drawn from Census Data.* Washington DC: President's Committee on Employment of the Handicapped.

Chesler, M. 1965. Ethnocentrism and Attitudes toward the Physically Disabled. *Journal of Personality and Social Psychology* 2:877–882.

Gellman, W. 1959. Roots of Prejudice against the Handicapped. *Journal of Rehabilitation* 25:4–6, 25.

Institute of Medicine. (1991). *Disability in America: Toward a National Agenda for Prevention.* Edited by A. M. Pope and A. R. Tarlov. Washington, DC: National Academy Press.

Murray, C. J. L. and A. D. Lopez, eds. 1996. *The Global Burden of Disease.* Cambridge, MA: Harvard University Press.

Nagi, S. Z. 1969. *Disability and Rehabilitation: Legal, Clinical, and Self Concepts and Measurement.* Columbus: Ohio State University Press.

Nagler, M. 1993. *Perspectives on Disability,* 2d ed. Palo Alto, CA: Health Markets Research.

Payne, G., eds. 2000. *Social Divisions.* New York: St. Martin's.

Wood, P. H. N. 1975. *Classification of Impairments and Handicaps.* Geneva: World Health Organization.

Wright, B. 1983. *Physical Disability: A Psychosocial Approach,* 2d ed. New York: Harper & Row.

Websites

General Reference

Global Burden of Disease Project, http://www.hsph.harvard.edu/organizations/ bdu/GBDseries.html

International Burden of Disease Network, http://www.ibdn.net

World Bank, http://www.worldbank.org

World Health Organization, http://www.who.int/en

Women and Disability

Center for Research on Women with Disabilities (CROWD), http://www.bcm.edu/crowd

Women and Disability Resources, http://members.tripod.com/%7EBarbara_Robertson/Women.html

Women with DisAbilities, http://www.4women.gov/wwd/index.htm

GENDER, INTERNATIONAL

THE MEANING OF GENDER

> Gender is the structure of social relations that centres on the reproductive arena, and the sets of practices (governed by this structure) that bring reproductive distinctions between bodies into social processes. (Connell 2002:10)

Why do we need to understand about gender in disability studies? What is the relationship between gender and disability? How are men's and women's experiences of disability similar or different? Indeed, are gender and disability such different concepts given that women have been seen as deformed men and disability is often associated with femininity? In order to address these questions, we must examine the meaning of gender.

Gender is closely connected to sex, although there are different ideas about how sex is usually understood as relating to the biological and physiological body. The term *gender* is often understood to refer to the cultural interpretation of sexed bodies, embedded in the whole apparatus of a society's roles and norms. Thus, a sex/gender binary is set up parallel to that of nature/culture. Gender, as a relationship between sexes in societies, is usually seen as operating hierarchically, with men being more powerful and dominant, and women being less powerful and weaker. These power relations produce stereotypes of masculinity and femininity—traits and behavior that are expected of men and women (see further below). Role expectations of women as nurturers, men as breadwinners, and so on define approved ways to perform gender.

While the simple binary has been persuasive, insofar as there are two sexes involved in biological reproduction, we now know that there are more than two sexes—including transsexuals and people with congenitally ambiguous sex organs—and many ways of performing gender. Far from being a simple dichotomy, gender turns out to be a complicated and evolving realm of meaning making among people with sexed bodies. Gay, lesbian, and transgender individuals suggest the fluidity of these performances and their capacity to change over time and across societies.

Many of these questions go to the heart of understanding disability. The simple binaries have become complicated as we have learned more about the social construction of bodies and the biological influences on human behavior. Nature and culture, sex and gender, have their reflections (although not mirror images) in the distinctions between impairment and disability. The term *impairment* has been used to describe functional limitations accruing to an individual as a consequence of embodied differences, whereas *disability* has been used to refer to a system of social relations that limit an individual in the course of daily life. This simple binary, while heuristically useful, masks the interpenetration of the social and the biological. Gendered analysis of disability has been particularly valuable in demonstrating the web of social and biological factors that disable people, not just women. Gendered analyses address the processes through which both femininity and masculinity are constituted and the implications of these processes for people with impairments, thereby moving beyond the particular focus of feminism on the experiences of women.

THE GENDERED EXPERIENCE OF DISABILITY

Disabled people have often been represented as *without gender,* as *asexual* creatures, as freaks of nature, monstrous, the "Other" to the social norm. In this way it may be assumed that for disabled people gender has little bearing. Yet the image of disability may be intensified by gender—for women a sense of intensified passivity and helplessness, for men a corrupted masculinity generated by enforced dependence. Moreover, these images have real consequences in terms of education, employment, living arrangements, and personal relationships, victimization and abuse that then in turn reinforce the images in the public sphere. The gendered experience of disability reveals sustained patterns of difference between men and women. For people with disabilities gendering is conditional. Age of onset combined with the type of impairment leads to gender expectations.

Gendered studies of disability in Western industrialized nations reveal the following patterns of public and private dimensions. In the public arena:

- More women than men are classified as disabled, particularly as aging populations mean that larger proportions of the elderly are women with impairments.
- Disabled people are much more likely than nondisabled to live in poverty, and disabled women are likely to be poorer than disabled men, especially in developing countries, where women are often heads of households.
- Younger disabled women achieve lower educational outcomes than do men.
- Disabled women are less likely to be in the paid workforce than either men with disabilities or nondisabled women, and in general have lower incomes from employment.
- Women are less likely than men to have access to rehabilitation and to employment outcomes when they do receive rehabilitation.
- The age distribution for disabled women is different from that for disabled men (older versus younger).
- The types of impairments are different for women and men, with women more likely to experience degenerative conditions and men more likely to experience injury-related events.
- Disabled women are more likely than disabled men to experience public spaces as intimidating and dangerous.

In the private and familial arena, disabled women compare with disabled men in the following ways:

- Disabled women are more likely to be living on their own or in their parental families.
- Disabled women are more likely to be divorced and less likely to marry.
- Disabled women are more likely to face medical interventions to control their fertility.
- Disabled women are more likely to experience sexual violence in relationships and in institutions.

- Disabled women experience more extreme social categorization, being more likely to be seen either as hypersexual and uncontrollable or as desexualized and inert.

Moreover, in the developing world, gender patterns in relation to disability indicate the following:

- Poverty hits women and girls harder due to patriarchal property ownership structures.
- Aid is less likely to reach women and girls who are less able to compete in situations of scarcity.
- Disabled women are more vulnerable to domestic violence.
- Disabled girls are likely to find their access to education even more limited than that experienced by girls in general.
- Women disabled by war have few resources with which to survive.
- Disabled women who are sexually abused are likely to have few if any social supports or options.
- Disabled women are less likely to be accepted as refugees by industrially advanced countries (e.g., Australia prohibits the immigration of people with disabilities).

Gender has been widely used within the humanities and social sciences as both a means to categorize differences and an analytic concept to explain differences. In both the humanities and the social sciences, feminist disability studies have emerged partly as a result of attempts to explain gendered experience of disability and partly as a challenge to contemporary feminist theory on gender that fails to take account of disability, such as the work of Judith Butler.

THE PSYCHE AND GENDER

Disability has been used as a powerful metaphor in psychology, particularly as a means to assign to women the status of incomplete or deformed men. In addition, gender stereotypes have been used to characterize disabled people, particularly men, who have been presented as feminized and lacking masculine traits. These approaches have confused the conceptual difference between disability and gender.

Gendered analyses of disability have tried to move beyond these metaphors, to create a disciplined account of the impact on the gendered psyche of disabling social relations. Here four elements are presented: the development of the "normal" individual, the impact of disabling events, support for the survival of the disabled psyche, and strategies for normalization and social role valorization.

Psychological models of individual development are increasingly taking account of gender formation. As the psyche takes form, it develops a sense of self through interaction with others, one result of which is the defining of relations through the lens of gender. This process of identity formation contains a deeply embedded set of responses geared to the hierarchies of value in the able-bodied world. The identities that coalesce are thus both gendered and embodied, affected by the hormonal changes of growth and the social influences of role expectations, peer groups, family, and the wider society. For people with impairments, the reading of them from significant others and the wider society combines with the gendered nature of relations to differentiate them from the "normal" world. For instance, disabled girls may have their desires to be mothers supported by their gender role expectations but simultaneously denied by their disability status.

For people without impairments who experience disabling events later in life, their suddenly changed status creates major conflicts in their expectations and self-images that are reinforced by public perceptions of them as disabled. For instance, women may no longer be able to mother and thus may have their children taken from them in custody battles. Or men may have their masculinity denied and thus face struggles to sustain an affirmed identity. Whatever the situation, in such cases gender is centrally implicated.

Psychologists and social workers can provide support to people with impairments who are seeking to survive their disabilities. Approaches include adjustment and adaptation as key mechanisms of "coping" used in such support; these are themselves gender saturated. Assumptions of appropriate behavior, suitable outcomes, and role allocation reflect professional stereotypes and models, and are often dominated by medical model assumptions about the gendered body.

There is ample evidence that women with disabilities experience major psychosocial problems that

remain largely neglected, including depression, stress, lowered self-esteem, and social isolation. Evidence also suggests that disabled women tend to be directed toward home-based activities, whereas disabled men are likely to be supported into more public and outward-looking opportunities.

People often recognize that disability can undermine masculinity, so many therapies assert traditional masculine identities—for example, encouraging disabled men to play wheelchair rugby. On those occasions when identity assertion occurs for women, it is likely to be about hyperfeminine self-presentation, such as makeup and grooming sessions.

With deinstitutionalization, there has been a growing emphasis on the social education of people with intellectual and developmental disabilities to support their living in the community. The primary orientation, *social role valorization* (SRV), uses a training approach to modify the behavior of people with impairments and thus reduce the disabling impact on them of social stereotypes. SRV adopts a "conservatism corollary" in its individual program plans, seeking to minimize the dissonance created for "normal" people by the presence in their midst of people with significant impairments and high support needs. This means, unfortunately, that training seeks to impose more traditional gender roles, and disabled people are drawn to perform these roles in order to reduce their visibility as stigmatized others.

While much of the professional practice concerned with the link between gender and disability occurs together within psychologically inflected professions, there is a wider social science involvement in the analysis of these questions.

CULTURE AND MEANING

Stereotypes are artifacts of culture that can be understood only through an exploration of their relations to each other in the cultural system. Gender stereotypes interact with disability stereotypes to constitute a deep matrix of gendered disability in every culture, developed within specific historical contexts and affecting those contexts over time. While language is the most analyzed site for the examination of both gender and disability, they interact in many other cultural locations as well—such as in cinema, television, fiction, clothing, body language, and gesture. Thus, cultures sustain the social relations of gendered disability in constant reiterations of stereotypes and expectations.

Put simply, disabled men are expected to behave and express their being differently than disabled women in all cultures, although the manner of these expressions is culturally specific. It is likely, however, that the hierarchies of power—usually male over female, able-bodied over disabled—will set the cultural parameters. In most cultures, too, the subordinate groups are not passive, but have developed strategies of resistance and self-affirmation.

Ironically, the interaction of stereotypes can generate resistance that consists of an embracing of stereotypes—for example, disabled women may be perceived as inappropriate mothers and only have status as receivers of care by others, so their resistance may consist of asserting a desire for a traditional female caregiver role in relation to their own children. Disabled men who are not able to behave in stereotypically competitive masculine ways may adopt a variety of strategies to cope with the stigma they experience from others, such as redefining masculinity as financial autonomy rather than physical prowess, building physical strength in areas of physical capacity (the "supercrip" phenomenon), or creating alternative masculine identities that stress personhood rather than gender roles.

Disabled men and women narrate their experiences in significantly gendered terms, with both the content and styles reflecting the ways in which gender expectations are modulated by disability status. Illness narratives are mobilized to make sense of the experiences, which are in each case centered on the impact on sexual identity, sexual relationships, and gender opportunities. Riessman-Kohler (2003), who has examined masculinity and multiple sclerosis, points to the breakdown of traditional marriage relationships when partners cannot cope with the disease state. She reflects on the importance of moving beyond the analytic binary of male/female sexual identities. She also reveals the analytic binary of able-bodied/disabled, which she argues can force descriptions of experiences into either/or categories rather than allow sensitivity to a complex range of responses and attitudes. When some men find themselves unable to perform

masculine roles (including employment) and resent their decreasing capacity to be independent, self-sufficient, and self-determining, they explore their sexuality and widen their definition of gender identity to include more feminine and bisexual components.

THE SOCIAL REALM

Sociological accounts of gender and disability stress the systemic nature of the social order and its reinforcement of powerful social institutions and their capacity to enact and impose definitions and allocate resources. For disability the most central institutions remain those associated with the medical profession, rehabilitation, and social support. Many other institutions also reproduce patterns of gendered discrimination—such as education, employment, and transport. One of the most potent patterns of discrimination is found in the area of access to and use of public space.

Both gender and disability have traditionally been seen as products of biology. Gender as a result of biology has been thought to determine all manner of social behaviors on the part of men and women. In a similar way, disability as biology has been seen as determining disabled people's choices and behaviors. In the 1970s, feminists attempted to differentiate gender from sex (the social from the biological) to counter the argument that women are naturally inferior and weak. So, too, disability theorists have attempted to separate disability from impairment (the social from the biological).

But it is no longer adequate to separate the social from the biological in this dichotomous way. The social relations of gender and the social relations of disability are now viewed as much more complex and nuanced. The social model of disability has demonstrated that wider power relations (e.g., class relations in capitalist societies) significantly affect the pattern of disability disadvantage, making disability survival into a lottery critically affected by individuals' income and other material resources. Because the model draws on political economy, it emphasizes political and economic processes that generate disabling environments.

For instance, scholars who have analyzed the medical establishment's uses of individualizing and victim-focused ideologies and technologies have argued that disability is devalued because disabled individuals have little economic worth. Rehabilitation is thus geared to prospective productivity. But this ignores the differences between men and women in their economic situations. In order to understand the differential outcomes for men and women, a gendered model that incorporates patriarchal structures into class structures is absolutely crucial.

Lorber (2000) has shown that while social action around disability issues has benefited both women and men, women with disabilities are less likely than men with disabilities to be economically self-supporting or to have spouses to care for them. These patterns, together with conventional norms of femininity, have hindered disabled women's quest for independence. Women thus confront major obstacles not only in relation to overcoming disabling environments, but also in achieving outcomes equal to those of men who are similarly disabled.

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See also Gender; India, Impact of Gender in; India, Marriage and Disabled Women in; Invalid Women.

Further Readings

Abu-Habib, L. 1997. *Gender and Disability: Women's Experiences in the Middle East.* Oxford: Oxfam.

Butler, Judith. 1990. *Gender Trouble: Feminism and the Subversion of Identity.* London: Routledge.

———. 1993. *Bodies That Matter: On the Discursive Limits of "Sex."* New York: Routledge.

Charowa, G. 2002. "Disability, Gender and Food Distribution Situation in Zimbabwe." Retrieved November 2, 2003 (http://www.dpi.org/en/resources/articles/10-10-03_dgfzim.htm).

Connell, R. 2002. *Gender.* Cambridge: Polity.

Corker, M. and S. French, eds. 1999. *Disability Discourse.* Buckingham: Open University Press.

Gerschick, T. J. 2000. "Towards a Theory of Disability and Gender." *Signs* 25:1263–1269.

Gerschick, T. J. and A. Miller. 1994. "Gender Identities at the Crossroads of Masculinity and Physical Disability." *Masculinities* 2(1): 34–55.

Grue, L. and K. Tafjord Laerum. 2002. "'Doing Motherhood': Some Experiences of Mothers with Physical Disabilities." *Disability & Society* 17:671–683.

Lorber, J. 2000. "Gender Contradictions and Status Dilemmas in Disability." In *Expanding the Scope of Social Science Research on Disability*, edited by B. M. Altman and N. Sharon. Stamford, CT: JAI.

Meekosha, H. and L. Dowse. 1997. "Enabling Citizenship: Gender, Disability and Citizenship." *Feminist Review* (Autumn): 49–72.

Nosek, M. A. and R. B. Hughes. 2003. "Psychosocial Issues of Women with Physical Disabilities: The Continuing Gender Debate." *Rehabilitation Counseling Bulletin* 46(4): 224.

Riessman-Kohler, C. 2003. "Performing Identities in Illness Narrative: Masculinity and Multiple Sclerosis." *Qualitative Research* 3(1): 5–33.

Schriempf, A. 2001. "(Re)fusing the Amputated Body: An Interactionist Bridge for Feminism and Disability." *Hypatia* 16(4): 53–79.

Snyder, M. 1999. "Issues in Gender-Sensitive and Disability-Responsive Policy Research, Training and Action." Retrieved (http://www.un.org/esa/socdev/enable/disrppeg.htm).

Thomson, Rosemarie Garland. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature.* New York: Columbia University Press.

GENE THERAPY

Gene therapy is the treatment or prevention of disease through the alteration (through addition or deletion) of genetic material in human cells, tissues, or organs. The term *gene therapy* is also used to describe the manipulation of genetic information already within the cells for the same purpose. However, at present most of the available technology relates to the addition of new genetic information, and many researchers prefer to use the term *gene transfer* rather than *gene therapy* to reflect the fact that the purpose of this work is not always therapeutic. Throughout this entry, however, the term *gene therapy* is used in reference to processes aimed at both the treatment and the prevention of disease.

There are two types of gene therapy: somatic and germ line. Somatic gene therapy modifies any cells except reproductive cells (i.e., sperm and ova). The aim of this modification is to treat or prevent disease in the individual. Many such treatments are temporary, as the genetic material is not permanently integrated into the cell. Germ line gene therapy modifies reproductive or "germ" cells. This includes modification of sperm or ova and altering the DNA in a fertilized egg. The aim of this treatment is to affect the individual who will develop from the reproductive cells or embryo, together with that individual's descendants. However, germ line modifications may also be carried out as part of the therapy for an existing subject, the modification of the germ cells being an inevitable part of the genetic modification overall.

Various possible approaches to gene therapy have been identified. Where a faulty gene exists, a normal gene could be introduced. Alternatively, the faulty gene could be repaired. Another possibility would be to introduce a gene to "switch off" the faulty gene. Gene therapy has also been seen as a way to treat disease rather than to correct inherited disorders. For example, genes that generate specific toxins could be introduced into diseased cells (such as cancer cells) to kill them. It might be possible to engineer resistance to both cancer and HIV/AIDS through gene therapy. If so, such modifications would be both therapeutic and enhancing, since humans are not naturally resistant to cancer or to AIDS. If such modifications affect the germ line, they would also constitute permanent enhancements.

Gene therapy first entered clinical trials (i.e., trials in humans) in the early 1990s. As of January 2004, according to the *Journal of Gene Medicine* clinical trial database, 636 gene therapy clinical trials had either been completed or were ongoing or pending. These trials involve 3,496 patients, the majority of whom are in the United States. The majority have been or are being directed at the treatment of cancer (63 percent) as well as genetic conditions (12 percent) and vascular conditions (8 percent).

ISSUES

Gene therapy raises several social, ethical, and legal issues, including those discussed below.

Playing God

Some objections to gene therapy are based on the view that humans should not "play God" and interfere in the natural order. In response, it may be argued that we already seek to frustrate the course of nature through medicine, whether by using treatments such as antibiotics or preventive measures such as vaccination. If we accept these practices, we cannot consider it wrong to interfere with nature. Viruses, bacteria, and genetic mutations are perfectly natural, after all.

Writing from a theological standpoint, Ronald Cole-Turner (1993) has argued that genetic engineering may be justified where it is consistent with the purposes of God as creator.

Safety

Some critics are particularly concerned about the safety of germ line gene therapy, because any harm caused by this treatment could be passed to successive generations. However, given that any benefits will also be passed on indefinitely, if the probability of the magnitude of possible harms can be brought to an acceptable level, germ line therapy would be both hugely beneficial and highly cost-effective. Concerns about safety (together with other ethical concerns) have been reflected in public policy. In the United Kingdom, the Gene Therapy Advisory Council, which scrutinizes proposals for gene therapy research, will not yet consider proposals for germ line gene therapy research. Similarly, the Recombinant DNA Advisory Committee, which scrutinizes research proposals seeking federal funding in the United States, has stated that it "will not at present entertain proposals for germ line alterations."

Although the successful use of somatic gene therapy has been reported, trials have also shown associated risks. In 1999, a U.S. teenager, Jesse Gelsinger, died after taking part in a trial. In 2000, a group of French researchers announced that they had successfully used gene therapy to treat two infants suffering from severe combined immune deficiency (X-SCID). The researchers treated 11 patients, 2 of whom are reported to have developed a leukemia-like illness. This highlights one of the difficulties foreseen in relation to somatic gene therapy. Vectors may be used to transport correctly functioning genes into the patient's cells. These vectors, which are often viruses, are inserted either through placement into cells that have been taken out of the patient's body *(ex vivo)* or through placement directly into the body *(in vivo).* However, this process may cause mutations that can lead to diseases such as leukemia. Although the viruses are "disabled" so that they cannot replicate, the patient may suffer an immune response, as was the likely cause of Jesse Gelsinger's death. Concern has also been expressed that there is a risk that even the use of somatic gene therapy may affect germ cells. Nevertheless, where gene therapy could be lifesaving or remove oppressively burdensome conditions, and where the alternative is death or severe disability, many would argue that it is ethically justified in spite of such risks, for the risks are to be borne by the subject who would suffer the risks of denial of therapy.

The Introduction of Eugenics?

In addition to safety, another concern has been whether the use of gene therapy is a form of eugenics. Although one can scarcely use the word *eugenics* without invoking events that took place in Europe during the twentieth century, the concept is nonetheless profoundly ambiguous, admitting of both benign and malign interpretations.

Adopting the definition of the adjective *eugenic* as "pertaining or adapted to the production of fine offspring," John Harris (1993:178) has argued that gene therapy is eugenic, but that this in itself is not morally significant. We can consider a scenario in which a woman has had five of her eggs fertilized in vitro and, following usual medical practice, then has two or three implanted. If preimplantation screening reveals that two of the embryos possess disabilities, would it be right to implant these two embryos rather than the others? If we consider it would be wrong to implant the "disabled" embryos, this suggests that disability is something we do not desire and have good reason to reject. It suggests that disability can be identified as "a physical or mental condition we have a strong rational preference not to be in" and a condition that is "harmed" (Harris 1993:180). This approach avoids the task of defining disability by reference to a "normal" human being. Furthermore, it provides an explanation of disability that can be applied to the "potentially self-conscious" (Harris 1993:181) such as embryos and also the temporarily unconscious. It is not based on the subjective viewpoint of the individual or of the future individual concerned.

Thus, according to this approach, gene therapy is eugenic, but it is the treatment parents should adopt when it will avoid disability for their child (on the assumption that the procedure is safe). However,

although parents may harm their child by not preventing avoidable disability, this approach does not state that parents should be compelled to adopt such treatment. Furthermore, to argue that parents should seek to avoid harming their children is not to discriminate against the disabled.

Some observers, such as Solveig Magnus Reindal (2000), have challenged this view of disability. Reindal refers to the distinction between impairment and disability, noting that the fact that an individual has an impairment does not necessarily mean he or she is disabled. Reindal propounds a "social model" of disability, which does not deny the fact that impairments exist but asserts that whether or not impairment leads to disablement depends on numerous other factors, such as the individual's view of the situation, social norms, and societal attitudes. Reindal is critical of "medical models" of disability such as that espoused by Harris. By focusing solely on impairment, Reindal argues, those who are unimpaired are led to make judgments about whether an impaired life is worth living. With reference to gene therapy, she holds that if a medical model is used in debate, those who are disabled will view such discussions as "eugenics in disguise." Such "biological determinist understandings" were, she argues, the foundation of sterilization laws passed in the 1930s. In Bill Albert's (2003) view, gene therapy not only legitimates the medical model of disability but also raises hope that research will lead to new treatments, which is followed by disappointment when these do not materialize.

Enhancement

Debate has also focused on whether gene therapy should be used to enhance individuals. Some enhancements might mirror the effects of other medical interventions currently in use. For example, if it were possible to use gene therapy to generate antibodies to infections such as HIV, this would be an enhancement similar to that provided by vaccination against diseases such as tetanus.

Eventually it may become possible to enhance, or at least alter, attributes other than health, such as height, behavior, and intelligence. However, it is acknowledged that many traits, even if found to have a genetic basis, are likely to be determined by complex interactions among perhaps many genes together with environmental factors. Gene therapy aimed at modifying such traits, even if it were to become possible, lies many years away. However, debate has focused on where the boundary should be drawn between acceptable and unacceptable enhancement, if indeed such a boundary can be defined. Even if it were generally agreed that an appropriate boundary would lie between "disease" and "disorder," there would remain the issue of how these terms are to be defined.

Individual Choice

Some observers have argued that if it were possible to do so, individuals should be permitted to use gene therapy for enhancements. For example, Jonathan Glover (1984) considers that it would be acceptable for individuals to improve their intellectual functioning even if theirs is currently in the "normal" range. In contrast, LeRoy Walters and Julie Gage Palmer (1997) consider it acceptable to use genetic enhancements to enable functioning within the "normal" range, but see further enhancement as more problematic, particularly given issues surrounding resource allocation (see below).

Parental Choice

Further issues arise in relation to the extent to which parents should be entitled to make enhancement choices on behalf of their children or future children. Walters and Palmer consider the issue of parents choosing intellectual enhancement for their children and express concern that this might present opportunities for a new form of child abuse. However, they accept that it might be appropriate for parents to seek some intellectual enhancement for their children; they note also that boundaries might need to be set to limit parental discretion in this area.

John Robertson (1996) considers this issue from the viewpoint of the principle of procreative liberty. He asserts that as reproductive decisions are so important, society has a sound moral basis for ensuring that these decisions are respected. In particular, he highlights the role of the law in this area. In relation to the

selection or control of the characteristics of future offspring, he considers that two questions will need to be addressed. First is the question of whether the characteristic is central to the decision to procreate; only if it is should the law uphold procreative liberty. Second, the extent of any harms that would flow from a policy allowing selection must be considered. In the context of the nontherapeutic enhancement of traits such as intelligence, Robertson argues that even if such decisions do not fall within procreative liberty, they might be argued to fall within the parental right to rear the child after birth. As he points out, the law already enables parents to influence their children's development after birth by sending them to tutors, orthodontists, and so on.

A final issue relates to whether parents should be entitled to choose treatments for their children that will affect future generations. An argument frequently made in this regard is that if the technology were to exist to make the alteration in the first place, the technology needed to reverse the process would also likely be available.

Justice

Resource Allocation

It is widely acknowledged that gene therapy technology will initially be very costly. Given that treatments cannot be provided to all those who might want to receive them, this raises long-standing debates concerning issues of justice and political theory. A libertarian approach, as espoused by Robert Nozick (1974), would suggest that access to such treatments should be based on free-market principles. In other words, those who can afford them should be entitled to them (although Nozick does foresee the need for some restrictions). Alternatively, if justice is viewed in terms of equality for all individuals, then access to treatment should be available to all on an equal basis. However, although there is no agreement as to how this principle should be applied in practice, it is clear that it would be unethical to deny therapies to some unless and until they can be provided for all. The development and availability of new and effective therapies cannot wait on agreement as to just principles of distribution.

Benefit

Additional questions relating to justice arise even if we resolve the problems associated with the allocation of treatment. Once such treatments have been allocated, classes of people may develop who are in stronger positions than others in certain respects. For example, individuals who have received therapy to slow down the aging process may be more attractive as employees, given their longer life expectancy.

Changing Humanity

Francis Fukuyama (2002) asserts that developments in biotechnology, such as gene therapy, have the potential to alter human nature and so lead us into a "posthuman" era. He therefore urges the establishment of regulation to ensure that we are not driven by technological progress to abandon values we might wish to protect. In contrast, Gregory Stock (2003) sees the potential to re-create ourselves as an expression of our humanity and argues that this process should be subject to minimal regulation.

Gene therapy is a new technology, and as yet it is unclear to what extent the expectations surrounding it will be fulfilled. It raises many of the same issues that are already under discussion in the larger health care arena, such as how limited resources should be allocated. It also raises specific issues linked to the possibility of affecting future generations and the consequences that might result.

—Catherine Stanton and John Harris

See also Eugenics; Genetic Counseling; Genetics; Genetics and Disabilities: Social and Ethical Dilemmas.

Further Readings

Albert, Bill. 2003. "Curing What? Curing When? Curing How? Gene Therapy and Disabled People." Pp. 115–120 in *Key Issues in Bioethics*, edited by R. Levinson and M. J. Reiss. London: Routledge Falmer.

Cole-Turner, Ronald. 1993. *The New Genesis: Theology and the Genetic Revolution*. Louisville, KY: Westminster/John Knox.

Fukuyama, Francis. 2002. *Our Posthuman Future: Consequences of the Biotechnology Revolution*. London: Profile.

Glover, Jonathan. 1984. *What Sort of People Should There Be?* Harmondsworth, UK: Penguin.

Harris, John. 1993. "Is Gene Therapy a Form of Eugenics?" *Bioethics* 7:178–187.

———. 1998. *Clones, Genes and Immortality*. Oxford, UK: Oxford University Press.

Nozick, Robert. 1974. *Anarchy, State and Utopia.* New York: Basic Books.

Recombinant DNA Advisory Committee. 2004. "About Recombinant DNA and Gene Therapy." Retrieved April 6, 2005 (http://www4.od.nih.gov/oba/rac/aboutrdagt.htm).

Reindal, Solveig Magnus. 2000, "Disability, Gene Therapy and Eugenics: A Challenge to John Harris." *Journal of Medical Ethics* 26:89–94.

Robertson, John A. 1996. "Genetic Selection of Offspring Characteristics." *Boston University Law Review* 76:421–482.

Stock, Gregory. 2003. *Redesigning Humans: Choosing Our Genes, Changing Our Future*. New York: Mariner.

Walters, LeRoy and Julie Gage Palmer. 1997. *The Ethics of Human Gene Therapy*. New York: Oxford University Press.

Websites

European Society of Gene Therapy, http://www.esgt.org

Journal of Gene Medicine Clinical Trial Database, http://www.wiley.co.uk/genetherapy/clinical

GENETIC COUNSELING

Genetic counseling is a process of communication in which a specially trained professional, often but not always a doctor or nurse, meets with an individual, couple, or family to provide information about a genetic condition that has affected the individual, couple, or family or may do so in the future.

The 1940s saw the establishment of genetic counseling clinics in both the United States and Great Britain. Initially, the purposes of these clinics were to aid in the delivery of eugenics policies and to control population growth among specific ethnic groups. The purpose of the clinical practice of genetic counseling has now changed considerably, and such counseling is available in most developed countries. The focus of modern genetic counseling is to provide people with balanced information and nondirective support so that they can make informed decisions regarding issues related to genetics. The expansion of genetic knowledge and improvement of diagnostic techniques has led to an expansion in the profession since the late 1990s, and professional courses in genetic counseling are taught worldwide.

WHO RECEIVES GENETIC COUNSELING AND WHY?

Genetic counseling should be an integral part of genetic testing at the points of the life cycle discussed below.

During Pregnancy Planning

Couples who are planning pregnancies often seek the assistance of genetic counselors when one or both of the partners themselves, one or more of their existing children, or other family members are already affected by genetic conditions. Members of ethnic communities in which recessive genetic conditions are particularly prevalent also frequently seek genetic counseling during pregnancy planning. The genetic counselor gathers relevant information from the counselees to assess their risk of passing on a particular condition to the next generation. DNA testing (e.g., from a blood sample) is often required for a clear diagnosis.

During Pregnancy

In developed countries, it is now routine for pregnant women, especially those over 35 years old, to be offered some form of genetic testing. Noninvasive screening tests such as ultrasound or serum screening, conducted between 10 and 20 weeks of pregnancy, can provide information about whether the fetus is developing normally or is at increased risk (greater than 1 in 250) of being affected by a chromosomal condition (e.g., Down syndrome) or neural tube defect (e.g., spina bifida). Usually, these tests allow counselors to provide risk estimates, not conclusive results. Diagnostic tests such as amniocentesis or chorionic villus sampling (CVS) are performed after a positive screen result to obtain accurate results for chromosomal conditions such as Down syndrome. However, these tests also carry some risk of miscarriage (approximately 1 percent). Population pregnancy screening can identify only a limited number of common genetic conditions; most genetic conditions are rare and difficult to detect.

If a diagnostic test reveals a positive result (i.e., that the fetus is affected by a genetic condition), the woman must decide whether to terminate the pregnancy

or continue with it and give birth to a disabled child. At this point, it is essential that the woman receives unbiased and accurate information about the relevant condition and feels supported in making the right decision for her.

Most women who undergo screening or testing in pregnancy will receive genetic counseling in some form, possibly from a midwife, general practice physician, or obstetrician rather than an individual who specializes in genetic counseling. Such counseling may be cursory and directive, sometimes even eugenic. Both before and after testing, a woman should have access to the services of a trained genetic counselor to ensure that she can make genuinely informed decisions and be confident that she has made the right ones, as terminating a wanted pregnancy can be as distressing as giving birth to a disabled child. Because the screening procedures used today are often noninvasive, and because many times full information on her options is not readily available, a woman may end up drifting into a situation in which she is forced to make a difficult choice about termination, whereas if she had been fully informed up front, she may have declined to embark on the "antenatal testing conveyer belt."

Childhood

Most babies in the developed world undergo genetic screening within the first 72 hours of life, through blood taken from a heel prick (Guthrie test). The blood is screened for a number of genetic conditions for which early detection and intervention can offer increased chances of effective management; these may include cystic fibrosis and phenylketonuria as well as rarer metabolic conditions. Although hospitals seek parental consent prior to taking an infant's blood, no formal genetic counseling is provided unless it is requested or a positive result is found. Frequently new mothers are unaware that the tests are being done, or, if they are aware, give very little consideration to what such tests could disclose.

Families and individuals who are directly affected by genetic conditions may also seek genetic counseling. They may want to gain more information about particular conditions and why those conditions affect them, to explore the specific ways in which genetic conditions affect them, to seek advice about managing their conditions, and/or to meet others who are similarly affected. Many genetic counselors specialize in certain groups of genetic conditions, such as bone dysplasias and metabolic conditions. Such counselors tend to be very familiar with the day-to-day effects of living with particular genetic conditions and can help individuals to find appropriate support groups.

Adulthood

One of the largest growth areas in genetic testing is that of predictive testing—that is, testing aimed at determining whether a person is at risk of developing a late-onset genetic condition (e.g., Huntington's disease, some forms of cancer) or has a genetic predisposition to a common disease (e.g., heart disease). Before individuals begin the predictive testing process, genetic counseling is advisable. Discovering that one is going to develop an incurable late-onset disease such as Huntington's can be highly traumatic. Individuals in affected families may not wish to know their status if there is nothing they can do to avoid their fate. Even when preventive action is possible—for example, mastectomy to minimize the risk of breast cancer—this knowledge itself can be traumatic. Also, some recommended preventive actions may be hard for individuals to comply with (e.g., behavioral or dietary changes). There is evidence that many individuals have difficulty understanding risk percentages: Without the benefit of counseling, some may underestimate their risk; alternatively, some individuals who receive diagnoses of genetic conditions may believe they are facing an unavoidable fate even though preventive action may be effective.

WHAT HAPPENS IN A GENETICS COUNSELING SESSION?

A typical genetics counseling session starts with the professional's ascertaining what it is that the counselee (usually called the *proband*) expects or wants to get out of the session. The professional spends a large proportion of the initial session taking the proband's pedigree, or recording the proband's family tree.

A pedigree usually includes the names, birth dates, ages, and causes of death and brief medical histories of the proband's family members over three or more generations. The pedigree may assist the counselor in calculating the likelihood of the proband's being affected by a genetic condition or passing it on to future generations. A geneticist may also physically examine the proband during the first session. Once all of the relevant information has been collected, the proband, counselors, and anyone else who may be present (e.g., family members, partners, other medical professionals) discuss the implications. This is the time when the proband asks questions and receives explanations from the counselor. Often, a clear diagnosis cannot be given based on the pedigree and a physical examination. In such a case, the counselee may be sent for follow-up diagnostic testing (e.g., blood tests, X-rays, MRI). Following a genetic counseling session, the counselor usually sends the counselee a letter documenting what was discussed during the session, giving details of the relevant genetic condition, and providing information about available support services and how to follow up the session.

WHAT ARE THE ISSUES FROM A DISABILITY PERSPECTIVE?

Many within the disability rights movement view the medical advances being made in genetics as a "return to the eugenic past"; they find the concept of genetic counseling confronting, inappropriate, and part of an eradication process. Societal investment in diagnostic technology and screening programs sends a message that disability is a major problem that should be prevented at all costs. The language of "risk," "abnormality," "burden," and "medical tragedy" is prejudicial to disabled people and ignores the high quality of life that many disabled people achieve. From this perspective, genetic counselors are implementers of eugenic policies, despite their professional rhetoric of supporting individual choice.

For individuals who are affected by genetic conditions, the process of genetic counseling can be a confronting experience. The aim of genetic counseling sessions for disabled persons should be exactly the same as for individuals without disabilities. But disabled persons who choose not to have children with the same conditions as theirs may feel that they are somehow "validating" society's view or belief that their own lives are not valuable or worth living. Deciding whether or not to take the risk of passing on a genetic condition can be challenging to a disabled person's sense of self, raising problematic emotions. A good genetic counselor should be able to provide such a client with accurate, balanced, and understandable information; help the counselee to explore his or her feelings about possible outcomes; and, most important, support the counselee through whatever choice he or she makes.

Since the 1990s, genetic counselors' stated aspiration to provide nondirective counseling has been debated, and some observers have questioned whether nondirective counseling is achievable. They argue that the language in which counselors present risks and the information they provide about disability are bound to influence counselees' decision making. In practice, counselees often look to genetic counselors for direction, asking, in essence, "What would you do in this situation?" Genetic counselors have to be able to support those they counsel whatever they decide; thus counselors need to have a heightened awareness of their own prejudices and moral stands on issues surrounding genetics and, more specifically, disability.

—Caroline Bowditch

See also Genetics; Genetics and Disabilities: Social and Ethical Dilemmas.

Further Readings

Clarke, A. 1991. "Is Non-directive Genetic Counselling Possible?" *Lancet* 388:998–1001.

———, ed. 1994. *Genetic Counselling: Practice and Principles.* London: Routledge.

Harper, J. 1981. *Practical Genetic Counselling.* Bristol, UK: John Wright & Sons.

Kenen, R. H. 1984. "Genetic Counseling: The Development of a New Inter-disciplinary Field." *Social Science & Medicine* 18:541–549.

Websites

Association of Genetic Nurses and Counsellors (UK), http://www.agnc.co.uk

Genetic Counselling: Coping with the Human Impact of Genetic Disease (a comprehensive and understandable look at the

evolution of genetic counseling), http://www.accessexcellence.org/AE/AEC/CC/counseling_background.html
International Society of Nurses in Genetic Counselling, http://www.globalreferrals.com/isong.html
National Society of Genetic Counselors (USA), http://www.nsgc.org/index.asp

GENETICS

The science of genetics has an increasingly powerful influence on contemporary ideas about the causes of disability and how impairment might be cured or—perhaps more controversially—prevented. It is important to be clear from the outset that "genetics" is no longer restricted to the ways in which characteristics, including impairments and chronic disease, are inherited. With the development of sophisticated molecular techniques, geneticists today are equally interested in uncovering the genetic bases for all the biological processes that keep organisms going and that, if disrupted, can contribute to disease or disability. This entry gives a brief outline of some key genetic concepts and goes on to discuss the relationship between genes and disease, the contribution of the Human Genome Project to genetic knowledge, recent developments in genetic medicine, and some issues in genetics that are of particular relevance to disability.

SOME KEY GENETIC CONCEPTS

As the study of the transmission of characteristics between generations, genetics has existed for more than 100 years. The early history of the discipline was dominated by attempts to understand *patterns* of inheritance while at the same time trying to identify the *mechanism* through which characteristics are transmitted. It was not until the 1940s that the chemical deoxyribonucleic acid (DNA) was conclusively shown to play a key role in heredity, and not until 1953 that a plausible three-dimensional structure for the DNA molecule was proposed. As Francis Crick and James Watson noted in the paper publishing this result, the structure of DNA also gave clues to genetic mechanisms. Over the next few decades, enormous effort was devoted to unraveling the fundamentals of gene action.

According to the simplest model of gene action (and it should be noted that even among biologists there is disagreement over the details and scope of models of gene action), genes give rise to proteins in a series of steps. The DNA sequence of a gene specifies ("codes for") the production of a related type of molecule, messenger RNA, which in turn specifies the sequence of constituent amino acids in a protein. Proteins play a number of diverse and crucial roles in the development and maintenance of an organism, forming structural components (e.g., the constituents of muscle), enzymes that regulate biochemical pathways, and components of the hormonal signaling systems of the body.

Although we often speak casually of a "gene for" a disease, as in the "cystic fibrosis gene" or the "Huntington's disease gene," this is a shorthand that can be misleading. Genes are not *there* to cause disorders; rather, disorders arise when changes (or mutations) in genes alter the production of proteins required by the organism. So the "cystic fibrosis gene" encodes a protein that transports ions across cell membranes. It is mutant forms of this protein that do not perform their transport function adequately and result in the condition called cystic fibrosis. Similarly, the commonest form of hereditary hearing impairment in European and American populations results from mutations in the cx26 gene, the unmutated form of which specifies the production of a gap junction protein, connexin 26.

GENETIC DISORDERS

Single-gene, or *monogenic,* disorders are caused by mutations in the DNA sequence of just one gene. More than 6,000 monogenic disorders have been identified, and these affect approximately 1 in 200 live births. They include some of the best known and most studied genetic disorders, such as cystic fibrosis (CF), sickle-cell anemia, achondroplasia, and Huntington's disease (HD).

Monogenic disorders may show *dominant*, *recessive,* or *sex-linked* inheritance. People who inherit only one copy of a mutated gene are described as *heterozygous* for that gene, whereas those with two copies are *homozygous.* Where a condition is dominantly inherited (e.g., achondroplasia, HD), a person need inherit only one copy of the mutated gene in order for the condition to be apparent (that is, for the *genotype,* or genetic constitution, to be expressed in

the *phenotype*). For recessive disorders, inheritance of two copies—that is, one from each parent—is necessary; a heterozygote will usually be phenotypically normal but be a carrier, and so can still transmit the mutated gene to his or her children. Probably the best known example of a recessive genetic disease is CF. In sex-linked disorders, the abnormal gene is on one or other of the so-called sex chromosomes, and this often means the condition occurs only in males. Sex-linked conditions include fragile X syndrome and Duchenne muscular dystrophy.

Geneticists and genetic counselors often show what seems to be a disproportionate interest in vanishingly rare monogenic disorders. This is because these disorders are relatively easy to diagnose and usually have straightforward inheritance patterns, so the inheritance may have been well characterized by classical genetics even before the relevant gene was identified. Nevertheless, it is now thought that most conditions of medical interest are *polygenic,* with numerous genes making greater or lesser contributions to the phenotype, alongside environmental factors such as diet and exposure to pollutants. Tracking the inheritance patterns of these disorders is difficult unless the gene loci have already been identified. Examples of conditions for which some of the genes involved have been tentatively identified include breast cancer, heart disease, asthma, and diabetes.

Mitochondrial disorders are much rarer genetic conditions caused by mutations in the DNA carried by mitochondria, small organelles that are found in cells and that carry their own tiny pieces of DNA.

In addition to genetic conditions there are *chromosome disorders*. These are larger-scale abnormalities in which entire chromosomes may be lost or duplicated, or show major structural changes (such as translocations). Probably the best known chromosomal disorder is trisomy 21, or Down syndrome, in which the affected person's cells contain three copies of chromosome 21 instead of the usual two.

THE HUMAN GENOME PROJECT

The Human Genome Project (HGP), an international effort to specify the 3 billion base pairs that make up the DNA sequence of the entire human genome, produced its first draft in June 2000. A key rationale for the massive investment of money and effort in the HGP is that the more we know about gene sequences, the more we will understand—and be able to prevent—disease and disability. Even at this early stage, the genome sequence has thrown up some interesting observations. For instance, only about 5 percent of the entire genome seems to contain sequences that actually do code for proteins, while the function of the remaining 95 percent remains unknown.

Nevertheless, it has rapidly become clear that the expanding knowledge of human genomic sequences will, at first, do no more than enable us to diagnose more genetic variations. The number of loci being linked to disorders is growing day by day, and this straightforward increase in diagnostic ability is coming onstream well before the genome sequence has provided much in the way of greater understanding of the complex developmental pathways that lead from gene to phenotype. Any possible therapeutic interventions lie even further in the future.

GENOTYPE, GENE ACTION, AND PHENOTYPE

Genetics' understanding of the route from gene to living organism is still very limited. The earliest and simplest model (the Central Dogma) held that DNA makes RNA makes protein, makes a particular phenotype. Thus, a given DNA sequence straightforwardly determines the final appearance of a characteristic. Mounting experimental evidence has shown that, although broadly correct, this model is inadequate. For example, it is clear that the molecular structure of genes is more complex than was once thought. There may be ambiguity about which DNA sequence elements in reality form a gene, multiple proteins can be produced from a single gene, and the protein product can be regulated in unexpected ways. Furthermore, molecular biologists now realize that genes in a genome interact with each other, and with the nongenetic aspects of the whole organism, such that facile extrapolation from experimental setup to the living individual may be misleading. And finally, the environmental context may also interact with the genetic constitution to produce the resulting phenotype in ways that are not predictable.

Equally, since any given protein can be implicated in a host of physiological functions, many genes are

pleiotropic—mutations in them will have numerous phenotypic effects. This is why many genetic disorders are classed as syndromes identified by characteristic constellations of signs and symptoms. For example, genes such as cx26 have been identified where mutation leads to hearing impairment, but there are also many genetic disorders that *include* hearing impairment among other features. Whether we consider the relevant genes to be primarily to do with hearing impairment or primarily associated with one of the other characteristics will depend more on our point of view than on the biology of the gene.

What all this means is that genetic determinism, the idea that the characteristics of individuals (and, in the extreme, their whole lives) are determined exclusively by their genes, must be abandoned. At the clinical level, it means that even for well-characterized genetic lesions it is rarely possible to predict exactly what the phenotypic consequences will be for each individual. In terms of disability, it means that the story is not as simple as "reading off" an impairment from a gene sequence, let alone understanding how that impairment will be experienced as disability. It is salutary to remember this when evaluating claims that the sequencing of the human genome will *by itself* increase our understanding of disability and illness.

GENETIC VARIATION

Perhaps the most provocative observation of the HGP is the sheer amount of variation between different people's genomes (known as *genetic polymorphism*). Each individual's genome differs slightly from everybody else's, and moreover everybody's genome carries a number of polymorphisms that have no phenotypic consequence, either because the change for some reason does not affect the production of a gene product or because the mutation is recessive and is compensated for by the normal copy inherited from the other parent.

According to standard evolutionary theory, this high degree of genetic variation is necessary to provide the raw material for adaptation to changes in selective environmental pressures. Any group of organisms, however currently well adapted they are to their habitat, needs to contain a reservoir of phenotypic diversity so that if things change (the environment gets hotter or wetter, food becomes scarcer, a new predator comes along), some individuals will find themselves flourishing better under the new conditions. Randomly generated genetic variation helps provide this diversity. Some of the variation will be extreme, producing phenotypes that would be regarded as impairment or disabling under any circumstances; examples here might be osteogenesis imperfecta (brittle bone syndrome) and Gaucher's disease. But even in some cases of apparently harmful mutations, there may be hidden advantages. Although both sickle-cell anemia and CF are disadvantageous, often painful, and life-shortening diseases for homozygotes, there is evidence that sickle-cell heterozygotes (carriers of one copy of the mutant gene) have greater resistance than noncarriers to malaria, and CF carriers have similar improved resistance to cholera.

GENETIC CAUSES OF DISABILITY

A focus on genetics tends to obscure the fact that a relatively small proportion of impairment is directly attributable to genetic causes. It is notoriously difficult to estimate the number of disabled people in any given population because of international differences in definitions of disability and in the methods used to collect the data, and these factors also make it impossible to compare the causes of disability across countries. However, the U.K. 1991 census gives a figure of 12.2 percent for the proportion of people with disabilities (Office of Population Censuses and Surveys 1993). Of this total, perhaps 10 percent may be directly attributable to monogenic disorders. Another, unknown but still probably rather small, percentage will be disabled by polygenic conditions such as heart disease or diabetes and its complications. But it remains the case that *most* disability is caused by events that occur after birth: aging, illness, and trauma, including war.

The fact that we can identify the inheritance pattern or can do a genetic test tells us something about the strength of the genetic contribution to a condition, but it may not tell us very much about the most significant causes of that condition in real life or its severity or prevalence. Prenatal testing for Down syndrome has been widely available for many years in Europe and the United States, not because Down syndrome is the

most devastating of all genetic disorders but because trisomy 21 is easy to detect by ultrasound and on a chromosome spread. Conversely, major depression, which according to many surveys is the condition with the most disabling global impact, has not been unequivocally linked to any gene loci and will probably turn out to have a multifactorial etiology. This is an important point, because it is tempting to assume that genetic knowledge is focused on (the most) severe or significant conditions, or that the existence of a genetic test reflects how severe the condition is, and this is not always true.

GENETIC MEDICINE

Until recently, genetic medicine was restricted to using classical genetic methods to study the transmission of familial disease and providing genetic counseling to affected individuals. The new genetics has not only made genetic diagnosis much more targeted and accurate, as more and more gene loci are identified, but has also opened up a range of novel interventions. Some of these are already part of clinical practice, whereas others are more or less likely to arrive in the foreseeable future. All have practical and ethical implications for the conceptualization of disability.

Prenatal screening has become standard antenatal practice in most parts of the developed world. To date, prenatal screening has relied on ultrasound scanning of the developing fetus, which detects only a few gross abnormalities, and examination of the fetal karyotype for chromosome disorders following amniocentesis or chorionic villus sampling. Again, as gene loci are identified it will become possible to test fetal genetic material specifically for genetic variations. And as with earlier forms of screening, if the test result is positive—that is, if an anomaly is detected—the question the parents then face is whether to terminate the pregnancy or not. Given that many more conditions will be diagnosable by genetic testing than by ultrasound or karyotyping, the number of affected pregnancies is predicted to increase. (Figures for the United Kingdom in 2000 indicate that about 1,760 of the total 175,542 legal terminations were performed solely because of fetal abnormality; Office for National Statistics 2001, Table 10.)

Preimplantation genetic diagnosis (PGD) is a technique that combines in vitro fertilization (IVF) with genetic diagnosis. After "test-tube" embryos are produced through IVF, they can be tested for the presence of disease-associated genes before a decision is made regarding whether or not to transfer them to the future mother's uterus to continue the pregnancy.

Both kinds of prenatal diagnosis are loaded with the same questions about what detecting the presence of a gene locus actually means for the life of the person who carries it (or will carry it if the pregnancy is continued to term or the embryo implanted). The ambiguities of the relationship between genotype and phenotype outlined above have to be borne in mind here. Other ethical questions are raised by carrier testing—where the embryo or fetus is heterozygous for a genetically recessive condition that, because it is recessive, will not directly harm the baby itself.

Genetic testing can also be done *postnatally,* in newborn babies, during childhood, or at any stage of adult life. The aim of this testing may be to *confirm a diagnosis* made on clinical grounds, perhaps to distinguish two similar disorders from each other, which may be necessary to provide the appropriate treatment or give the right prognosis. In other cases, postnatal genetic testing may be *presymptomatic.* Presymptomatic genetic testing may be offered for disorders that develop later in life, the best known example probably being Huntington's disease. HD is a late-onset autosomal dominant condition in which symptoms of neurological degeneration generally first appear when the individual is aged 40 or older. The gene responsible for HD produces an aberrant version of the protein huntingtin. Until it was identified, people who knew they were at risk of the disease could only wait to see if they developed symptoms. In 1983 the gene was located, and in 1993 it was cloned. Since then it has been possible for at-risk individuals to determine their genetic status—if they want to.

Moving beyond diagnosis, the identification of genes strongly associated with particular characteristics opens up the possibility of *gene therapy.* This involves removing an impairment by replacing a variant gene that plays a significant role in the development of the condition with a normally functioning gene. Numerous disorders are potentially treatable by

gene therapy, including classic single-gene diseases such as CF and muscular dystrophy, but also more complex conditions such as diabetes, cancer, and AIDS. Although the idea behind it is straightforward, technically gene therapy is highly complicated. Among the problems that have to be overcome are delivering the gene to enough cells to be useful, to the right type of cell to correct the defect (e.g., into the epithelial lining of the respiratory tract to treat CF). The exogenous gene must be expressed as the right protein at the right time (which demands a good understanding of these processes) and must not interfere with the normal functioning of any other gene or cause a new clinical problem. Clinical trials of gene therapy began in the early 1990s and were successful in treating some rare blood disorders, but by the early years of the twenty-first century no form of gene therapy is in routine clinical use, and there is skepticism about whether the technical barriers will ever be overcome successfully enough to make it a practical clinical intervention.

A more realistic use of genetic information is *pharmacogenomics.* The idea here is to understand the genetics behind the physiological responses to medication. When people take a drug, most respond as expected, but a minority prove to be more sensitive or less sensitive, fail to respond at all, or show unusual or dangerous side effects. This variation can make treatment dangerous, time-consuming, and expensive; identifying which class of antihypertension drug a patient will respond best to, for example, is generally a matter of trial and error over weeks or months. Much, although not all, of the variation in individual response to drugs can be traced back to genetic differences, and the idea behind pharmacogenomics is to use genome data to identify which genetic compositions make people best or least suited to treatment with particular pharmaceuticals.

GENETICS, ETHICS, AND DISABILITY

Genetics is a discipline that has grown up in close association with medicine and with developmental biology, both of which make it conceptually relevant to thinking about disability. Moreover, advances in genetic medicine provide a range of new or foreseeable interventions in disability. Hence it can be argued that the ethics of genetics and disability are especially pertinent to each other. Over the years, writers in disability studies, disability activists, bioethicists, and others have raised concerns about all of the genetic medical technologies outlined above. Although the practical implications have received most attention so far, the impact of genetic thinking on disability ethics—and the impact of a disability perspective on genetic ethics—may have more subtle but equally far-reaching effects.

Prenatal genetic screening and PGD both raise the specter of what is frequently referred to as "eugenics," although many scholars are not convinced that contemporary genetic selection is directly comparable with the well-characterized eugenics movement of the twentieth century. The disability critique suggests that selection against fetuses or embryos on the grounds that they have detectable impairments is based on unexamined prejudices about living with genetic disorders. These prejudices are encouraged by societal unwillingness to accommodate to disability and by a model of disability that sees it as a biomedical (and currently genetic) issue. The expressivist argument claims that selecting against fetuses and embryos with genetic disorders sends out a negative message to disabled people, and to society as a whole, about the value of disabled lives. Similar arguments might be made about any form of therapy, in that removing an impairment could be interpreted as a message that the person is more acceptable without the impairment than with it. But therapy does not involve the same existential life-or-death moral choices that are clearly part of prenatal genetic screening or PGD. Postnatal genetic testing may exacerbate the existing marginalization of disabled and chronically ill people, generating a new underclass of people and families with genetically detectable disorders who may be discriminated against in health or life insurance, employment, education, or other areas—even when they are presymptomatic. Pharmacogenomics has been criticized for threatening the same on a grander scale in which whole groups of people are marginalized because their genetic constitutions make them less attractive to pharmaceutical companies interested in developing drugs targeted at the profitable majority.

Lurking behind the regulation of the practice of genetic medicine, however, are wider ethical issues that extend beyond the topic of disability as such. Trying to set limits to prenatal screening or to gene therapy means taking a closer look at some fundamental but often unexamined community beliefs about the goodness of choosing the kind of people we want to have, the value of choice in general, and whether human diversity has any moral or metaphysical meaning. This set of questions in turn links to a discussion of the contemporary significance of human genetic data: how genetics' scientific authority confirms sequence data as the most fundamental description of an organism and whether the current dominance of genetics is impoverishing our repertoire of culturally available models of what it is to be a human being. The ethical dimension of genetics will necessarily focus on the proximate, practical applications, but it will become increasingly necessary to consider the broader moral background as well.

WHAT DOES GENETICS HAVE TO SAY ABOUT DISABILITY?

There is no doubt that genes make a contribution to many illnesses and disabilities, but the level of that contribution, and exactly how gene action interacts with environmental and social factors, is likely to be different for every condition. For some, the genetic influence is overwhelmingly strong, and here genetics can offer an understanding of pathology and, potentially, therapy. For others, genetic knowledge will never do more than offer a partial insight into the etiology, and nongenetic interventions (changing working conditions, for example) are likely to remain the most effective.

The disability rights movement has often been skeptical of or hostile toward genetics. The major concrete objection is that genetic diagnostic technologies will be abused for eugenic ends. But genetic science has also been condemned as just another way of locating the source of disability in an individual's deviation from the (genetic) norm, simply acting to reinforce the undesirable methodological and political individualism of the medical model of disability.

Genetics certainly has the potential to do this, alongside an equally worrying potential to divert attention and resources away from any nongenetic etiologies or to encourage the misclassification of all forms of genetic variation as pathological. Arguably, these potential misuses are not inevitable. They will depend on the social and economic climates in which genetic knowledge is put to use. It is just as conceivable that the information about human genomes generated by the HGP can radically and positively destabilize some entrenched assumptions about norms, normality, and deviation. As described earlier, the HGP provides material evidence of the huge degree of interindividual genetic variation, with many apparently "normal" people identified as the unwitting bearers of highly atypical genetic sequences. The implication of this is that in genetic terms, any line running from normality to defect, or normal to abnormal, is a continuum along which the cutoff points are determined by the needs of human groups rather than by biology. Extreme variations would impair or disable under any circumstances, but for others the point along the continuum where "variation" becomes "impairment" is dependent on environmental, cultural, and social factors. So, for example, many people with genetic short stature claim that they are chiefly disabled by society's inability to accommodate to their size. As another example, the effect of a genetic variation that reduces reading ability (there is evidence for a genetic component in dyslexia) is unlikely to have been experienced as problematic in preliterate societies. By this interpretation, genetics supports the radical consensus within disability studies that disability cannot be theorized as a fixed, stable dichotomous category. The model in which there are two groups of people, one with "the" normal genome and the other made up of people with deviations from that genetic norm, is no longer tenable, and it is genetic knowledge that makes its abandonment necessary.

—Jackie Leach Scully

See also Bioethics; Biological Determinism; Ethics; Eugenics; Gene Therapy; Genetic Counseling; Genetics and Disabilities: Social and Ethical Dilemmas; Health; Medicine; Sterilization.

Further Readings

Judson, Horace Freeland. 1996. *The Eighth Day of Creation: Makers of the Revolution in Biology.* Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press.

Kay, Lily E. 2000. *Who Wrote the Book of Life?* Stanford, CA: Stanford University Press.

Keller, Evelyn Fox. 2002. *The Century of the Gene*. Cambridge, MA: Harvard University Press.

Kirschner, K. L., K. E. Ormond, and C. J. Gill. 2000. "The Impact of Genetic Technologies on Perceptions of Disability." *Quality Management in Health Care* 8:19–26.

Marteau, Theresa M. and Harriet Drake. 1995. "Attributions for Disability: The Influence of Genetic Screening." *Social Science & Medicine* 40:1127–1132.

Office for National Statistics. 2001. *Abortion Statistics 2000.* London: Her Majesty's Stationery Office.

Office of Population Censuses and Surveys. 1993. *1991 Census Report for Great Britain Part 1.* London: Her Majesty's Stationery Office.

Parens, Erik and Adrienne Asch. 2000. *Prenatal Testing and Genetic Diagnosis*. Washington, DC: Georgetown University Press.

Scully, Jackie Leach. 2002. "A Postmodern Disorder: Moral Encounters with Molecular Models of Disability." Pp. 48–61 in *Disability/Postmodernity: Embodying Disability Theory*, edited by M. Corker and T. W. Shakespeare. London: Continuum.

———. Forthcoming. "Admitting All Variations? Postmodernism and Genetic Normality." In *Ethics of the Body*: *Post-conventional Challenges,* edited by M. Shildrick and R. Mykytiuk. Cambridge: MIT Press.

Shakespeare, Tom. 1998. "Choices and Rights: Eugenics, Genetics and Disability Equality." *Disability & Society* 13:665–681.

———. 1999. "Losing the Plot? Medical and Activist Discourses of Contemporary Genetics and Disability." *Sociology of Health and Illness* 21:669–688.

Walters, Leroy and Julie Gage Palmer. 1996. *The Ethics of Human Gene Therapy*. New York: Oxford University Press.

Watson, James D., Nancy H. Hopkins, Jeffrey W. Roberts, Joan Argetsinger Steitz, and Alan M. Weiner. 2003. *Molecular Biology of the Gene,* 5th ed. San Francisco: Benjamin/Cummings.

Websites

National Center for Biotechnology Information, education pages, http://www.ncbi.nlm.nih.gov/Education

University of Montreal, HumGen (hosts a database on the legal, social, and ethical aspects of human genetics), http://www.humgen.umontreal.ca

Wellcome Trust, human genome pages, http://www.wellcome.ac.uk/en/genome

GENETICS AND DISABILITIES: SOCIAL AND ETHICAL DILEMMAS

The scientific community has made enormous strides in the knowledge of genetics since the landmark discovery of the double-helical structure of DNA more than 50 years ago. While the promises of genomic medicine are manifold, the coming decades of genetics and biotechnological developments will undoubtedly raise social and ethical concerns that may undermine the human rights of people with disabilities.

Inclusion International, a nongovernmental organization representing agencies from more than 115 countries and promoting the inclusion of persons with intellectual disabilities, has articulated the fear that genetic data, although anticipated to do much good, may also lead to discrimination. Also, this organization argues that developments in genetics could be used in ways that restrict rather than enhance the rights and choices of people with disabilities and their families.

This entry examines the social, ethical, and policy implications arising from developments in genetics against the backdrop of four core ethical principles that are emphasized in much of the discussion about disability and human rights. These principles are as follows: justice (every person has the right to have access to services and to develop to his or her full potential), nondiscrimination (every person has the right to be respected for who he or she is, and to live as an equal citizen), diversity (every person has the right not to be judged on the basis of notions of perfection and normality), and autonomy (every person has the right to make his or her own decisions and to participate in decisions that will have an impact on his or her life). In light of the social and ethical issues raised by genetics and biotechnology, this entry presents a selection of ethical norms emanating from such international and regional bodies as the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), the Council of Europe, as well as other documents from nongovernmental organizations.

The suspicion that people with disabilities and their representatives entertain toward genetic technology can be explained by the discrimination they have historically faced. This anxiety is notably exacerbated by past eugenic abuses in which it was deemed appropriate and desirable to sterilize those considered unacceptably different. Moreover, during the 1920s and 1930s, two Canadian provinces implemented laws that allowed for the sterilization of mentally disabled persons; these laws, which led to the undue restriction

of the rights of people with disabilities, were not repealed until the late 1970s.

DEFINITION OF DISABILITY

Over time, approaches to disability have evolved. Initially, disability was considered within an individual framework. This focus on the individual was promoted by what is commonly known as the medical or rehabilitation model of disability. The next generation of approaches focused on society—that is, on the social, economic, policy, and legal conditions that lead to disability. This paradigm shifted the emphasis to culture and environmental factors. More recently, the model adopted has been based on human rights, which is a powerful framework from which to defend and protect persons with disabilities from genetic discrimination.

For the purposes of this entry, a broad-based definition of disability is adopted, a definition that encompasses the WHO 2001 International Classification of Functioning, Disability, and Health. This definition views the etiology of health conditions as neutral and reflects the interactive relationship between health conditions and the contextual factors of the environment and the individuals.

ETHICAL PRINCIPLES AND INTERNATIONAL POLICIES

Overall, human genetics concerns figure prominently in statements issued by international and regional health- and culture-related organizations. Some of the policy documents of such organizations specifically mention disability. Furthermore, in response to advances in human genetics and biotechnology, a number of governmental and nongovernmental organizations at the international and regional levels have taken an interest in addressing genetics within a human rights framework. A broad consensus of remarkable consistency is emerging. It addresses four ethical principles: justice, nondiscrimination, diversity, and autonomy.

A starting point for the discussion about ethical principles is the 1948 Universal Declaration of Human Rights, which promotes and affirms the fundamental rights to life, liberty, and security (Article 3); to medical care and social services (Article 25[1]); and to the benefit from scientific progress and its uses (Article 27[1]). The WHO, notably in its 2001 International Classification of Functioning, Disability, and Health, focuses on social and environmental barriers and on the rights to which people with disabilities are entitled. Nevertheless, developments in genetics raise particular new concerns that need to be addressed. 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. A core principle of the UNESCO declaration is respect for human dignity; the declaration promotes a perspective based on the basic rights to justice, nondiscrimination, diversity, and autonomy. As a policy statement it provides the first signs that genetics will be applied in ways that maintain human rights. Even though most of the documents under review here do not expressly address disability, they can be interpreted as implicitly applying to disabled individuals, as most of them address the "new" genetics, either tacitly or explicitly.

Justice

The principle of justice implies the obligation to distribute benefits and risks equally. Genetics and biotechnology may harm people with disabilities by classifying and possibly devaluing people who are different and treating them as deviations from the norm. In the extreme, some believe that preventing the birth of a disabled child following preimplantation genetic diagnosis (PGD) or prenatal testing is a rejection of people affected by the specific genetic disorders tested for. However, others argue that it is not rejection of the individual per se but of the disorder. There are other ways, not limited to persons with disabilities, in which genetics and biotechnology can breach the principle of justice. For example, physicians' lack of awareness of the need for genetic referral and consumer lack of knowledge of genetic services might also lead to inequality of availability and accessibility to genetic services and care for all citizens.

Justice and International Policies

Internationally, many guidelines, although not specifically addressing persons with disabilities, consider

that all humans, regardless of differences, are entitled to access to medical and genetic developments. Foremost in this area, UNESCO's 1997 Universal Declaration on the Human Genome and Human Rights specifically addresses the principle of justice in Article 12(a), stating that advances in biology, genetics, and medicine concerning the human genome shall be made available to all, with due regard to the dignity and human rights of each individual. Article 12(b) of the declaration recommends that research (including applications in biology, genetics, and medicine) concerning the human genome shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole. In other words, equitable access to care, services, treatments, and research findings in the field of genetics is a fundamental human right of individuals and, where applicable, of groups of people.

The Council of Europe and the council's Steering Committee in Bioethics, concerned with genetic developments, have issued policy statements of general relevance to persons with disabilities. The council's 2003 working document Application of Genetics for Health Purposes recommends equitable access to preventive, diagnostic, and therapeutic genetic services (Article 10). Also, its 1997 Convention on Human Rights and Biomedicine holds that screening must be made available to all (Article 3). The binding force of the convention depends on its being signed and ratified by the council's member states. Furthermore, each ratifying member country may adapt these obligations with regard to its own health needs and resources.

In the case of gene therapy, in 1994 the Group of Advisors on the Ethical Implications of Biotechnology of the European Commission (GAEIBE) voiced concern regarding equity. It recommended that within the European Union appropriate measures should be taken to ensure equal access to gene therapy. With regard to prenatal diagnosis (PND), the GAEIBE (1996) agrees that all genetic services that are available for the entire population should be equally available for persons with disabilities. The GAEIBE specifically mentions that prenatal diagnosis should not discriminate against people with disabilities or those who do not terminate a pregnancy. This organization expresses two concerns regarding the application of genetic tests to persons with disabilities: First, people who test positive for genetic mutations have a variable likelihood of developing the disorder in question; and second, it is difficult to define the severity of disorders. In view of these concerns, the GAEIBE concludes that it is inappropriate to generate a list of disorders that qualify for prenatal genetic diagnosis.

Finally, Inclusion International (2003) stresses that genetic research must not lead to the reduction or suppression of opportunities for health and social services, education, employment, leisure, or citizenship responsibilities for people with disabilities.

Nondiscrimination

Issues related to genetic discrimination by insurers, employers, and educators are of major concern to many persons with disabilities. There is some evidence, admittedly anecdotal, that genetic information is being used or could be used to deny access to life or health insurance and employment. Advances in genetics may have major financial implications for people seeking health insurance, especially in countries that do not have universal health care funding. Moreover, in such countries employers may use genetic information to maximize their economic benefits by denying jobs to people with particular genetic profiles. This serious concern merely aggravates the already widespread discrimination that people with disabilities face. If genetic testing is increasingly successful in predicting genetic susceptibility, even those with "future" disabilities may suffer in the present.

The issue of discrimination is not limited to employers and insurers. Some individuals might be denied fertility treatment or adoption rights in light of past mental illnesses. There is also a fear that genetic information will lead to stigmatization and have a negative impact on disabled people's rights to accept or refuse medical treatment and to reproduce according to their own wishes.

PGD and genetic screening raise similar concerns of discrimination. Whereas testing for very rare monogenic conditions such as Tay-Sachs disease and Huntington's disease is generally accepted, testing for less "severe" diseases is more controversial, especially if the results may determine whether a fetus will be aborted or not. In some situations, and in order to

increase their chances, couples with disabilities may request PGD to select embryos without hereditary conditions such as deafness, achondroplasia, or intellectual disabilities; such couples may also wish to have children who have the same disabilities they do.

"Wrongful life" lawsuits are seen as inherently discriminatory toward persons with disabilities. The Perruche case, which urged France to modify its health law policy, is an example of the concern. The case concerned a boy who was born deaf and severely disabled due to the rubella his mother contracted while pregnant. The boy claimed damages from doctors who, because of laboratory negligence, did not diagnose the mother's rubella. Even though medical negligence was proven, this ruling offended people with disabilities who felt the decision implied that disabled people were not worthy of life. The Perruche lawsuit is just one of a number of similar suits that have suggested that disabilities are injuries worthy of compensation.

Issues concerning discrimination are likely to intensify and become more widespread, particularly if research succeeds in linking genes to behavior, intelligence, and personality traits. The topics of the genetics of mental disorders and behavioral genetics are sensitive, controversial, and complex, and research in these areas may rekindle the old debate between nature and nurture and serve as a basis for discrimination and stigmatization, as suggested by the Nuffield Council on Bioethics (2002).

Nondiscrimination and International Policies

Overall, there are strong indications that key international organizations, through their policies and guidelines, promote the principle of nondiscrimination based on genetic information. Generally, these organizations' statements avoid singling out persons with disabilities; rather, they promote collective human rights irrespective of race, ethnicity, gender, or physical or mental characteristics.

Mention should be made of two influential United Nations documents specific to genetics. The UNESCO Universal Declaration on the Human Genome and Human Rights states that people should not be excluded because of certain genetic characteristics and that no one should be subjected to discrimination based on genetic characteristics. In the International Declaration on Human Genetic Data, the United Nations proposes that genetic data should not be used for discriminatory purposes or in any way that will stigmatize a group. The declaration also states that there should be no unauthorized disclosure of genetic data to third parties (e.g., insurers, employers, and educational institutions).

The World Health Organization explicitly recommends adopting language that is sensitive and nonpejorative; terms such as *mentally retarded* and *defective fetus* are absolutely unacceptable. At the regional level, the Council of Europe prohibits any form of discrimination on grounds of genetic heritage in its Convention on Human Rights and Biomedicine.

The Council for International Organizations of Medical Sciences has developed ethical guidelines for biomedical research in which the organization recognizes behavioral genetics as a very sensitive area and recommends that behavioral geneticists publish their research findings in a manner that is respectful of the interests of all concerned.

Finally, although an emphasis on nondiscrimination toward all individuals and populations is a core ethical principle, and seen as a collective right, many organizations still explicitly recognize a need for the special protection of persons with disabilities. For instance, the European Parliament highlights disability in its Charter of Fundamental Rights. Under the terms of Article 21.1, any discrimination based on any ground such as genetic features and disability shall be prohibited.

Diversity

Respecting diversity entails valuing and accepting a wide variety of human characteristics, including disabilities ranging from the relatively mild (such as ectodactyly, or partial fusion of fingers or toes) to the very severe (such as Huntington's disease). Many observers fear that genomics will menace human diversity. Some persons with disabilities feel their rights are threatened by genetic advances such as PGD and prenatal testing and screening. Disabled Peoples' International (DPI) and a number of nongovernmental

organizations within the disability community have voiced concerns that these reproductive technologies challenge the principle that all individuals have equal value and deserve respect.

In medical circles, the word *serious* is often used to differentiate disorders. Studies suggest that among professionals, interpretations differ concerning the "seriousness" of various conditions, including cleft lip/palate, hereditary deafness, diabetes, Huntington's disease, cystic fibrosis, sickle-cell anemia, Down syndrome, and bipolar disorder. Such divergent interpretations raise difficult ethical questions because individuals, families, and medical professionals may perceive the seriousness of particular genetic conditions very differently.

Currently, PGD is offered when there is a high risk of a "serious" genetic disorder. Further developments in genetics may change what is considered a serious disorder and what is perceived as falling within the range of normal. DPI has noted that the field of genetics is threatening to undermine the rights of persons with disabilities because only a few genetic conditions are so severe as to make living unbearable. The organization points out that the views of people living with disabilities have not been heard.

Finally, there is also a concern that developments in genetics will allow policy makers to increasingly treat disability as a medical problem and conceivably overlook policies that advance the integration of people with disabilities into society by adapting the environment to the needs of these individuals. Over the past 20 years, the social model of disability, which emphasizes the role society plays in the experience of disability, has achieved legitimacy. However, with developments in genetics and biotechnology, the disability community fears a rekindling of the medical/biological model of disability, which places genetic factors at the forefront and overlooks environmental, social, political, and economic factors.

Diversity and International Policies

UNESCO's Universal Declaration on the Human Genome and Human Rights asserts every individual's right to dignity and human rights regardless of genetic characteristics (Article 2). Similarly, in its Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services, the WHO recognizes the need to respect human diversity and minority groups.

In a similar vein, the GAEIBE maintains that in light of the current controversies raised by germ line therapy and the actual state of the art, germ line therapy on humans is not currently considered ethical.

Regarding the complex interplay among several societal factors, the WHO's International Classification of Functioning, Disability, and Health serves as a focal point for addressing the importance of the interactions among physical, social, economic, environmental, and genetic factors.

Autonomy

The right of persons with disabilities to participate in decisions affecting their lives is central to the principle of autonomy. However, in addressing the needs of persons with disabilities, two problems emerge: First, it is often presumed that persons with intellectual/mental disabilities lack the capacity to make their own decisions, and second, there is a tendency to make choices for competent disabled adults and their families because they are often seen as vulnerable and thus in need of protection, their choices are not perceived as appropriate, or the public sometimes has low expectations of them.

A distinction is generally made between care and research. Research requires more stringent conditions in terms of justification, disclosure, and consent. Research should be undertaken with and personal health services administered to human beings only as long as the persons involved are given exhaustive background information that will enable them to make informed decisions about whether or not to participate in research or clinical care (e.g., on the risks and benefits of participation, alternatives to the testing, treatability of the disorder). Some individuals may interpret the simple offering of prenatal screening or genetic testing as a suggestion that such screening or testing is necessary, desirable, and in their "best interest." Also, it has been argued that if parents refuse prenatal tests they may later be made to feel guilty or blamed if their child is born with a disability.

Another important ethical issue is the need to involve the public and to provide forums in which the community can participate in identifying needs, setting priorities,

and making decisions involving health services and medical research. Persons with disabilities feel they have a great deal to offer in this respect because they are most affected by and aware of the issues associated with their conditions. The phrase "Nothing about us without us," originated in the early 1990s by disability rights activists, is today a widely recognized motto for people with disabilities who want to take a full and active role in their care as well as at all levels of decision making in matters concerning their lives.

Autonomy and International Policies

Two core issues concerning autonomy are addressed by international policies: The first is consent, a principle at the foundation of any ethical research and health service; the second is the right to participate and be involved in policy decisions that have an impact on services and research.

UNESCO's Universal Declaration on the Human Genome and Human Rights recognizes the importance of informed consent, stating that in all cases, the prior, free, and informed consent of research participants shall be obtained. Obtaining meaningful informed consent from people with disabilities who are participating in genetic research raises challenges. There is an ongoing debate about the adequacy of the safeguards currently in place to protect disabled participants. The UNESCO declaration tries to strike a balance between the need to protect individual rights and the need to ensure freedom of research, primarily in relation to genetic information. Article 5(a) of the declaration states that research, treatment, and diagnosis should be made only following an assessment of the potential risks and benefits of performing these research activities and should adhere to a national standard.

As a health service, genetic testing of incapacitated adults also raises special concerns. The UNESCO declaration requires that the testing of an incapacitated adult be done only on the basis of that person's best interest. Article 5 of the declaration states that if, according to the law, a person does not have the capacity to consent, research affecting his or her genome may be carried out only for his or her direct benefit, subject to the authorization and protective conditions prescribed by law. The Council of Europe's Steering Committee in Bioethics recommends that testing should be permitted on an incompetent person only if certain safeguards and the following conditions are met:

- The purpose of the test is to allow the family member or members to obtain important preventive, diagnostic, or therapeutic health benefit, or to allow them to make an informed choice with respect to procreation.
- The implementation of such test is essential to obtain the benefit envisaged.
- The importance of the benefit foreseen has been independently assessed.
- The risks and burden of the intervention, and risks to private life that may arise from the collection, processing, or communication of the results of the test, are minimal for the person who is to undertake the test.
- The person undergoing the test does not object.
- The authorization of the person's representative, or an authority or a person or body provided for by law, has been given.
- If the person tested has expressed the wish not to be informed of the result of the test, this wish shall be observed.

During the prenatal period, the GAEIBE recommends that no prenatal genetic testing be imposed by law, by public health services, or by any other institution or person. Tests should be done only at the request of the woman or couple after they have been fully informed through genetic counseling.

Regarding population-based genetic screening, Inclusion International stresses the importance of every individual's having the choice to opt into or out of genetic (population) screening. This organization also suggests that a disabled person should not be pressured either tacitly or explicitly to undergo genetic testing and that the disabled person and his or her parents or other personal caregivers should be allowed to refuse to receive any test results.

Recognizing the need for public participation, internationally, agencies such as the WHO, UNESCO, and their advocates are vocal about the importance of providing people with the means to play a greater role in policy development with regard to genetic research. Responding to this need, the WHO (1997), in a report on ethical issues in medical genetics, stresses the necessity for close cooperation between medical

professionals and patients' organizations. In a research context, a similar participatory approach is promoted by the Human Genome Organization's Ethics Committee (1996), which recommends that consultation should precede the recruitment of participants and should continue throughout the research.

In addition, recognizing the double discrimination experienced by women with disabilities, Rehabilitation International (1997) demands that the concerns and input of disabled women and girls be heard clearly in all debates and policies concerning genetic engineering, bioethics, prosthetic design, and human engineering, with regard notably to cochlear implants, abortion on grounds of disability, assisted suicide, and other eugenic practices.

SUMMARY

While the promises of genomic medicine are manifold, the coming decades of advances in genetics and biotechnological developments will undoubtedly raise social and ethical concerns with regard to the human rights of people with disabilities. The rights of disabled people that may be violated include the right of each individual to develop according to his or her potential, the right to equality and respect for each individual, the right to be valued in positive terms and not solely based on notions of perfection and normality, and the right of each individual to make his or her own life choices and to have a voice in discussions that shape and define genetics policies.

UNESCO's Universal Declaration on the Human Genome and Human Rights remains a pivotal document because it lays down general principles and provides a framework for addressing a complementary approach between human rights and medical sciences. The World Health Organization, the Council of Europe, and consumer organizations such as Inclusion International and Disabled Peoples' International also play major roles in translating genetic innovations into the health service and public health fields. Current policies have adopted an all-encompassing approach, focusing on the general recognition, respect, and protection of the rights to which all people, whether disabled or nondisabled, are entitled.

—Denise Avard and Clémentine Sallée

See also Bioethics; Ethics; Eugenics; Gene Therapy; Genetic Counseling; Genetics.

Further Readings

Andrews, Lori B. 2001. "The Impact of Genetics on Cultural Value and Social Institutions." Pp. 130–150 in *Future Perfect: Confronting Decisions about Genetics.* New York: Columbia University Press.

Asch, Adrienne. 1996. "Genetics and Employment: More Disability Discrimination." Pp. 158–172 in *The Human Genome Project and the Future of Health Care*, edited by T. H. Murray, M. A. Rothstein, and R. F. Murray. Bloomington: Indiana University Press.

Beresford, Peter and Anne Wilson. 2002. "Genes Spell Danger: Mental Health Service Users/Survivors, Bioethics and Control." *Disability & Society* 17:541–553.

Carson, Ronald A. and Mark A. Rothstein, eds. 1999. *Behavioral Genetics: The Clash of Culture and Biology*. Baltimore: Johns Hopkins University Press.

Council for International Organizations of Medical Sciences. 2002. "Ethical Guidelines for Biomedical Research Involving Human Subjects." Retrieved February 8, 2005 (http://www.fhi.org/fr/topicsf/ethicsf/curriculum/pdf_files/cioms.pdf)

Council of Europe. 1997. "Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine." *International Digest of Health Legislation* 48(1).

Department of Health and Genetics Branch. 2003. *Our Inheritance, Our Future: Realizing the Potential of Genetics in the NHS* (Genetics White Paper). Norwich, UK: Her Majesty's Stationery Office.

Disabled Peoples' International Europe. 2003. "Disabled People Speak on the New Genetics: DPI Europe Position Statement on Bioethics and Human Rights." Retrieved February 8, 2005 (http://www.dpieurope.org/htm/bioethics/dpsngfullreport.htm).

European Parliament and Council and Commission of the European Council. 2000. *Charter of Fundamental Rights of the European Union*. Nice: European Parliament.

Group of Advisors on the Ethical Implications of Biotechnology of the European Commission. 1996, February 20. *Ethical Aspects of Prenatal Diagnosis*. Brussels: European Union.

Human Fertilization and Embryology Authority and Advisory Committee on Genetic Testing. 2000. *Consultation Document on Preimplantation Genetic Diagnosis*. London: Human Fertilization and Embryology Authority.

Human Genome Organization, Ethics Committee. 1996. *Statement on the Principled Conduct of Genetic Research*. London: HUGO.

Inclusion International. 2003. *Major Policy Points in Bioethics* (Position paper). London: Inclusion International.

Nuffield Council on Bioethics. 2002. *Genetics and Human Behaviour: The Ethical Context.* London: Nuffield Council on Bioethics.

Office of the United Nations High Commissioner for Human Rights. 2002. *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability.* New York: United Nations.

Parens, E. and A. Asch 1999. "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations." *Hastings Center Report* 29(5): S1–S22.

Rehabilitation International. 1997. *International Leadership for Women with Disabilities, Consensus Statement.* Washington, DC: Rehabilitation International.

Roeher Institute and Inclusion International. 1999. *Genome(s) and Justice Reflections on a Holistic Approach to Genetic Research, Technology and Disability.* Toronto: Roeher Institute.

Shakespeare, T. 1998. "Choices and Rights: Eugenics, Genetics and Disability Equality." *Disability & Society* 13:665–681.

Spriggs, M. and J. Savulescu. 2002. "The Perruche Judgment and the 'Right Not to Be Born.'" *Journal of Medical Ethics* 28(2): 63–64.

UNESCO. 1997. *Universal Declaration on the Human Genome and Human Rights.* Paris: UNESCO.

———. 2004. "International Declaration on Human Genetic Data" (October 16, 2003). Retrieved April 4, 2005 (http://unesco.org/images/0013/001361/136112eb.pdf).

Working Party on Human Genetics. 2003, February 7. "Working Document on the Applications of Genetics for Health Purposes" (CDBI-CO-GT4). Retrieved February 8, 2005 (http://www.bmgs.bund.de/downloads/CDBI.pdf).

World Health Organization. 1997. *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services.* Geneva: World Health Organization.

———. 2001. *International Classification of Functioning, Disability, and Health*. Geneva: World Health Organization.

Websites

University of Montreal, HumGen, http://www.humgen.umontreal.ca/int

GENNARO, ALDO (?–1987)

Chilean-Australian theater and dance director

> *Institutions suppress individual creativity; creativity is our tool to keep growing.*
>
> —Aldo Gennaro (in the film *Stepping Out*, 1980)

Aldo Gennaro was born in Chile, where as a young man he became an Augustinian priest in his quest for "spiritual energy." One manifestation of Gennaro's subsequent attainment of this energy came after he migrated to Sydney, Australia, when as a dancer and director, he worked with young people with Down syndrome from the Lorna Hodgkinson Sunshine Home on a dance theater project. The project emerged from the activity therapy center that Gennaro had established at the home. He saw the body as "an instrument of communication" and developed a "language of gestures" with the group that enhanced the young people's ability to communicate through dance.

In the first piece developed by the dance group, one of the performers took the role of the Clown. This offended some observers, who felt that the young man was somehow being mocked. But he himself insisted: "Yes, I can be a clown. There is nothing to be ashamed of to be a clown, not because I am Downs Syndrome, and when I go in the street people look at me funny . . . . I can be a clown. I can laugh from inside and invite you to laugh with us."

During the preparation of the group's major dance piece, which was eventually performed at the Sydney Opera House, Gennaro developed a special relationship with the group. In an interview given shortly before his death of an AIDS-related illness in 1987, he described this as "the first time I experienced real love in my life, unconditional love." The dance piece made an enormous impact. One critic described it as a "marvelous, colourful, creative, vibrant performance." The piece reached a far wider audience when Chris Noonan (who later directed *Babe*) made a documentary film about the group's dance project. The film, *Stepping Out,* was released in 1980; it was shown throughout the world and won 14 major awards.

—John Brotherton

See also Dance; Down Syndrome; Drama and Performance.

Further Readings

Radio National. 2001, December 12. "100 Years of Radio: Aldo Gennaro." In *The Religion Report.* Retrieved April 5, 2005 (http://www.abc.net.au/rn/talks/8.30/relrpt/stories/s438268.htm).

GENOCIDE

This entry describes the disability-genocide nexus. Conceptions of genocide are distinguished, and

practices that may accompany genocide and historical examples are described. Little has been written about the disability-genocide nexus, except for the Nazi example, although more is written about disability-related topics that can accompany genocide, such as eugenics, euthanasia, and famine. Genocide has legal, political, anthropological, and moral aspects, and this entry seeks to capture all of these.

The relationship between genocide and disability depends on how disability is defined. Weapons tipped with depleted uranium and posttraumatic stress disorder in Kosovo and spirit injuries in Rwanda have major individual and social consequences that may or may not be classified as disabilities.

Two approaches to identifying genocide are described below. The order is not hierarchical; thus the legal definitions mentioned first resulted from popular debate, which is mentioned second.

EVOLVING ATTEMPTS TO PREVENT AND PUNISH THE PRACTICE OF GENOCIDE

I. Limited Conceptions

The term *genocide* has multiple definitions. As with *disability,* definitions are not neutral; rather, they serve to spotlight or obscure particular practices. Each definition calls attention to particular aspects of what is done in a genocide and to whom it is done. Depending on one's definition, there may either be many instances of genocide or very few.

The word *genocide* first appeared in Polish lawyer Raphael Lemkin's 1944 book *Axis Rule in Occupied Europe.* Lemkin combined the Greek *genos* (race, tribe) with the Latin *cide* (killing). He was describing Nazi Germany's practices, but also sought the adoption of legal restrictions so that genocide would not recur. After that book's publication, Lemkin discussed genocide in a 1946 article in the *American Scholar,* in a 1947 article in the *American Journal of International Law,* and elsewhere. Lemkin's definition for the term was simple: "the destruction of a nation or ethnic group." Lemkin identified political, social, cultural, economic, biological, physical, religious, and moral dimensions of genocide. These included practices such as "racial discrimination in feeding" and "endangering of health," both often sources of disablement and death. In Lemkin's definition, "destruction" was not equivalent to "killing." Instead, it could mean measures such as prevention of births, endangering of health, and discrimination in feeding.

Earlier, in 1933, in an essay titled "Acts Constituting a General (Transnational) Danger Considered as Offences against the Law of Nations," which extended a report presented to the Fifth Conference for the Unification of Penal Law in Madrid, Lemkin proposed a multilateral convention making the extermination of human groups an international crime. The crime Lemkin identified in 1933, "Acts of Barbarity," would be a subject of a later convention under another name, genocide.

In the wake of the Nazi genocide, the United Nations adopted first a declaration and then a convention on genocide. Article 2 of the 1948 UN Convention on the Prevention and Punishment of the Crime of Genocide describes both against whom genocide might be directed and acts constituting genocide: "Genocide means any of the following acts committed with intent to destroy, in whole or in part, a national, ethnical, racial or religious group." The convention goes on to specify a set of acts that can constitute genocide: "(a) Killing members of the group; (b) Causing serious bodily or mental harm to members of the group; (c) Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part; (d) Imposing measures intended to prevent births within the group; (e) Forcibly transferring children of the group to another group."

People with disabilities (PWDs) do not literally qualify as "the group." The disability community, however, is especially vulnerable to practices such as forced resettlement, famine, and diversion of resources that may be part of genocides. Prosecution of violators of rights of PWDs, specifically, has been for war crimes or crimes against humanity, but not genocide. People prosecuted for genocide under the UN convention have been violators of PWDs' rights, but the evidence has been anecdotal rather than gathered by prosecutors who were focused on the disability-genocide nexus.

Cases brought under the UN convention have run into procedural difficulties. Even with a limited

conception, governments have been reluctant to cede the identification of genocide to international institutions. Article 9 of the convention provides for the resolution of disputes by the International Court of Justice in the Hague. However, many parties to the convention, including the United States, conditioned their ratifications by taking exception to this article.

Language identical to that in the UN convention is used to define genocide in Article 6 of the Rome Statute of the International Criminal Court (ICC). The ICC became a reality in 2002, and more than 90 countries, from Afghanistan to Zambia (but not the United States), are parties.

The Rome Statute contains provisions for the prosecution of many crimes against PWDs. Before destruction reaches the level of "genocide," there may be matters receiving the ICC's attention. Article 7, on "crimes against humanity," includes many offenses that have given rise to genocide (with great consequences for PWDs), among them deportation in paragraph 7(1)(d) and enforced sterilization in 7(1)(g). Similarly, Article 8, on "war crimes," includes enforced sterilization, unlawful deportation, biological experiments (as a form of torture or inhumane treatment), intentional starvation, and medical or scientific experiments. Some instances qualify as war crimes and could be the basis of prosecutions. But other instances would not; for instance, mutilation or experiments on occupied populations might be "justified by the medical, dental or hospital treatment of the person concerned."

Under Article 30 of the Rome Statute, prosecution requires that the material elements of a crime were committed "with intent and knowledge." That a defendant "must have known" or "should have known" is not sufficient. So the elimination of groups cannot be prosecuted as genocide unless it was intended.

The prohibition of genocide is fundamental in international law, and even where states have not consented to prohibition by written treaty, they are bound to obey the prohibition as a peremptory norm of international law (*jus cogens;* literally, constraining law). Leaders and scholars therefore often attempt to distinguish mass killings (sometimes permitted as self-defense or humanitarian intervention) from genocide (always prohibited).

II. Conceptions Challenging the Limits

Jus cogens has changed over time, so the public struggle over concepts such as genocide may eventually be reflected in law. Raising narrow definitional arguments is a strategy of genocide deniers, countered by advocates who insist that genocide be confronted.

In the 1948 UN Genocide Convention, limit to four types of groups was chosen over interpretations that might have added linguistic, political, or economic groups. "Political and other groups" were mentioned in a 1946 draft resolution, one that came from the drafting committee of the United Nations General Assembly's Sixth Committee, but later were excluded. Like the ICC, the International Criminal Tribunal on Rwanda (ICTR) used the fourfold enumeration, but it held that "all 'stable' groups, constituted in a permanent fashion and membership of which is determined by birth," should be included. By these criteria, some groups of PWDs would be included, but others would not.

Anthropological Conceptions

Alexander Hinton (2002) and others have followed the ICTR's example in calling for a broad definition of genocide, even suggesting that disabled people might be a "stable group." They contend that the essence of genocidal practices is "otherness," based on race or ethnicity in some contexts, but based on sexual orientation, gender, disability, political, or economic status in others. Genocidal circumstances may make group membership less stable, for instance, because of many people becoming newly disabled.

Other Conceptions

Cultures, advocacy organizations, and countries have sometimes adopted less exclusive conceptions of genocide. The use of cochlear implants has been described as "cultural genocide" directed at Deaf culture. Many opponents of forced institutionalization and involuntary practices of psychiatric drugging describe the practices as "genocidal." Philosopher Jean-Paul Sartre persuaded the nongovernmental Bertrand Russell Tribunal that the Vietnam War was "genocidal." The Spanish statute under which former Chilean dictator Augusto Pinochet was indicted

included "political groups." French and Belgian approaches to defining genocide also include nonexhaustive lists of groups.

Users of broader conceptions of genocide apply the term to bring public focus to humanitarian issues faced in the present and future, not just the past. Users of narrower conceptions contend that this dilutes attention to important instances of genocide that must not be repeated.

PAST AND PRESENT PRACTICES REFLECTING THE DISABILITY-GENOCIDE NEXUS

Once "genocide" entered public discussion, it was applied to many practices and cases, some of which are described below. The disability-genocide nexus is seldom mentioned by observers, usually because they ignore it rather than because it does not exist.

Practices That Illustrate the Nexus

Many past and present practices reflect the disability-genocide nexus. If not part of genocide, they may constitute crimes against humanity or war crimes under the Rome Statute. Often, however, they have been accepted practices not just by prosecuted genociders, but by the prosecutors.

Eugenics was an important part of the Nazi genocide, but it was explicitly practiced in the United States and is advocated by many policy makers today. Thinking about eugenics intensified in the nineteenth century. In 1883, Francis Galton, a cousin of Charles Darwin, defined eugenics as "the science of improving the stock." That intention was invoked in efforts common in the twentieth century, including bans on marriage, sterilization, and rationing of scarce resources.

Advocates of euthanasia sometimes make eugenic arguments. PWDs are especially likely to be targeted as "worthy of death" as they were during the Nazi genocide.

Weaponry used to perpetrate and respond to genocide will mean that many people will become PWDs. Elaborate new weapons may help genociders, but they are not necessary to it. New and old forms of weaponry will kill many PWDs but will also make PWDs of other formerly nondisabled people. In Rwanda the machete killed many people but made amputees of others. Land mines are used both by perpetrators of genocide and by counterforces. Depleted uranium on modern weapons and posttraumatic stress disorder are two more reflections on the disability-genocide nexus.

Food is a common weapon in genocides, sometimes the primary weapon. Deprivation of food kills many people; it may also mean disability. For some people who are already disabled, the struggle for food, either where genocide is being practiced or in refugee camps, may mean death. Malnutrition's consequences for learning are great, even where the ultimate message is one of human resilience.

Historical Examples

The case most written about by far is the Nazi Holocaust. The Holocaust included practices of eugenics and euthanasia—labeled "child's play" compared to what followed by historian Daniel Goldhagen. Henry Friedlander (1995), Hugh Gallagher (1990), and others present a compelling contrary view that the actions against PWDs were central to the Nazi genocide. The techniques later used in the death camps were perfected in killings of disabled people.

A German law enacted on July 14, 1933, allegedly to prevent "hereditarily sick offspring" was the basis for sterilizations, initially voluntary, later mandatory. Many disabled people were killed in T-4, a project named for the street of its location, Tiergartenstrasse, that began in 1939 and ended in 1941. Others were "selected" at concentration camps as unlikely to be useful for arduous forced labor. The 14F13 program operated during most of World War II, and occupying forces found that killings of disabled people continued throughout the war.

Imprecise criteria resulted in hundreds of thousands of killings (about 250,000 PWDs). "Mental patients" describes some victims, but certainly not all; some had epilepsy, others were blind or deaf, and still others were killed for offenses such as bed-wetting.

Although each genocide has unique aspects, each can be compared and contrasted with others. The following 10 propositions explore the disability-genocide

nexus. Each is more applicable to some genocides than others. (Earlier iterations of this list appear in Blaser 2001, 2002.)

1. PWDs may be selected as direct targets by a genocidal regime.
2. The earliest effects of genocide are likely to be felt by PWDs.
3. Genocidal movements' or regimes' perspectives on medicine may have disproportionate effects on PWDs.
4. Genocidal movements' or regimes' diversion of resources to carry out genocide may have disproportionate effects on PWDs.
5. Genocidal movements' or regimes' minimizing of contacts with other governments and nongovernmental organizations may have disproportionate effects on PWDs.
6. PWDs are disproportionately affected by genocide (in comparison with the nondisabled population).
7. Genociders may increase numbers of PWDs in the furtherance of genocide.
8. International organizations and intermediate national organizations may assist PWDs.
9. The "survivor syndrome" that is a result of genocide reflects the continuing relevance of disability.
10. Regimes following genocidal regimes are unlikely to deal successfully with issues affecting PWDs.

Cambodia in the late 1970s provides illustrative comparisons. The prosthetic devices used by many PWDs were identified as indicating ties to the West and therefore as bases for killing. Observers noted that people found near hospitals were targets for killing, all the easier if they were mobility impaired. Medical supplies were scarce, and temporary disabilities became permanent ones. In some cases, death resulted. Aid from humanitarian organizations was suspect, to the detriment of PWDs.

As in the Cambodian genocide, in 1994 Rwanda, ideology took precedence over human needs. In Rwanda it was a vaguely defined ideology of "Hutu power," where the more numerous Hutu destroyed many of the Tutsi minority. Early targets included institutions such as schools and hospitals that housed disabled people. Some people who survived lost limbs from machete attacks. Wing and Johnson (2002) suggest that genocide survivors are disproportionately women, many of them disabled. They also note the importance of including "disability" in the equality clause of Rwanda's postgenocide constitution.

Genocides were common in the twentieth century, and the term also applies to prior and later practices. The conquest of indigenous peoples and their lands, the status of Armenians in Turkey, the status of Kosovar Albanians in 1979, and the widespread use of sanctions are cases in which the consequences of "genocide" were felt disproportionately by PWDs. Contemporary practices of forced institutionalization and euthanasia include characteristics of past acts widely acknowledged as genocidal.

—Arthur Blaser

See also Eugenics; Euthanasia; United Nations.

Further Readings

Blaser, Arthur. 2001. "Always the First to Go? People with Disabilities and Genocide." In *The Anatomy of Genocide,* edited by Alexandre Kimenyi and Otis Scott. New York: Edwin Mellen.

———. 2002. "People with Disabilities (PWDs) and Genocide: The Case of Rwanda." *Disability Studies Quarterly* 22:53–65.

Friedlander, Henry. 1995. *The Origins of Nazi Genocide: From Euthanasia to the Final Solution.* Chapel Hill: University of North Carolina Press.

Gallagher, Hugh G. 1990. *By Trust Betrayed: Patients, Physicians, and the License to Kill in the Third Reich*. New York: Henry Holt.

Hinton, Alexander Laban, ed. 2002. *Annihilating Difference: The Anthropology of Genocide.* Berkeley: University of California Press.

Lee, Roy S., ed. 2001. *The International Criminal Court: Elements of Crimes and Rules of Procedure and Evidence.* Ardsley, NY: Transnational.

Lemkin, Raphael. 1944. *Axis Rule in Occupied Europe: Laws of Occupation, Analysis of Government, Proposals for Redress.* Washington, DC: Carnegie Endowment for International Peace.

———. 1946. "Genocide." *American Scholar* 15(2):227–230.

———. 1947. "Genocide as a Crime under International Law." *American Journal of International Law* 41(1):145–151.

———. [1933] 2000. "Acts Constituting a General (Transnational) Danger Considered as Offences against the Law of Nations,"

translated by James T. Fussell. Retrieved April 12, 2005 (http://www.preventgenocide.org/lemkin/madrid1933-english.htm).

Porter, Jack Nusan, ed. 1982. *Genocide and Human Rights: A Global Anthology.* Washington, DC: University Press of America.

"Rome Statute of the International Criminal Court" (proposed for signature and ratification November 10, 1998; entry into force July 1, 2002). Retrieved April 4, 2005 (http://www.un.org/law/icc/statute/romefra.htm).

Rubenstein, Richard L. 1983. *The Age of Triage: Fear and Hope in an Overcrowded World*. Boston: Beacon.

Schabas, William A. 2000. *Genocide in International Law: The Crime of Crimes*. New York: Cambridge University Press.

"UN Convention on the Prevention and Punishment of the Crime of Genocide" (proposed for signature and ratification December 9, 1948; entry into force January 12, 1951). Retrieved April 4, 2005 (http://www.hrweb.org/legal/genocide.html).

Wing, Adrien Katherine and Mark Richard Johnson. 2002. "The Promise of a Post-genocide Constitution: Healing Rwandan Spirit Injuries." *Michigan Journal of Race and Law* 7:247–315.

Websites

Disabled Peoples' International, http://www.dpi.org

Prevent Genocide International, http://www.preventgenocid.org

United Nations, Persons with Disabilities page, http://www.un.org/esa/socdev/enable

GEOGRAPHY AND DISABILITY

In its most common understanding, geography can be defined as the science of the earth's physical features, resources, climate, and population. From a broader perspective, geography is also the study of landscapes. Landscapes include spaces that can be classified as either environmental (natural) or human (built). Each type of space has important implications for persons with disabilities. Space plays a critical role in the lived experience of persons with disabilities because space is directly tied to accessibility and mobility. Therefore, space can be used to enable or disable persons with disabilities. Landscapes can have real (objective) or perceived (subjective) barriers for persons with disabilities. Thus, for persons with disabilities who may already experience social segregation, the presence of physical barriers due to space may further contribute to marginalization and lack of full integration into the community. These circumstances contribute to health disparity and inequity present in society worldwide.

Space is considered to be a social phenomenon that is influenced by the interactions of people, organizations, and systems in a historical process. As new landscapes are produced, those with power in that particular social structure are able to decide who will be advantaged and who will be disadvantaged. Therefore, the ability of persons with disabilities to participate in or influence decision makers has profound implications for how space will be built or altered to have a positive impact on people with disabilities.

Space is produced both naturally and socially. *Natural space* refers to geographic features such as mountains, rivers, oceans, and deserts. The ability of persons with disabilities to negotiate natural space is an important topic. It is often the case that the natural environment may pose obstacles for persons with disabilities; for example, those who are blind or physically disabled may have difficulty mountain climbing or skiing. In recent times, human guides and specially designed equipment have become available that permit disabled persons access to and mobility within natural environments. Similarly, innovations and alternations to the natural environment from engineering, architecture, and urban planning have increased access to and mobility in the natural environment. Physical change to the natural environment through human intervention is often referred to as the *built* environment.

A second way to view geography and its implications for disability is as social space. *Social space* is defined as nature that has been transformed through human practice. Human social space can be thought of as being physically produced (e.g., construction of a school)—the built environment—and socially produced (e.g., interaction between students and teachers in a classroom). In this sense, social space is viewed as the interaction of both a process (educational interaction) and an outcome (a building). It is important to note that environmental or natural space also plays a role in the creation of human social space (e.g., the construction of cities and towns near a river). Likewise, human creation of "built" space may also alter natural space so as to create a new environmental space that is oppressive to some groups such as those with disabilities

(e.g., the lack of wheelchair-accessible street curbs in a city). When geography is viewed as a social phenomenon, several policy implications arise.

POLICY IMPLICATIONS

Employment

The experience of physically disabled persons is socialized in different times and in different places. Historically it has been shown that in capitalist-oriented Western societies, landscapes have been built that have a tendency to desocialize or marginalize persons with disabilities. This phenomenon has been characterized as the production of landscapes of exclusion. One example of this exclusion is the creation of sheltered workshops worldwide. Sheltered workshops often exclude disabled persons from mainstream employment opportunities and the work is often low paying and conducted under harsh conditions. In this regard, sheltered workshops have been viewed as places of exploitation and marginalization. Progressive social policies that view sheltered workshops as a source of production within the larger economy are needed, such as those in Germany, where federal policy mandates the employment of a certain proportion of disabled people in the country's large firms. Because research shows that poverty due to "work" disability is associated with geography, it is important for policy makers to consider the economic implications of the geography of disability.

Community Integration

Historically in Western societies, the disabled have often been isolated and institutionalized in hospitals, asylums, and other forms of sheltered housing. With the movement toward deinstitutionalization in the mid-1970s in the United States, persons with disabilities were transitioned to community-based forms of social care. This change in landscape, brought about by social policy, has implications for geography and disability. Most notable have been studies of community and neighborhood resistance to relocation of persons with mental and physical disabilities into their areas. This resistance has been termed "not in my backyard," or NIMBYism. Social policy directed at the deinstitutionalized has often resulted in poverty and social isolation, including increases in the numbers of homeless.

Incorporating a broader understanding of geography that includes not only attention to natural and built landscapes but also social spaces will help to create places that are more inclusive of persons with disabilities.

—Karen E. Peters

See also Accessibility; Accessibility Codes and Standards.

Further Readings

Butler, R. E. 1994. "Geography and Vision Impaired and Blind Populations." *Transactions, Institute of British Geographers* 19:366–368.

Chouinard, V. 1997. "Making Space for Disabling Differences: Challenging Ableist Geographies." *Environment and Planning D: Society and Space* 15:379–387.

Dyck, I. 1995. "Hidden Geographies: The Changing Lifeworlds of Women with Disabilities." *Social Science & Medicine* 40:307–320.

Gleeson, B. 1999. *Geographies of Disability.* London: Routledge

Golledge, R. G. 1990. "Special Populations in Contemporary Urban Regions." In *Our Changing Cities,* edited by J. F. Hart. Baltimore: Johns Hopkins University Press.

Imrie, R. F. 1996. *Disability and the City: International Perspectives.* London: Paul Chapman.

Imrie, R. F. and P. E. Wells. 1993. "Disablism, Planning and the Built Environment." *Environment and Planning C: Government and Policy* 11:213–231.

Parr, H. 1997. "Naming Names: Brief Thoughts on Geography and Disability." *Area* 29:173–176.

Vujakovic, P. and M. H. Matthews. 1994. "Contorted, Folded, Torn: Environmental Values, Cartographic Representation and the Politics of Disability." *Disability & Society* 9:359–374.

Websites

Geography and Disability Resources, http://www.disabilitystudies.com/geography.htm

Disability and Geography International Network (DAGIN), http://courses.temple.edu/neighbor/research/dagin-about.html

GEORGENS, JAN DANIEL (1823–1886)

German educator

Jan Daniel Georgens, a typical "restless worker," was born on June 12, 1823, in Bad Dürkheim, Germany.

He visited a teacher seminar and quickly became interested in the *Volksschule* (elementary school), which he regarded as the central educational institution for the nation. Beginning in 1844, he worked as a teacher in various locations. In 1848, the year of the failed German revolution, he founded a girls' grammar school in Worms, and two years later, the first south German nursery school in Baden-Baden. He had close contact with Friedrich Fröbel (1782–1852), the founder of *Kindergarten* (German nursery schools). In 1852, Georgens went to Vienna, where he accepted a private tutoring position for four years.

In 1856, Georgens developed a plan to erect the Institution for Special Education in Vienna. Together with the author Jeanne Marie von Gayette (1817–1895)—his future second wife—and the pedagogue Heinrich Deinhardt (1821–1880), whom he most likely met in Weimar while visiting the German *Idiotenanstalten* (institutions for the feebleminded), Georgens was able to open the private Heilpflege- und Erziehungsanstalt Levana (Remedial and Educational Institution Levana) a year later in Vienna. The institution focused its efforts on children of the noble and middle classes but also had a few openings for needy children. "Normal" children as well as the "infirm" and "degenerate" were accepted. Levana was conceived as a pedagogical model institution. It had a department for infant care and general and occupational training facilities as well as a Gesunden- und Krankenabteilung (Healthy and Ill Division) for up to 30 children. In 1857, the institution was relocated to the Liesing castle near Vienna. Due to low demand, the institution had to abandon the castle in 1859 and occupy a smaller building near Vienna. The ultimate end of the entire enterprise came during the mid-1860s. Numerous factors—including personal conflicts, lack of organizational experience, unprofessional business practices, and lack of governmental and private support—contributed to the failure of this reform-pedagogical experiment.

One permanent outcome of these years was an extensive two-volume publication that covered the theoretical foundations of special education as a scientific discipline. The dual-authored publication, which was titled *Die Heilpaedagogik. Mit besonderer Berücksichtigung der Idiotie und der Idiotenanstalten* (*Pedagogy of Special Education: With Special Consideration of Idiocy and Institutions for the Feebleminded*), was published in 1861 and 1863 in Leipzig. After that period, Georgens and his wife lived in Switzerland, Nuremberg, and Berlin. Georgens involved himself in other educational projects and worked professionally and politically with the Allgemeinen Deutschen Lehrerversammlung (Public German Teachers' Association). At the same time, he devoted himself more extensively to literary activities. He died on November 9, 1886, in Bad Doberan on the Baltic Sea.

—Anne Waldschmidt

See also Heinrich Marianus Deinhardt.

Further Readings

Georgens, Jan Daniel and Heinrich Marianus Deinhardt. 1861. *Die Heilpaedagogik. Mit besonderer Berücksichtigung der Idiotie und der Idiotenanstalten*. Vol. 1, *Zwölf Vorträge zur Einleitung und Begründung einer heilpädagogischen Gesammtwissenschaft*. Leipzig: Friedrich Fleischer.

———. 1863. *Die Heilpaedagogik. Mit besonderer Berücksichtigung der Idiotie und der Idiotenanstalten*. Vol. 2, *Zwölf Vorträge über die Idiotie und die Idiotenerziehung in ihrem Verhältnis zu den übrigen Zweigen der Heilpädagogik und zu der Gesundenerziehung.* Leipzig: Friedrich Fleischer.

Möckel, Andreas. 1988. *Geschichte der Heilpädagogik*. Stuttgart: Klett-Cotta.

Selbmann, Frank. 1982. "Jan Daniel Georgens: Leben und Werk." In *Giessener Dokumentationsreihe Heil- und Sonderpädagogik*, Vol. 5. Giessen: Dissertation der Justus-Liebig-Universität Giessen, Fachbereich Erziehungswissenschaften.

GERMAN TRAINING SCHOOLS (*HILFSSCHULEN*)

The concept of the training school emerged during the last third of the nineteenth century in Germany. It was designed for the so-called feebleminded, who were excluded from the elementary school system. The foundations of the concept cannot be detached from industrialization, because of its nature as a practical training school (*Erziehungsschule*). The training school was intended not as a model of "normal" education, but rather as one of occupational training for a predominantly proletariat clientele.

Karl Ferdinand Klein (1814–1868)—a teacher for deaf-mutes—and Heinrich Ernst Stötzner (1832–1910) are considered the founding fathers of the training

school. In a memorandum written in 1864, Stötzner called for the establishment of this new school system:

> In all of the large cities, people ought to create schools for less capable children, with the goal of taking individuals—who would on the whole otherwise become burdens of the state—and training them, by appropriate personnel and through relevant instruction methods, in order to create useful and productive members of society (quoted in Klink 1966:55).

The main argument of the founders of the training school was that elementary schools must be relieved of the strain associated with educating less gifted children. Having no elaborate diagnostic instruments at their disposal, the school's administrators maintained that a person should be considered "feebleminded" if he or she remained unsuccessful in the elementary school for two years. The so-established categorization of "feeblemindedness" was then certified by additional doctors who served as consultants and fixed within the personal learning curves of individual students. The concept of feeblemindedness—which was borrowed from psychopathology—served to legitimate a new pedagogical institution and profession.

Through the establishment of the Verband der Hilfsschullehrer Deutschlands (Association of German Training Schools' Teachers) in 1898, the training school gained enormous attention: In 1893, there were 110 special classes in 32 cities in Germany, with a total of approximately 2,300 students. By 1911, the number of classes had increased to 1,544, with approximately 33,000 students.

In spite of further expansion in following years, the training school system first experienced formal recognition during the period of German fascism through the Allgemeine Anordnung für die Hilfsschulen (General Order for Training Schools) in 1938. Even opponents of the National Socialist state protected the position of the training school by claiming that the productivity of their clientele would be useful for the armament industry and again that the training schools relieved strain on the elementary school system. In addition, the training schools saw themselves as holding tanks with respect to the sterilization law and participated in the selection of the "uneducable" (*Nicht-Bildungsfähige*), who fell victim to the so-called Euthanasia program between 1939 and 1945.

After 1945, a restoration of the previous training school system emerged in West and East Germany. In the Federal Republic of Germany the newly founded (as of 1949) Verband Deutscher Hilfsschulen (Association of German Training Schools) published a 1954 memorandum that appealed to the Deutsche Städtetag (German Congress of Municipal and Local Authorities) to proceed with haste to reconstruct and extend the Special School System *(Sonderschulwesen).* This memorandum stimulated the *Gutachten zur Ordnung des Sonderschulwesens* (*Report of the Rules of the Special School System*) of 1960, published by the Kultusministerkonferenz (Commission of the School Ministers of West German Federal States). This report explained that, in addition to the training school, other types of special schools (e.g., for children with sensory, speech, and physical disabilities; the sick; and those with behavior problems) were also elements of the German education system. At the beginning of the 1960s, the Special School for the Cognitively Disabled was added. Likewise in the 1960s, the classical training school successfully renamed itself Sonderschule für Lernbehinderte (Special School for the Learning Disabled).

Modern critics of the Special School for the Learning Disabled in Germany focused on the high overrepresentation of socially and economically underprivileged students in this type of school, such as children with immigrant backgrounds. Another area of criticism was that the relatively low achievement level was not, on average, being raised through small classes and individualized instruction methods. In this respect, the Special School for the Learning Disabled proves to be a significant component of the selective German educational system.

—Vera Moser

See also Education, International; Education and Disability.

Further Readings

Altstaedt, Ingeborg. 1977. *Lernbehinderte: Kritische Entwicklungsgeschichte eines Notstandes* (Learning Disabled: Critical Developmental History of a State of Need). Reinbek: Rowohlt.

Hänsel, Dagmar. 2003. "Die Sonderschule—ein blinder Fleck in der Schulsystemforschung" ("The Special School: A Blind Spot in Educational Research"). *Zeitschrift für Pädagogik* 49:591–609.

Klink, Job-Günter, ed. 1966. *Zur Geschichte der Sonderschule* (Toward a History of the Special School). Bad Heilbrunn: Klinkhardt.

Möckel, Andreas. 2001. *Geschichte der besonderen Grund- und Hauptschule.* (History of Specific Primary and Secondary Schools), 4th ed. Heidelberg: Winter.

GERMANY

See Advocacy Movements: Germany; Disability Law: Germany; Eugenics: Germany

ARNOLD GESELL (1880–1961)

American physician and psychologist

Arnold Gesell is best known for pioneering work in child development and as the founder of the Yale Child Development Clinic. Gesell was born and raised in Wisconsin, completing a Ph.D. in psychology at Clark University in 1906 and an M.D. at Yale in 1915.

When Gesell started his investigations into child development, he was most interested in the child with disabilities. Like Edouard Séguin and others before him, Gesell was fascinated by the pathological as it reflected on the normal, particularly in the form of a feral child discovered in the early twentieth century. Nevertheless, most of his work was concerned with describing the "normal child." A number of his publications caught the eye of James Angell, then president of Yale University, who orchestrated Gesell's move to New Haven. The Child Development Clinic, institutionally, began in the Yale Psychology Department but later moved to the Medical School and the Department of Pediatrics. Gesell received funding from the General Education Board of the Rockefeller Foundation as well as the help of Abraham Flexner. Eventually, Gesell and his work split, with the Child Development Clinic remaining at the Yale University Medical School (to this day) and another group creating the private Gesell Institute in New Haven. At times, these two institutions vie for the mantle of successor to Gesell's work.

Gesell was one of the first child developmentalists to use quantitative measures as tools for assessment throughout the continuum of childhood. He also extensively employed film and photographs to illustrate his arguments. He created orderly sequences of developmental stages to explain maturation of the child, resulting in the Gesell Development Schedules, which describe a child's motor, language, adaptive, and social responses to a variety of stimuli and produce a "developmental quotient" (DQ) suggesting a child's proximity to a "normal" child of the same age.

Into the central decades of the twentieth century, Gesell assumed a position as doyen of child development in the public mind. The author of many books, Gesell popularized his ideas of normal development through a series of lay guides. Middle-class mothers in particular found his work appealing, bringing his books with them when they visited their children's pediatricians. He helped standardize issues around developmental expectations in the minds of the public as well as in the minds of pediatricians, psychologists, and educators. Into the second half of the century, his ideas were overshadowed by more "environmental" developmentalists such as Jean Piaget.

—Walton O. Schalick III

See also Edouard Onesimus Séguin.

Further Readings

Benzaquén, Adriana Silvia. 2001. "Kamala of Midnapore and Arnold Gesell's Wolf Child and Human Child: Reconciling the Extraordinary and the Normal." *History of Psychology* 4:59–78.

Gesell, Arnold and Frances L. Ilg. 1943. *Infant and Child in the Culture of Today*. New York: Harper & Row.

Herman, Ellen. 2001. "Families Made by Science: Arnold Gesell and the Technologies of Modern Child Adoption." *Isis* 92:684–715.

GILMAN, CHARLOTTE PERKINS (1860–1935)

American writer and feminist theorist

Charlotte Perkins Gilman's childhood was spent in poverty after her father essentially abandoned the family. Her own first marriage was an unhappy one and ended in divorce. These early experiences were instrumental in forming Gilman's theoretical approach to feminism—expressed most fully in her 1898 classic

work *Women and Economics,* which stripped away romantic notions about the family and called for society to view domestic duties as social responsibilities.

Gilman's personal experience with what she described as long-standing melancholia—what today would be called major depression—led her to write the short story "The Yellow Wallpaper," which has endured as a feminist and disability classic and has been the subject of wide critical commentary. Gilman herself had been advised by a leading medical specialist to "live as domestic a life . . . as possible" and "never to touch pen, brush, or pencil again." She reported that following this advice brought her "so near the borderline of utter mental ruin that I could see over" (Gilman 1913). In "The Yellow Wallpaper" she transmutes these experiences into powerful and disturbing fiction.

In addition to writing other fictional and theoretical works, Gilman also lectured widely and was one of the founders of the Women's Peace Party.

—Anne Finger

See also Depression; Feminism.

Further Readings

Gilman, Charlotte Perkins. 1913, October. "Why I Wrote *The Yellow Wallpaper.*" *The Forerunner.* Retrieved April 14, 2005 (http://www.classiclit.about.com/library/bl-etexts/cpgilman/bl-cpgilman-whyyellow.htm).

Lane, Ann J. 1997. *To Herland and Beyond: The Life and Work of Charlotte Perkins Gilman.* Charlottesville: University of Virginia Press.

GLOBAL INEQUITIES

Numerous historical, economic, political, and cultural factors and forces have contributed to significant inequalities in the lives of disabled persons worldwide. These include inaccessible or uneven geographies; underdevelopment; globalization; the strengthening of state structures and surveillance mechanisms; the imposition of Western-style rehabilitation models; warfare; a burgeoning refugee population; indigenous values, categories, and practices; and cultural representations that circulate through art, film, literature, the media, and theater. These factors and forces are refracted through the lenses of race, class, gender, and sexual orientation, creating multiple and intersecting marginality and invisibility for some. Nonetheless, an emerging and expanding global disability rights movement is currently seeking recognition from national and international bodies, demanding that disability rights be recognized as human rights.

Approximately 80 percent of all disabled people live in the majority world (third world). James Charlton (1998) argues that the imbalance between the minority world (first world) and the majority world needs to be placed in the context of world-systems theory. This theory purports that wealth inequities between these spheres emerged as formerly colonized countries were forced to remold their economies to meet the demands of the West. Leaving these countries resource poor has produced disability by generating inadequate food supplies, unsanitary living conditions, and unsafe working conditions. It has also stripped these countries of the assets necessary to guarantee disabled citizens integration and self-determination, contributing to underdevelopment and a sense of internalized oppression for some disabled people. This pattern of underdevelopment has been exacerbated by globalization processes that support unfair trade policies propelled by profit-seeking capitalists promoting a world open-market economy. The pattern is also bolstered by structural adjustment policies devised by the World Bank that require debtor nations to repay loans at the cost of undercutting basic safety nets, health care, education, and employment opportunities and training. These policies further disenfranchise already disenfranchised disabled populations. Additionally, these policy restrictions and stipulations perpetuate paternalistic models of development, silencing majority world voices that the minority world needs to hear.

Benedicte Ingstad and Susan Reynolds Whyte (1995) have published an edited collection that examines disability in cross-cultural perspective. The volume outlines criteria for such comparisons, including mind/body understandings, concepts of personhood, and values that determine an individual's social worth. Ingstad and Whyte have been criticized for failing to focus on social oppression exposed by considerations of political economy and for failing to account for the subjective experiences of disabled embodiment

captured by phenomenological approaches. Nonetheless, their work is useful in that it serves to remind us that universal theories of oppression may obscure the diverse responses that specific cultures have had to disability, reinforcing misbegotten assumptions about the superior humanitarian impulses of the West.

Following on the work of Henri Stiker, Ingstad and Whyte's work reveals that there is a movement in many majority world countries to adopt Euro-American-style institutions and government procedures, often an artifact of colonialism. This style rests on the premise that equality equates with sameness, supporting uniform legal codes and uniform bodies and suppressing or replacing local or populist interpretations and practices even when they are beneficial to the disabled. Although there is a trend toward community-based rehabilitation (CBR), this appears to be driven more by cost concerns than by a desire to reimagine criteria for social belonging, encouraging input from disabled people themselves.

Matthew Kohrman (2003) offers an interesting ethnographic example of the ironies of a majority world country's struggles to establish criteria to determine eligibility for disability services and rights, placing his research in the context of modernity's nation-building projects. He conducted research in China on a state-run institution, the Disabled Persons' Federation. Founded in 1988 by Deng Pufang, Deng Xiaoping's eldest son, himself paralyzed in an attempted suicide during the Cultural Revolution, the Federation has attempted to redeem the moral status of the Communist Party by demonstrating its concern for China's most vulnerable citizens. Moreover, the state and the Federation have striven to prove to the rest of the world that China is deserving of first world status by devising statistical surveys that identify and count disabled people and by developing criteria for disability based on biomedical definitions.

The ironies are at least threefold. First, the criteria sometimes confuse and exclude persons applying for eligibility because they fail to consider functional limitations as imposed by disabling environments and because they ignore more fluid local categories. Second, government officials initially omitted mental illness because of its cultural associations with destabilizing social structures until pressure was brought from psychiatric elites who argued that recognizing mental illness is a mark of advanced civilization. Third, China established its goal for the total number of disabled to be located on the basis of a worldwide statistic of 10 percent first put forward by Rehabilitation International and then adopted by the United Nations. The statistic was not derived from rigorous evidence, but was meant to impress relevant national and international bodies that the magnitude of disability suggested that it was a pressing concern deserving immediate attention. However, when Chinese statisticians fell short of the 10 percent quota, they felt that they had lost face and embarked on another statistical count. Thus, unfortunately, the desire to be accepted as modern may actually draw energy away from more creative problem-solving forums that enable distinct nations to arrive at unique solutions.

Contemporary warfare, with its "advanced" strategies and technologies of death and destruction, serves as another catalyst for global inequality. The consequences of warfare are not random but intentional, such that "spoiled" and displaced bodies are evidence of the power of the victors over the vanquished, creating injuries and amputations that societies are unprepared for and generating refugees unhinged from familiar arrangements, social networks, and modes of survival. International policies, such as the 1997 Land Mines Treaty, set the tone for "fairness" in war, while reconstruction efforts are often hampered by a lack of consideration for disabled citizens. Modern nation-states also insist on preparedness for war, placing an emphasis on physical fitness as a requirement for full citizenship. Those who return from war may be classified as heroes or martyrs, potentially generating a two-tier system, with nonmilitary disabled citizens on the bottom rung of the social ladder.

John Hockenberry, a one-time reporter for National Public Radio, was stationed in Israel/Palestine during the first Intifada (Palestinian uprising that took place during the late 1980s). In his memoir titled *Moving Violations* (1995), he notes the enormous discrepancies he found between the conditions of the Israeli and Palestinian war wounded. The Israelis had lightweight, high-tech wheelchairs and were distributed vans with special government-issued license plates.

Elevated to the status of hero, they maneuvered their wheelchairs with militaristic confidence. Paralyzed Palestinians, on the other hand, were sequestered in rehabilitation hospitals, hopelessly awaiting the promise of cure in some other country. Reintegration into society was not a viable option for most, both because the role of martyr precluded a return to "normal" life and because old equipment, grinding poverty, and inaccessible terrain made it difficult for these individuals to return to their hometowns or villages.

Gender inequalities are another important factor to be taken into consideration in the analysis of global inequalities. Disabled girls and women are often the targets of various forms of violence, have their reproductive rights violated, are kept more sequestered than males, and are less likely than their male counterparts to have access to education and employment opportunities. Anita Ghai (2001) reports that disabled girls are particularly vulnerable in India for the reasons stated above. However, Ghai also notes, in an interesting twist, that disabled sons are thought to be a threat to "lineage capital" (a term borrowed from Emma Stone 2001), a form of capital that consists of the ability to fulfill expected family obligations, resulting in greater attention being paid to their rehabilitation needs.

Additionally, the voices of disabled women and girls may be dismissed and discounted, contributing further to a sense of nonpersonhood and invisibility. Veena Das and Renu Addlakha (2001) discuss the case of a woman in Delhi who was diagnosed with chronic schizophrenia and placed in a state-subsidized hospital. While there, she attempted to express concerns about her mistreatment by her husband and mother-in-law but was ignored because anything that she said was attributed to her "madness." In this case, the patriarchal structures of the state and the domestic spheres served to reinforce this woman's status as persona non grata.

Both disabled males and disabled females may be looked upon as lessening marriage opportunities for their siblings or otherwise symbolically polluting the kinship domain. Das and Addlakha recount the story of an Indian female born with a major facial blemish whose relatives wanted her quickly married off to a person of lower social standing as a means of containing the threat that she posed to their extended domestic circle. In this instance, her parents were her allies, ensuring that she acquired some education and allowing her to wait to get married until she found a suitable match. Such a stance necessitated that the parents be cut off from an ongoing relationship with their relatives. However, because they were a Punjabi family, displaced by the 1947 Partition between Pakistan and India, wartime conditions actually denaturalized taken-for-granted social arrangements. Moreover, when the woman married, she and her husband were able to take advantage of civil marriage statutes passed after India gained its independence from the British; this case provides an example of state policy helping to carve out new domestic practices that may prove beneficial to disabled citizens.

Finally, changing conventions of cultural representations of disability in art, film, literature, the media, and theater may create ruptures in ways of looking at and thinking about disability. Disrupting established narrative patterns by no means automatically undercuts entrenched inequalities, because old inequalities often resurface in new guise, sometimes rendering the processes of detection and interpretation multifaceted and opaque. Take the case in China of Liu Zheng's collection of photographs titled "My Countrymen." Before Mao Tse-tung's death in 1976, Chinese artists were expected to depict images of an idealized socialist society in which citizens were hardworking, physically fit, and mentally stable. Various genres of art have surfaced in the post-Mao era, some of which focus on unmasking the "reality" obscured by this ideal, and Liu Zheng's work falls within one such genre. Zheng photographs various categories of people living on the margins of society, including disabled people. While these categories may be reminiscent of Erving Goffman's typology of social stigma, as Wu Hung (2001) points out, there are aspects of Zheng's work that might strike one as disturbing. His juxtaposition of photos of disabled people with cadavers suggests an equation of disability with decay rather than a liminality that excites creativity or the forging of new norms. Zheng claims that as someone alienated from Chinese society, he feels an affinity with those photographs. However, even if these photos are aesthetically and empathically rendered, it still remains unclear as to whether they can be construed as progressive.

In recent decades disability rights activism has been sweeping the globe, confronting myriad inequalities. Global disability activism may be overlooked because of stereotypes that equate activism with fitness and the majority world with dependency and a passive femininity, making the pairing of disability and third world appear redundant. Activism may pose specific challenges for the disabled. In Canada, Vera Chouinard (1999) reports, a women's activist group was formed in 1977 called the Disabled Women's Network (DAWN). This organization made an effort to extend itself to women who had originally been excluded from the women's movement (people of color, immigrants, lesbians) in order to formulate broad-based objectives. Nevertheless, group members were faced with multiple constraints, such as lack of transportation, inability to afford the cost of conferences, inaccessibility of places in which to meet and places in which to stage protests, and uneven access to computer technology. Such obstacles, of course, are likely to be magnified in majority world countries, but as Anita Ghai recounts, even the urban slums of India are beginning to give rise to parental groups fighting for the rights of their disabled children and disabled people advocating for their own concerns. Moreover, as Chouinard points out, disabled activists in late-industrial societies are not necessarily guaranteed a voice because their bodies are often seen as lacking or contaminating corporate capital.

One of the benefits of globalization has been the circulation of information about global disability activism such that disabled activists can learn from each other and form coalitions. As with the minority world women's movement, however, disabled activists from first world countries need to exercise caution to avoid imposing their priorities and strategies on majority world activists who may face different conditions and political structures. It is equally important that the elites of majority world countries not be the sole decision makers regarding what discrimination and access issues are to be raised with local, national, and international bodies. A case in point is the Philippines, where a disabled talk-show host launched a campaign against disabled people in carnival freak shows. These entertainers protested his actions, noting that they preferred this form of employment to sheltered workshops, the only alternative supported by government officials for poor, disabled Filipinos.

This case underscores the importance of demanding economic and social rights and not simply focusing on individual civil rights. International disability rights assemblies, such as Disabled Peoples' International and representatives from the World Institute on Disability, have been working with the Union Nations to establish a convention that will recognize disability rights as human rights. Such a convention could prove useful to nations interested in developing their own policies and methods of implementation concerning disabled people. While such a convention would raise international awareness of disability issues, the process and outcome are also fraught with problems. For example, underscoring economic rights incites resistance from some minority world countries that benefit from the underdevelopment of the majority world. Additionally, there are problems with enforcing the stipulations of such a convention once it is forged and with ensuring broad-based input, including the most disenfranchised, into deciding the process of implementation.

—Sumi Colligan

See also Advocacy, International; Economic and Social Development, International; Employment, International.

Further Readings

Charlton, James I. 1998. *Nothing about Us without Us: Disability Oppression and Empowerment.* Berkeley: University of California Press.

Chouinard, Vera. 1999. "Body Politics: Disabled Women's Activism in Canada and Beyond." Pp. 269–294 in *Mind and Body Spaces: Geographies of Illness, Impairment and Disability,* edited by Ruth Butler and Hester Parr. London: Routledge.

Das, Veena and Renu Addlakha. 2001. "Disability and Domestic Citizenship: Voice, Gender, and the Making of the Subject." *Public Culture* 13:511–531.

Disabled Peoples' International. 2003. "DPI Position Paper Regarding a New Human Rights Convention for Disabled People." Retrieved September 26, 2003 (http://www.dpi.org/en/resources/pdfs/03-04-09-1_Position_Paper_Draft3.pdf).

Favis, Michelle. 2002. "Freak Shows: Demeaning Depictions or Empowering Employment?" *Disability World* 15 (September-October). Retrieved September 26, 2003 (http://www.disabilityworld.org/09-10_02/art/freaks.shtml).

Ghai, Anita. 2001. "Marginalization and Disability: Experiences from the Third World." Pp. 26–37 in *Disability and the Life Course: Global Perspectives,* edited by Mark Priestley. Cambridge, UK: Cambridge University Press.

Hockenberry, John. 1995. *Moving Violations: A Memoir.* New York: Hyperion.

Hung, Wu. 2001. "Photographing Deformity: Liu Zheng and His Photo Series 'My Countrymen.'" *Public Culture* 13:399–427.

Ingstad, Benedicte and Susan Reynolds Whyte, eds. 1995. *Disability and Culture.* Berkeley: University of California Press.

"International Convention on the Human Rights of People with Disabilities: An Idea Whose Time Has Come." 2002. *Impact: The Newsletter of the World Institute on Disability.* Retrieved September 26, 2003 (http://www.wid.org/publications/impact/Impact_fallwinter2002).

Kohrmann, Matthew. 2003. "Why Am I Not Disabled? Making State Subjects, Making Statistics in Post-Mao China." *Medical Anthropology Quarterly* 17:5–24.

Stone, Emma. 2001. "A Complicated Struggle: Disability, Survival and Social Change in the Majority World." Pp. 50–63 in *Disability and the Life Course: Global Perspectives*, edited by Mark Priestley. Cambridge, UK: Cambridge University Press.

"Towards a Gender Sensitive Disability Rights Convention." 2003. *Disability World* 19 (June-August). Retrieved September 26, 2003 (http://www.disabilityworld.org/06-08_03/un/gender.shtml).

GLOBALIZATION

Globalization is a process of change whereby local conditions or entities succeed in crossing national borders and reaching all over the world. Often associated with changes in global dimensions of politics, economics, and cultural practices, globalization is characterized by tensions, contradictions, and unequal power relations. Different regions of the world are at once implicated in multiple overlapping processes of many different globalizations. The globalization of disability issues constitutes one among many globalizations that simultaneously interact with, conflict, and relate to other globalizations. For example, economic dimensions of globalization conflict with disabled people's goals of social justice and equity when competition and deregulation processes involved in market economies exclude people with disabilities from full participation in society. Other major dimensions and processes of globalization that are pertinent to disability include the following: (a) the rapid spread of democracy and push for universal human rights, (b) technologies and the processes of communication and knowledge exchange, (c) social-political dimensions of education and the processes of changing negative beliefs and attitudes toward disability, and (d) health dimensions that produce processes of access to services and applications of medical research. These four broad areas constitute the major focus of disability in relation to globalization.

ECONOMIC DIMENSIONS OF GLOBALIZATION

With its intimate links to capitalization, globalization contains tendencies toward deregulation, decentralization, and privatization. These tendencies are most often associated with economic policies and practices of transnational corporations (TNCs), which exert pressures on industrialized states to shape events and decisions in developing countries. Currently, the top 200 TNCs have wealth equivalent to 28.3 percent of the world's gross national product, and five industrialized countries hold 90 percent ownership of these 200. Further, all industrialized states together comprise only 19 percent of the world's population yet control 71 percent of global trade in goods and services.

At the same time, 80 percent of the world's 600 million disabled people live in developing countries, yet these countries expend 20 percent of the world's health care moneys. Disability is also widely recognized as inextricably linked to poverty. The World Bank estimates that disabled people account for as many as 25 percent of the world's poorest. What is meant by *poor?* Half of the world's 6 billion people live on the equivalent of less than two U.S. dollars a day, and 40 percent of the people in Africa live on less than one U.S. dollar a day. Conditions linked to poverty, such as limited access to health care, food, education, and shelter, in addition to hazardous working conditions, increase the risk of disability. Impairments often lead to exclusion, unemployment, and further poverty, in turn creating and increasing the numbers of disabled people with impairments. The high unemployment rates of disabled people and their subsequent poverty is exacerbated by their countries' debts and privatization policies.

Global pressures for efficiency and competition in deregulated and privatized market economies have created conditions under which disabled people suffer greatly. First, free-market ideologies, by their very nature, create winners and losers, and inequalities are justified in terms of their contribution to economic growth. Second, because deregulation has weakened nation-states' ability to intervene and provide "safety nets," disabled people have lost income maintenance programs. Further, economic structural adjustment programs imposed by donor agencies such as the International Monetary Fund have been geared toward debt repayment. As a result, these programs have forced governments to reduce education and social services that are critical for disabled people in order to pay off these debts. Third, economic policies and interpretations of individual "rights" are increasingly in the hands of unelected technocrats in TNCs, whose interests are profits, not social justice, social responsibility, or equality.

On the positive side, the push to increase productivity, economics, and labor market participation rates has produced a global agenda for education reform, poverty reductions, and increased social responsibility. For example, the World Summit's Program of Action (1982) formally acknowledges conditions of poverty as a prima facie cause of disability. Further, one of the principal goals of the Program of Action is to ensure that society acknowledges and responds to the consequences of disability by securing the legal rights of the individual and by making the physical and social environment accessible. The Program of Action, ratified by 155 countries and in its fourth cycle of five-year review, now requires progress reports as well as resources and funding solutions to ensure access and equity for disabled people.

It is predicted that by the year 2025, the number of disabled people worldwide will have risen from the current 600 million to 900 million. The causes behind this projection can be directly linked to globalization and its effects. Global agendas are clearly driven by economic goals linked to development. These goals hold both a danger and a promise for the future of disabled people. On the one hand, the needs of large numbers of disabled people, coupled with an urgent need for economic development, have led many countries to focus on untapped sources of development by increasing the numbers of disabled people in the workplace. On the negative side, this focus on economic development and disabled people as workplace commodities has led to greater intolerance toward those disabled people who cannot work.

TECHNOLOGIES OF GLOBALIZATION AND UNIVERSAL HUMAN RIGHTS

Globalization has also produced positive benefits in the area of technological advances. Technologies of globalization, such as the Internet and advanced communication systems, have brought disabled people together to document and focus attention on the plight of disabled people and to insist on universal human rights. For example, Disability Awareness in Action (DAA) is an international coalition of the organizations Disabled Peoples' International (DPI), IMPACT, Inclusion International, and the World Federation for the Deaf. Largely linked through Internet communication, DAA has documented evidence of human rights abuses in 28 of the 30 articles of substantive rights contained in the Universal Declaration of Human Rights. As of March 2003, the DAA database contained a total of 1,910 reports of abuse affecting a known 2,466,348 disabled people. These abuses are widespread. For example, in the area of education alone, DAA has documented 118 cases affecting 768,205 people in 67 countries of the world.

Responding to this documentation and other reports, the United Nations Commission on Human Rights created the Global Rights campaign to address human rights abuses. Disability rights organizations such as the International Disability Alliance (IDA) have used this information to insist on a UN Convention on the Rights of Disabled People that would be legally binding on nation-states. The IDA's member organizations include DPI, Inclusion International, Rehabilitation International, the World Blind Union, the World Federation of the Deaf, the World Federation of Deaf-Blind, and the World Network of Users and Survivors of Psychiatry. DPI alone, as an international network of disabled people, works with organizations in 158 countries around the world.

The push for a universal declaration to address basic human rights of disabled people globally carries with it some problems and tensions. The primary tension is in the differences between the situation of disabled people in more advanced industrialized countries and the situations of those in poorer developing countries. More than three-fourths of the world's disability population struggles for the right to life. One-fourth of the population fights for quality of life—often framed in terms of choices, access, and equal opportunity. To many disabled people in developing countries, such quality-of-life issues often seem to be empty slogans because they fail to recognize issues of privilege, power, and control. The push for human rights and self-determination assumes that disabled people have autonomy and a real capacity for choice. Many disabled women and children around the world simply do not have this status or capability. Their lack of food and basic education also affects their ability to advocate for themselves—either individually or collectively.

Some disability scholars and advocates argue that laws regarding equal opportunity do not automatically or even probably lead to improved standards of living, nor do they necessarily lead to social change or change in economic policies. For example, in the United States, 14 years after passage of the Americans with Disabilities Act, unemployment of disabled people remains virtually at the same level as before the law went into effect.

On the other hand, many believe that these programs, declarations, and conventions constitute a universal moral imperative, bring human rights to center stage, and along with it, the right of the international community to intervene in specific countries to protect these rights. The work of DPI, IDA, DAA, and others has been the driving force behind the globalization of disability issues through the World Program of Action (1982), the United Nations Standard Rules on 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.

In addition to human rights implications, the role of information and communication technologies in disseminating information in a knowledge-based economy carries with it social and political implications. Prominent among these implications is the issue of bridging the digital divide between haves and have-nots in different regions of the world.

SOCIAL-POLITICAL DIMENSIONS OF GLOBALIZATION

In a globalized world, strategies that recognize interactions among rights, culture, and political-economic policies become imperative. For example, decisions to allocate resources for education and health services may reveal more about societal beliefs or government priorities than they do about a given country's ability to fund these services.

Education is widely recognized as inextricably linked to development. In response, UNESCO in particular has launched a global inclusive education project to increase the number of disabled children and youth who have access to education as well as opportunities for participation in quality education. In 2001, UNESCO launched pilot projects in Cameroon, 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. Advocates as well as governmental bodies differ on the subject of the nature and extent of inclusion for people with disabilities. For example, many countries still offer segregated educational experiences for certain populations of disabled children and youth, such as for blind, deaf, and deaf-blind individuals. However, all agree on the importance of education, not only as a basic human right, but as a primary source of individual and collective enhancement and development.

In reaction to globalization, age-old prejudices have also been reawakened, to the detriment of disabled people. For example, many nation-states are pushing for a return to traditional cultural practices to stem the tide of globalization, which is seen as a threat to tradition. Some Islamic states, for example, have reasserted that amputation for theft and stoning to death for marital infidelity are central to Qur'anic law, which overrides human rights declarations pertaining to cruel and unusual punishment.

Both the Declarations of Asia and the Pacific and the Africa Decade of Disabled People list as key objectives the fostering of positive attitudes toward disability and the challenging of traditional practices and beliefs detrimental to disabled people. For international disability organizations, a primary goal is not only educating children and youth, but educating civil society as well as political and governmental representatives. 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. Inclusion International and virtually every recent declaration (such as those of the African Decade and the Asia and Pacific Decade) list social-political agendas on which global partnerships to promote good government and full participation of disabled citizens are prominent goals.

HEALTH DIMENSIONS OF GLOBALIZATION

The new universe of disability is shifting and expanding. The shift is evident in the new World Health Organization classification of people with disabilities. In 2001, the new International Classification of Functioning, Disability, and Health (ICF) replaced the old International Classification of Impairments, Disabilities, and Handicaps (ICIDH-2). The new ICF was developed using a process of consensus involving both developed and developing countries. Basically, the ICF organizes disability along two dimensions: functioning and disability (including body functions/structures and activities/participation in society). This ICF definition shifts the focus from disability as an innate deficit to disability as constructed through the interaction between the individual and the environment. This shift encourages a focus on the kinds and levels of interventions appropriate to the needs of individuals within specific contexts and is consistent with the social model of disability that is upheld by disability rights organizations. The ICF distinctions are seen as particularly important in many developing countries, where personhood often depends more on social identity and fulfilling family obligations than on individual ability.

The expanding nature of disability is apparent in proposals to include persons with active, acute conditions such as HIV/AIDS under the rubric of disability. Prevention of these conditions has become an important public policy goal worldwide and introduces a need to reconsider the conceptual basis and terminology associated with disability. For example, including HIV/AIDS in definitions of disability challenges the thinking of disability advocates who have sought to separate notions of disability from disease.

Forces of globalization are also apparent in the area of rehabilitation and health-related services in the changing of language, such as the shift from the term *barrier-free design* to *universal design. Accessibility* used to refer mainly to the built environment, but new dimensions encompassed in the concept of universal design now include age-related factors, gender, culture, social context, levels of decision making, and control over major life activities. Guidelines for planning and design based on principles of universal design are now available in such disparate locations as Lebanon, Malta, and Peru.

Finally, global advances in medical research, genetics, and biotechnology have implications for people with disabilities. Genetic research has many practical applications to health care. Inclusion International (a nongovernmental advocacy organization on behalf of people with intellectual disabilities) recognizes that genetic research can be beneficial but also argues that it may undermine human rights and has implications for autonomy and informed decision making. As an example of these concerns, a formal policy statement issued in 2003 by Disabled Peoples' International demands a prohibition on compulsory genetic testing. The policy also demands prohibition of pressure on women to terminate pregnancies when their unborn children are considered likely to become disabled. As these organizations note, advances in genetic research and its applications may substantially alter the global diversity that disability offers human society.

CHALLENGES FOR THE FUTURE

To address economic, technological, social-political, and health dimensions of globalization simultaneously, a growing number of people with disabilities,

professionals working in disability fields, and disabled people's organizations are developing a form of disability politics referred to as a *twin-track approach.* In such an approach, disability issues are included as a crosscutting theme in all poverty reduction work, rather than as a "special issue" or convention. At the same time, local issues particular to a specific culture, context, or disability group are attended to. For example, Bangladesh used a twin-track approach to improve the situation of people with leprosy. To overcome the stigma of leprosy, health education for the society as a whole was coupled with socioeconomic rehabilitation of people with leprosy. This approach makes the assumption that removing prejudice (through education) facilitates early detection and prevention.

Another example of a twin-track approach is found in the work of disabled people's organizations in the Slovak Republic. The organizations collaborated to provide community-based services for persons with disabilities at the same time they created a database on the health care needs of disabled persons and undertook intensive education of the Parliamentary Commission for Health and Social Affairs. This twin-track approach assumes that rights in and of themselves do not equal or produce justice. In other words, social justice requires economic justice, and political democracy requires economic democracy.

The small but growing number of disability scholars and those working in disability professions who advocate the twin-track approach point us in a promising direction for the future. First, in terms of legal/policy issues, the choice may not be between a social welfare state and market economies, but a hybrid of what has been termed a *radical democratic socialism*. In this hybrid one type of politics can facilitate the other. Second, some disability advocates and scholars recommend that all of us who are concerned about global disability issues, as a collective, develop a "politics of hope." The critical task of such a politics of hope would be to develop not only universal human rights laws and conventions but also context-specific tactics or strategies for their implementation. Further, hope involves the recognition of the unacceptable nature of certain negative conditions and relations of globalization, coupled with a desire for change and the conviction that change is possible.

Because of the complex interactions among dimensions and processes of globalization, what is desperately needed is concerted action to bridge the economic, digital, and other divides between people with disabilities in different regions of the world. Ultimately, the advancement of people with disabilities in the twenty-first century and beyond requires a globalized agenda for action that addresses universal rights but at the same time is sensitive to particular historical, political, cultural, and economic conditions.

—Susan J. Peters

See also Advocacy, International; Economic and Social Development, International; Employment, International.

Further Readings

Barton, Len. 2001. *Disability, Politics and the Struggle for Change.* London: David Fulton.

Charlton, James I. 1998. *Nothing about Us without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press.

Christensen, Carol and Fazal Rizvi. 1996. *Disability and the Dilemmas of Education and Justice.* Buckingham: Open University Press.

Coleridge, Peter. 1996. *Disability, Liberation and Development*. London: Oxfam.

Holland, Daniel. 2003. "Grass Roots Promotion of Community Health and Human Rights for People with Disabilities in Post-Communist Central Europe: A Profile of the Slovak Republic." *Disability & Society* 18:133–143.

Ingstad, Benedicte. 2001. "Disability in the Developing World." Pp. 772–792 in *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury. Thousand Oaks, CA: Sage.

Light, Richard. 2003. *Review of Evidence Contained on the DAA Human Rights Database*. London: DAART Centre for Disability and Human Rights.

Peters, Susan. 2003. *Inclusive Education: Achieving Education for All by Including Those with Disabilities and Special Education Needs*. Washington, DC: World Bank, Disability Group.

Reinders, Hans. 2000. *The Future of the Disabled in Liberal Society*. Notre Dame, IN: University of Notre Dame Press.

Roth, William. 2002. *The Assault on Social Policy*. New York: Columbia University Press.

Stromquist, Nelly. 2002. *Education in a Globalized World: The Connectivity of Economic Power, Technology, and Knowledge*. Lanham, MD: Rowman & Littlefield.

Yeo, Rebecca and Karen Moore. 2003. "Including Disabled People in Poverty Reduction Work: 'Nothing about Us, without Us.'" *World Development* 31:571–590.

Websites

United Nations DESA, http://www.un.org/esa/society
Disability Awareness in Action, http://www.daa.org
Disabled Peoples' International, http://www.dpi.org
Inclusion International, http://www.inclusion-international.org

GODDARD, HENRY HERBERT (1866–1957)

American psychologist and educator

Henry Herbert Goddard was born in Vassalboro, Maine, and graduated from Haverford College in 1887. In 1899, he finished a Ph.D. from Clark University under G. Stanley Hall. In 1906, he became the director of the Vineland (New Jersey) Training School for the Feeble-Minded. Eventually receiving funding from the wealthy soap manufacturer Samuel Fels, Goddard carried out research and writing at Vineland that would gain him national notoriety. Between 1908 and 1910, he introduced an American version of the Binet and Simon intelligence test. At the 1910 annual meeting of the American Association for the Study of the Feeble-Minded, he coined the term *moron* to identify so-called high-grade imbeciles. In addition to intelligence testing and classification, Goddard's interests included eugenics. In regular communications with America's leading eugenicists, Goddard's writings reflected the linkage of intelligence, "feeblemindedness," criminality, and heredity—all prominent aspects of what Goddard (and others) called the "menace of the feebleminded." Among his writings are *The Kallikak Family: A Study in the Heredity of Feeble-Mindedness* (1912) and *Feeble-Mindedness: Its Causes and Consequences* (1914). In 1918, Goddard assumed the leadership of the Ohio State Bureau of Juvenile Research, and from 1922 to 1938 he was professor of psychology at the Ohio State University.

The definitive biography of Goddard is Leila Zenderland's *Measuring Minds: Henry Herbert Goddard and the Origins of American Intelligence Testing* (1998).

—James W. Trent

See also Developmental Disabilities; Eugenics; Mental Retardation, History of.

Further Readings

Zenderland, Leila. 1998. *Measuring Minds: Henry Herbert Goddard and the Origins of American Intelligence Testing.* Cambridge, UK: Cambridge University Press.

GOETHE, JOHANN WOLFGANG VON (1749–1832)

German poet, playwright, and novelist

Johann Wolfgang von Goethe was born on August 28, 1749, in Frankfurt am Main, Germany, and died on March 22, 1832, in Weimar. He was the central figure of the classical period of German literature and was knighted in 1782. He wanted to study philology and history, but as an obedient son he followed his father's orders and studied jurisprudence in Leipzig and Strasbourg. Beginning in 1771, Goethe practiced law in Frankfurt. His first historical drama *Götz von Berlichingen mit der eisernen Hand (Götz von Berlichingen with the Iron Hand)* was published in 1773. A year later he published the epistolary novel *Die Leiden des jungen Werthers (The Sufferings of Young Werther),* which was enthusiastically received and made him famous. In 1775, Goethe moved to Weimar at the invitation of Duke Carl August. There, in 1779, he became the head of the highest finance authority. Between 1786 and 1788, Goethe made the famous trip to Italy that accounted for his transformation to writing classical epics. In 1788, he met fellow author Friedrich Schiller (1759–1805) and, despite their different perspectives, these two important representatives of the classical period of German literature developed a productive creative friendship. Goethe's long-term relationship with Christiane Vulpius (1765–1816), a member of the working class with whom he had a son (August, 1789–1830), created a scandal in the distinguished and aristocratic city of Weimar. By this time, Goethe had completed his major body of literature, and therefore important works such as *Wilhelm Meister's Lehrjahre (Wilhelm Meister's Apprenticeship), Faust I,* and *Die Wahlverwandtschaften (Elective Affinities)* had already appeared when he published his scientific study *Farbenlehre (Color Theory)* in 1810. Goethe considered this study his

principal work; however, this claim met with much disapproval.

Goethe's contemporaries described him as a disciplined, stately man, although they often deplored his crooked teeth; he was, however, often ill. For example, he suffered a heavy hemorrhage due to tuberculosis as a student. He also had chronic kidney disease as well as facial neurosis, and in 1823 he suffered his first cardiac infarction. Sometimes people speak of Goethe's "healthy depression." He himself argued that misfortunes and sufferings form human beings. In his comprehensive, collection of 400 poems, *West-östlicher Divan (West-Eastern Divan)*, from 1819, he states:

> Wenn der schwer Gedrückte klagt:
> Hilfe, Hoffnung sei versagt,
> Bleibet heilsam fort und fort
> Immer noch ein freundlich Wort.
>
> [Should the one oppressed bewail:
> That both help and hope must fail,
> Remedy that's still preferred
> Is an ever-friendly word.]

From "Hikmet Nameh: Buch der Sprüche"
["Hikmet Nameh: Book of Proverbs"]

—Christian Mürner

Further Readings

Goethe, Johann Wolfgang von. 1971. *Goethe's Farbenlehre: 1805 bis 1810* (Goethe's Color Theory: 1805 to 1810), edited by Rupprecht Mathhaei. Ravensburg: Otto Maier.

———. 1974. *West-Eastern Divan*. Translated by J. Whaley. London: Oswald Wolff.

———. 1976. *Maximen und Reflexionen* (Maxims and Reflections), edited by Max Hecker. Frankfurt: Insel.

Nager, Frank. 1994. *Goethe, der heilkundige Dichter* (Goethe, the Healing Poet). Frankfurt: Insel.

GRAMSCI, ANTONIO (1891–1937)

Italian politician and theorist

Antonio Gramsci was a revolutionary from a poor Sardinian family who cofounded the Italian Communist Party in 1921 and inspired the Eurocommunist movement after 1945. His writings stress civil society, culture, praxis, and the struggle for intellectual "hegemony"—by which ideas become accepted as "normality" or are challenged.

Gramsci had a spinal deformity and never grew to average stature. As a child, he was strapped into a harness and suspended from the roof of a barn to "straighten him out." His impairment excluded him from military service, hence he became prominent in the Italian workers' movement in 1917 after other leaders were either mobilized or arrested. Elected to Parliament, he gave speeches that commanded attention for their content, not their force.

In 1926, Gramsci was arrested by the Fascists. At his trial, the prosecutor said, "We must prevent this brain from functioning for twenty years" (quoted in Fiori 1970:24). Although imprisonment segregated him from politics and ruined his health, it did not stop him from producing seminal Marxist analyses of history and culture in the form of the *Prison Notebooks,* which were later smuggled out of his cell. Gramsci's idea of the "organic intellectual" who expresses and defines the will of a movement still has resonance within disability studies.

—Tom Shakespeare

Further Readings

Fiori, G. 1970. *Antonio Gramsci: Life of a Revolutionary*. Translated by Tom Nairne. London: New Left.

Forgacs, D. 1988. *A Gramsci Reader.* London: Lawrence & Wishart.

GREEK AMPUTEES AT PERSEPOLIS

See Amputees at Persepolis

GROUP THERAPY

The concept of group therapy covers a wide range of therapeutic (mainly verbal) activities in which people gather in professionally led groups to ameliorate suffering caused by psychological or somatic problems or

difficult social circumstances. The field has multiple origins, and current theory and practice integrate material from different disciplines, including psychiatry, psychology, sociology, education, social work, and organizational theory.

Therapy groups have been used in medicine in a systematic way since the beginning of the twentieth century. Joseph Pratt, a Boston internist, is considered to be one of the pioneers, as he in 1905 gathered his tuberculosis patients in groups to teach them behavior and home-care measures he thought were crucial for the cure of their illness.

Therapy groups can be distinguished according to a number of different characteristics, including the following: They may make therapeutic use of the specific forces created by the group situation (dynamic, process-oriented groups) or they may use the group setting primarily as a time-saving device to deliver a message to several persons at the same time (didactic groups), they may be time limited or long-term, they may be closed or open for new members, and they may be homogeneous (e.g., only women, elders, or alcoholics) or heterogeneous (both sexes, different diagnoses, different ages). Group therapy may be the only treatment offered for a certain disorder, or it may be given in combination with other forms of treatment, such as medication or individual psychotherapy. It is also offered in many different settings, such as during hospitalization, in outpatient clinics, or in private practice. Most forms of group therapy involve a small group (6–10) of participants led by one or two therapists.

During the past few decades a wide array of self-help groups have appeared. These groups, which are based on principles of social support and mutual validation, may be very useful for patients and their families alike. Although such groups do not provide group therapy in a strict sense, they provide considerable benefit and reduce the amount of disability associated with chronic illness.

The goals of group therapy vary greatly and are related to the types of problems and levels of psychopathology of group participants (e.g., personality change, reduction in destructive drinking, improvement of social skills, learning to live with a chronic mental or somatic illness, or working through traumas). The effectiveness of group therapy for a wide range of different psychiatric/psychological disturbances has been documented through clinical experience and empirical research and can be summarized as follows: Group therapy is as effective as individual therapy for many conditions; group therapy based on cognitive behavioral theory may be most effective for specific disorders (e.g., social phobia), but for most disorders the empirical evidence for differential efficacy among various theoretical approaches (psychoanalytic, interpersonal, psychodrama) is not convincing. One reason for the current lack of clarity is that long-term (usually psychoanalytic) group therapy has been studied far less than short-term therapy.

—Steinar Lorentzen

See also Psychiatric Disorders; Psychology.

Further Readings

Fuhriman, Addie and Gary M. Burlingame, eds. 1994. *Handbook of Group Psychotherapy: An Empirical and Clinical Synthesis*. New York: John Wiley.

Lorentzen, Steinar, Kjell-Petter Bøgwald, and Per Høglend. 2002. "Change during and after Long-Term Analytic Group Psychotherapy." *International Journal of Group Psychotherapy* 52:419–429.

Yalom, Irvin D. 1995. *The Theory and Practice of Group Psychotherapy*. New York: Basic Books.

GUGGENBÜHL, JOHAN JACOB (1816–1863)

German-Swiss physician

Johan Jacob Guggenbühl was, during his lifetime, one of the best-known men of science in Europe and America. In 1840, he opened a medico-pedagogical asylum for cretins on the Abendberg overlooking the village of Interlaken in the Bernese Alps of Switzerland. Combining an approach to education based on the senses, evangelical Protestant faith, and a spirit of experimentation in medical matters (dietetics, naturopathy, heliotherapy, electrotherapy), he was able to attract the support of physicians, educators, and philanthropists such as Father Grégoire Girard and Philippe-Emmanuel de Fellenberg. There were numerous visitors to the "holy mountain," fascinated

as much by the beauties of nature as by the work of this "savior of the cretins" and as much by the professor's "system" as by the myth of the cretins' healing mountain.

The success met by Guggenbühl between 1840 and 1856, the date of the closure of "his" Abendberg, was equaled only by the doubts raised by this same success and the oblivion into which his pioneering work fell after his death in 1863. This neglect lasted until the rehabilitation of his reputation in 1905. Since that time, Guggenbühl has been recognized by history for the groundbreaker that he was: the founder of care for the mentally impaired in Switzerland, the precursor of medico-pedagogical treatment, and the pioneer of paedopsychiatry, even of sociotherapy.

—Henri-Jacques Stiker

See also Cretinism.

GUILLAIN-BARRÉ-STROHL SYNDROME

Guillain-Barré-Strohl syndrome (GBS) is the most commonly employed eponym for acute inflammatory demyelinating polyradiculoneuritis—inflammatory loss of the outer coating (myelin). It is termed *polyradiculoneuritis* because it tends to affect a large number and variety of nerve types. Peripheral nerves are all of the nerves that connect the central nervous system (brain and spinal cord) to the rest of the body. These nerves carry orders for motor movement or sensory information back to brain and spinal cord. They also send information back and forth to the brain and spinal cord that regulates the automatic functions of the body, such as muscle tone, balance, blood pressure, breathing, temperature regulation, reaction of pupils, bowel function, bladder function, and sexual function. Therefore, with the loss of myelin—and in severe cases the nerve fiber (axon) itself—these important functions may be disturbed or lost.

Occurring worldwide and in all seasons, GBS is the most common cause of acquired dysfunction of the peripheral nervous system, with 30,000 to 500,000 cases each year. It was not clinically recognized until Jean-Baptiste Landry of France gave the earliest systematic description in 1859 of the most common type, onset in the feet with ensuing ascending paralysis. Many decades later GBS was clearly set apart from poliomyelitis, a clinically similar condition. GBS, it would be discovered, is a disease of the peripheral nerves themselves and includes both motor and sensory dysfunction since both modalities are carried in peripheral nerves. It would also become clear that GBS tends to be symmetrical, to be more gradual in onset than poliomyelitis, and to have better recovery rates.

The names of Georges Guillain, Jean-Alexandre Barré, and André Strohl are commemorated in the name of the disease because their detailed description of it made the clinical distinction between GBS and poliomyelitis quite clear *and* because they described test findings that distinguished the two conditions. They found that protein concentration is elevated in spinal fluid in GBS as it is in polio, but that, unlike in polio, very few inflammatory white cells are found in the cerebrospinal fluid of GBS patients. This finding remains important in diagnosis of GBS to this day. The distinction of GBS from poliomyelitis was a very important contribution to the understanding of the hierarchical organization of the nervous system.

GBS is an acute autoimmune condition. A respiratory or gastrointestinal infection usually occurs days to weeks before the onset of GBS. This infection appears to cause the immune system to mount an attack against myelin by way of a protein target. One theory suggests that this occurs because of (a) the expression of a similar protein on the surface of that particular infecting organism and (b) the fact that the protein on the invading organism has been selected as the target of the immune response that is attempting to destroy the invading organism.

People who develop GBS may be more vulnerable to an autoimmune attack either because of the inheritance of an immunoregulatory weakness or because they have delayed development of an inherited protection against autoimmunity. A third possibility is that experiences such as early childhood infections help the immunoregulatory system to develop properly and that individuals without the right kinds of such experiences may be more vulnerable to autoimmunity. For unknown reasons, males are at greater risk for GBS than females. Stimuli other than infection may

also provoke GBS; these include such things as immunizations, bee stings, pregnancy, malignancies, and even other kinds of autoimmune conditions, an important example of which is systemic lupus erythematosis.

In GBS, a complicated cascade of immune manifestations attacks patches of myelin along the course of these nerves and, by removing this important nerve covering (which is somewhat analogous to insulation), may severely disrupt transmission along the central part of the nerve, the axon (more closely analogous to an electrical wire). In the most common ascending form of GBS, this can cause loss of all motor and certain sensory functions, particularly those governing joint position sense, that are involved in finding one's way while walking in the dark. In severe cases of GBS, the axon itself may be injured by intense inflammation, the importance of which is that although the recovery from demyelination may be excellent, recovery from axonal injury often is not.

Weakness ascending from feet to higher locations is usually the earliest and most noticeable sign of GBS. Progression to maximal weakness generally takes less than four weeks, usually about 12 days, followed by a period termed the *plateau.* If disease ascends high enough in the trunk, it may imperil breathing. Tendon reflexes are usually lost. In addition to sensory loss, odd sensations called *paraesthesiae* develop in about 70 percent of cases. Unsteadiness develops in many cases, due to weakness and sensory abnormalities. There is usually no fever as GBS develops. Various automatic cardiovascular, gastrointestinal, urinary, sexual, sweating, and other functions are lost in 25 percent of cases, and in some these losses may not be recovered. Changes in blood pressure and heart rhythm are particularly serious and, together with loss of breathing, are the most important causes of death in GBS. Many patients experience mild to severe pain. Sophisticated electrophysiological tests that involve electrical stimulation of muscles are positive in 90–99 percent of GBS cases.

It is of the greatest importance that GBS patients be carefully monitored for the development of serious complications such as failure of breathing (20 percent of cases), swallowing, and blood pressure fluctuations. Skillful management must be provided to prevent serious consequences of such deficits. Even without such potentially dire events, support must be provided for other disabilities, including management of problems with bowel and bladder function and prevention, in bed-bound patients, of the development of bedsores. Emotional support is also quite important. The onset of recovery in GBS usually starts within two to four weeks of onset of the plateau. Most patients, particularly children, who have sufficient support recover well from GBS without other interventions. However, there are treatments aimed at correcting the autoimmune process itself. These include use of anti-inflammatory drugs and techniques to remove circulating immune complexes from plasma. Some of these appear to shorten the duration and perhaps the severity of the disease.

Recovery may be a long process during which carefully designed physical, occupational, and other therapies may be important and provision must be made for residual automatic functions, particularly bladder and bowel problems. Disappointingly, many patients whose recovery is otherwise excellent have residual urinary or sexual deficits. Once the individual is ambulating well, it still may require many months before a sense of fitness and loss of excessive fatigue are achieved. Individuals who have had significant axonal involvement recover even more slowly, although as many as half of these recover completely within a year. A small number of patients who are initially labeled GBS turn out to have a difficult-to-manage chronic and recurrent peripheral neuropathic condition termed *chronic inflammatory demyelinatig polyneuropathy.*

—Robert S. Rust Jr.

See also Polio.

GUTTMANN, LUDWIG
(1899–1980)

German-English physician

Commonly known as "the founder of the Paralympic movement," Ludwig Guttmann was born in Upper Silesia, Germany, in 1899. He studied medicine and neurosurgery in Breslau and arrived in England as a refugee in 1939. As head of the Stoke Mandeville

Spinal Injuries Unit in Aylesbury from 1944 until 1966, he championed the concept of early treatment for injured servicemen in specialized spinal units and promoted the use of compulsory sport and physical activities as a form of rehabilitation, integration, and motivation.

Guttmann organized the first Stoke Mandeville Games for the Paralysed, held on July 28, 1948 (to coincide with the 1948 Olympic Games); that first event involved 16 competitors. The Games became international in 1952, and he founded the International Stoke Mandeville Games Federation (ISMGF), now the International Stoke Mandeville Wheelchair Sports Federation (ISMWSF). In 1960, the first Paralympic Summer Games were held in Rome following the Olympic Games, and the first Paralympic Winter Games followed in 1976.

Guttmann served as president of the International Sports Organization for the Disabled (ISOD) and as president of the International Medical Society of Paraplegia; he also founded the British Sports Association for the Disabled. Throughout his life, he worked to help integrate people with disabilities into society. Even after his retirement, he helped build facilities for athletes with disabilities. Among his many awards and honors, Guttmann was knighted in 1966.

—Miriam Wilkens

See also Sports and Disability.

Further Readings

Scruton, Joan. 1998. *Stoke Mandeville: Road to the Olympics*. Aylesbury, UK: Peterhouse.

Websites

International Paralympic Committee, http://www.paralympic.org

GUTZLAFF, AGNES
(CA. 1836–1869?)

Chinese missionary and educator

"Agnes Gutzlaff" was the name given by Carl and Mary Gutzlaff to one of several young blind Chinese girls, orphaned or abandoned, whom they adopted while in Macau in the 1830s. She was sent to London for formal education at the London Blind School, enrolling on January 3, 1842, at age five and a half. Agnes completed 13 years of education in London and shortly afterward returned to China as a missionary to teach blind people, almost certainly the earliest trained missionary with such a role. She joined Miss Aldersey at Ningpo in June 1856, learned the local language, and began teaching blind children and adults to read using materials first in Lucas's symbols and then in Moon's embossed script. After Miss Aldersey retired, Agnes moved to Shanghai, living and working there independently from 1862 until her death around 1869. "She worked hard, lived sparingly, and saved money, and at her death her property was left to found a hospital called by her name" (*Fortieth Report* 1878). The "Gutzlaff Hospital," in a back street of the English settlement in Shanghai, was a small, low-budget, general-purpose institution. It was later incorporated into St. Luke's Hospital.

—Kumur B. Selim

Further Readings

"The Blind Chinese Teacher." 1867. *Female Missionary Intelligencer* 10:33–34.

Fortieth Report of the London Society for Teaching the Blind to Read, 1878, May 28, pp. 15–16.

[Letter from Agnes Gutzlaff, December 1858]. 1859. *Female Missionary Intelligencer* 2:96.

H

HANAWA, HOKIICHI (1746–1821)

Japanese bibliographer

Hokiichi Hanawa, the son of a humble farmer, lost his eyesight in early childhood. At age 13 or 14, he went to Edo (now Tokyo) and enrolled at a private school for blind youths, under Ametomi Kengyō. Hokiichi should have learned music and acupuncture, but it seems that he did not gain much proficiency in those skills. He succeeded in memorizing much Japanese classical literature under a famous teacher, Kamo no Mabuchi, who had just retired from active service. Later, Hokiichi became a notable professor of literature.

Hokiichi spent many years editing documents to compile the vast *Gunsho Ruijū* (*Classified Collection of Japanese Classics*) (1779–1819), in 530 volumes containing more than 1,200 books and documents. He was also obliged to raise funds over a long period to produce the collection from wooden printing blocks. Hokiichi is recognized as one of the founders of modern bibliographical work in Japan, setting high standards in a field that most people would have thought unsuitable for a blind person.

—Kumur B. Selim

See also Blind, History of the.

Further Readings

The Japan Biographical Encyclopedia & Who's Who, 2d ed., p. 232. 1960. Tokyo: Rengo.

Kodansha Encyclopedia of Japan, Vol. 1, pp. 69, 95. 1983. Tokyo: Kodansha.

HAND AND ARM MANIPULATION

Hand manipulation is the action of using the distal portion of the arm and involves skillful use of the hand and fingers on objects in the environment. It includes "dexterous grasp and release patterns, isolated finger movements, and coordinated in-hand manipulation patterns when interacting with task objects" (Fisher 2003:195). Hand manipulation is a skill that contributes to functional performance and enables an individual to perform activities of daily living.

Problems with hand manipulation may be observed as "difficulty manipulating task objects, limited dexterity or difficulty with in-hand manipulation" (Fisher 2003:195) and may cause disruption of task performance or result in inefficient use of time or increased effort. This may result in the individual adapting posture and position of the body in relation to the object being manipulated.

Hand and finger manipulation deficits can be managed by either improving the actual skill or by compensating for the impairment. Compensatory strategies might include the following:

Change the demands of the task (e.g., restructuring the time spent on a task on any given instance).

Modify the environment (e.g., the social environment can be modified so that another individual can perform those tasks that require manipulation).

Use other parts of the body (e.g., using a mouth stick to type in the absence of adequate or lack of hand manipulation).

Provide adaptive equipment (e.g., splints and other orthotic devices, gadgets such as an electric can opener, and electronic equipment).

—Supriya Sen and Kathy Preissner

See also Assistive Technology.

Further Readings

Fisher, Anne G. 2003. *Assessment of Motor and Process Skills: Development, Standardization, and Administration Manual.* Fort Collins, CO: Three Star.

HANDICAP

The term *handicap* was used during the twentieth century to apply both to the impairments of individuals and to certain ways of evening the chances of success among contestants in sporting contests. With the rise of the disability rights movement in the past quarter of the century, the term's association with paternalistic attitudes toward disability has made *handicap* objectionable to many activists. Folk etymologies have grown up to explain why the term is offensive. It is often claimed that the original meaning of handicap referred to the fact that people with impairments could make a living only by begging, "cap in hand." This etymology is mistaken. The *Oxford English Dictionary*, the best etymological source on the English language, shows a much more interesting and complex history of the term.

Handicap originally referred to a sort of gambling game, practiced between the fourteenth and seventeenth centuries. One move in the game involved two contestants placing their hands in a cap and removing them at the same time, either open or closed (hence "hand in cap"). The game involved estimating the difference in value between two items. Some value (called the "boot" or "odds") was added to one item to make it equal in value to the other. During the seventeenth century, the technique of equaling the values of two items by addition of a boot was adopted in horse racing. A "handicap race" is one in which the faster horse carries extra weight. The game of golf adopted a system in which less skilled golfers were allowed to deduct strokes from their score, to be competitive with more skilled opponents. In horse racing and the gambling game, the term *handicap* referred to the game itself, not to the factor (the boot) that evened its outcomes. In golf, the handicap is a benefit for the less skilled, not a penalty on the more skilled.

In the late nineteenth century, the term came to be applied to disadvantages themselves, though not yet to impairments. The first recorded use with respect to impairments was in a 1915 poster labeled "the Handicapped Child."

Impairments were commonly called handicaps during the twentieth century, but the older sporting uses continued. In 1980, the World Health Organization (WHO) introduced another new definition according to which *handicap* referred not to an impairment itself but to the disadvantages that resulted from social discrimination against people with impairments. But by this time the term was distasteful to many. *Handicap* was offensive by association. The folk etymologies about "cap in hand" begging are mistaken, but they reflect a very real distrust of traditional attitudes toward disability.

Unfortunately, the loss of the term *handicap* creates a semantic vacuum in the American vocabulary of disability politics. British activists (unlike Americans) use the term *disability* to refer to what the WHO called *handicap:* the disadvantages caused by discriminatory treatment of people with impairments. They distinguish between impairments (biological conditions) and disability or disablement (the consequences of social arrangements). Americans use the term *disability* as a synonym of *impairment.* How do Americans refer to the social disadvantages? The 1980 WHO vocabulary had distinguished disability from handicap, the same distinction as the British but with different terminology. But because the term *handicap* was rejected as offensive, both in Britain and the United States, Americans are left without a simple term to designate the disadvantages that social arrangements create for people with impairments.

—Ron Amundson

See also *Cripple*; Impairment; International Classification of Functioning, Disability, and Health.

Further Readings

World Health Organization. 1980. *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease.* Geneva: World Health Organization.

HANDICAP INTERNATIONAL

Handicap International is an international nongovernmental solidarity organization, founded in 1982 in Lyon, France. The French section is at the origin of an international movement, with sections now existing in Belgium, Switzerland, Germany, Luxemburg, and the United Kingdom and representations in Denmark and the United States. Its goal is to ensure that people with a disability are able to regain their independence and their place in society, particularly in countries with difficult living conditions. The Blue Laces® are the symbol of this. The organization is active in various areas associated with all the causes of handicaps, both traumatological (e.g., land mines, road accidents) and infectious (e.g., polio, leprosy). Handicap International works especially in countries that are experiencing an acute or chronic crisis situation. Its activities are systematically based on a three-part approach: prevention, rehabilitation, and socioeconomic reintegration.

Prevention: Preventing handicaps, for example, by mine clearance and removal of unexploded ordnance, road safety campaigns, and prevention of injuries caused by disabling diseases such as leprosy and polio

Rehabilitation: Setting up centers for physical rehabilitation and rehabilitation and offering the required technical aids, physiotherapy, and rehabilitation programs

Reintegration: Facilitating the reintegration of people with a handicap into their social environment by offering education and vocational training in a targeted way, promoting social reintegration, and improving the rights of people with a handicap

Handicap International works with local partners and government bodies within a contractual framework and helps them to take over the project after a specific period of time. Seventy percent of financial resources come from institutional funds and 30 percent from private donations.

Its activities began in 1982 when the first orthopedic centers opened in refugee camps in Cambodia, Thailand, Myanmar (formerly Burma), and Laos to help several thousand amputees. The use of simple and locally available materials is one of the major strengths that allows Handicap International to bring quick and efficient help and to train competent local teams. By 1986, the organization realized that providing artificial limbs is not enough, and consequently, it moved toward a more global approach to disability by creating networks of local educational workers and strengthening family and community groups.

By the beginning of the 1990s, the disability issue became enlarged to include people in situations of exclusion and vulnerability. Actions to prevent disability were undertaken. Handicap International started working on mental disability issues as a result of experiences with Romanian orphanages and the war in the Balkans. In 1992, the organization created its first two mine clearance programs in Cambodia and Kurdistan and took part in the creation of the international campaign to ban land mines.

The period 1993–1995 was characterized by the development of partnerships, both locally and internationally. National orthopedic and physiotherapy centers opened in various countries. Training leading to a degree was set up in Cambodia, Mozambique, and West Africa. Between 1996 and 2002, Handicap International took part in the development of national policies in favor of disabled people. In 1996, the organization received the Nansen Prize, the highest prize given by the UN High Commissioner for Refugees. A high point in its organizational history, the organization was the joint winner of the 1997 Nobel Peace Price for its leading role in the fight against land mines.

—Patrick Devlieger

See also Developing World; International Disability Organizations.

Further Readings

Ingstad, Benedicte. 2001. "Disability in the Developing World." Pp. 772–792 in *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury. Thousand Oaks, CA: Sage.

Websites

Handicap International, http://www.handicap-international.org/english

HANSELMANN, HEINRICH (1885–1960)

Swiss educator and author

The Swiss special education pedagogue Heinrich Hanselmann was born in Wald bei St. Peterszell

(St. Gallen). Hanselmann was based out of Zurich. There, he was a cofounder of the Heilpädagogische Seminar (Special Education Seminar) and took over the direction of this special education training center in 1924. At the same time, Hanselmann and his wife, Annie (née Heufemann), founded and ran the appropriately named Landerziehungsheim für Schwererziehbare und Entwicklungsgehemmte (State Home for the Education of the Learning and Developmentally Disabled) in Albisbrunn bei Hausen am Albis (Zurich). In 1930, a year after he published his chief work, *Einführung in die Heilpädagogik* (*Introduction to Special Education*), Hanselmann was promoted to Extraordinary Professor of Special Education at the University of Zurich. He held this position, which was the first of its kind in Europe, until 1950. He died in 1960 in Locarno (Ticino).

The concepts of special education or special education pedagogy and *inhibited development* (as a synonym for *disability*) go back to Hanselmann, concepts that are still customary to use in German special education theory. In addition, he stressed that we should consider the question "Who is normal?" before we can occupy ourselves with the objectives and goals of special education. Special education has to focus on the whole person. For example, it is wrong to describe visually or hearing-impaired people as "so-called normal, albeit without the visual or auditory senses."

Hanselmann tried to popularize his views on special education. He supervised a private office for educational and marriage counseling and wrote columns in popular magazines, despite the fact that such behavior irritated many of his professional colleagues. Hanselmann saw himself as an educator of the people, following the tradition of Johann Heinrich Pestalozzi (1746–1827). His writings were accessible to most readers and were therefore widely disseminated. They carried such titles as *Sorgenkinder, daheim und in der Schule* (*Problem Children, at Home and in School*) (1934) and *Vom Sinn des Leidens* (*Making Sense of Suffering*) (1934). Through such disciplinary transgressive actions, Hanselmann hoped to be able to abolish the "Inselhaftigkeit der Heilpädagogik" ("solitariness of special education"), which he criticized.

—Christian Mürner

See also Heinrich Marianus Deinhardt; Special Education.

Further Readings

Hanselmann, Heinrich. 1930. *Einführung in die Heilpädagogik* (Introduction to Special Education). Zurich: Rotapfel. (9th ed., 1976).

———. 1934. *Sorgenkinder, daheim und in der Schule* (Problem Children, at Home and in School). Zurich: Rotapfel. (2d, completely new, ed., 1954).

———. 1941. *Grundlinien zu einer Theorie der Sondererziehung* (Basis for a Theory of Special Education). Zurich: Rotapfel.

Mürner, Christian. 1985. *Die Pädagogik von Heinrich Hanselmann: Zum Verhältnis von Entwicklung und Behinderung* (The Pedagogy of Heinrich Hanselmann: Towards an Understanding of Development and Disability). Lucerne: Schweizerische Zentralstelle für Heilpädagogik.

HATHAWAY, KATHARINE BUTLER (1890–1942)

American author

Katharine Butler Hathaway was born in Baltimore, Maryland. At the age of five, she contracted tuberculosis of the spine. To prevent the infection from causing any deformities, Hathaway spent the next 10 years of her life strapped to a stretcher. After being liberated at the age of 15 feeling that her incarceration was completely in vain due to a residual curvature, Hathaway and most of her family fell under the assumption that her deformity and resultant impairments would prevent her from ever gaining a "normal" life (i.e., getting married and having children). Yet, despite the unavoidable internalizations of societal stereotypes regarding disabled people, Hathaway's journeys as a single, disabled young woman proved a hidden benefit, which allowed her to throw herself into her creative writing and artistic endeavors.

The Little Locksmith: A Memoir, first published in 1943, reflects the internal conflicts of being a disabled woman. Struggling with her body's difference, Hathaway nevertheless feels blessed that it has granted her an independence few of her contemporary able-bodied women were allowed. Having lived during the height of the eugenics movement in the United States, Hathaway's memoir reflects her unease at being a disabled person when people with disabilities were so disposable. Yet she recognizes that her society tends to be very ignorant with respect to the lives of

disabled people. Throughout *The Little Locksmith,* Hathaway is continually revising the assumptions surrounding disability, sexuality, and gender, allowing the memoir to become a mode of resistance and social redress with respect to disability. By presenting her "counterstory," she helped to challenge the power of eugenic master narratives and the subsequent demise of the disabled body.

—Sara Vogt

See also Feminism; Sexuality.

Further Readings

Hathaway, Katharine Butler. 1946. *The Journals and Letters of the Little Locksmith.* New York: Coward-McCann.

———. [1943] 2000. *The Little Locksmith: A Memoir*. New York: Feminist Press.

Mairs, Nancy. 2000. "Afterword." Pp. 239–258 in *The Little Locksmith: A Memoir,* by Katharine Butler Hathaway. New York: Feminist Press.

HAÜY, VALENTIN (1745–1822)

French pedagogue

Valentin Haüy devoted his life to the education of the blind and created the first school for the blind in Paris, which served as a model for the entire world.

The brother of the founder of crystallography, Valentin Haüy perfected a system of raised letters (and not dots, as in Braille). From his concern that the blind not be reduced to begging, in 1784 he opened, at his own expense, the first free school in Paris for blind young boys and girls. With the support of the Philanthropic Society, this school became the Institution for Blind Children. It was nationalized during the French Revolution, and in 1791, by the decree of the Constituent Assembly, became the National Institute for Blind Young People (INJA, Institut National des Jeunes Aveugles).

An important member of the Arsenal section during the Revolution, he was one of the leaders of the theophilanthropic movement under the Directory. This was a cult of natural religion devoted to "bringing hearts together by preaching mutual indulgence and forgiveness of all wrongs." Disagreeing with the trends taken by the Institution, which was progressively losing its educational character to the detriment of professional activity, he preferred leaving his post in 1802. Soon afterwards, he left Paris to devote himself to the education of the blind and deaf-mute at the request of the Russian czar. He lived in Russia from 1806 to 1817. When passing through Berlin in 1806, he inspired the creation of the Berlin School for the Blind and founded a similar school in Saint Petersburg in 1808.

—Jean-François Ravaud

See also Blind, History of the; Denis Diderot; History of Disability: Early Modern West.

Further Readings

Haüy, Valentin. 1786. *Essai sur l'éducation des aveugles*. Paris: Clousier.

HAY, WILLIAM (1695–1755)

English author

William Hay, author and member of the House of Commons as a loyal Whig from 1734 until his death, was arguably the first person in the history of English letters to claim disability as an identity in print. Attacked by smallpox as a young man, which left him both visually impaired and visibly scarred, a hunchback barely five feet high, Hay nevertheless insisted on accurate portraiture. His complete works contain a variety of political, religious, and belle-lettristic pieces, most important, "Deformity, An Essay" (1754), written in response to Francis Bacon's influential "Of Deformity." Fusing the scientific impulse to objectify "nature" with the premodern belief in disability as mark of divine punishment, Bacon argued that deformed persons, marked by nature, and "void of Natural affection, are "commonly even with nature" by acts of antisocial "revenge." Removing deformity from the register of variable interpretation to that of scientific hypothesis, Bacon concluded, "It is good to consider of Deformity, not as a Sign, which is more Deceivable; But as a Cause, which seldom faileth of the Effect." Hay contests Bacon's theory by joining an alternative essayistic tradition of self-exposure practiced by his professed models, Michel de Montaigne and Alexander Pope, interpreting his deformity as a source of ineffable subjectivity and exemplary self-knowledge.

Balancing Christian stoicism with gentlemanly civility, he begins with a desire to "lay open my own Heart to the Reader" and concludes with the demand that his body be autopsied after death, "so that Mankind may be informed" of the effect of ingesting castile soap on bouts of the stone (kidney stone). Hay's deformity is a sign at the crossroads of literature and science; the ultimate evidence of his humanity is the clinical exposure of his body's interior in proof of a common disease.

—Helen Deutsch

See also Deformity; Alexander Pope.

Further Readings

Davis, Lennard. 2000. "Dr. Johnson, Amelia, and the Discourse of Disability." Pp. 54–74 in *"Defects": Engendering the Modern Body,* edited by Helen Deutsch and Felicity Nussbaum. Ann Arbor: University of Michigan Press.

Pender, Stephen. 2000. "In the Bodyshop: Human Exhibition in Early Modern England." Pp. 95–126 in *"Defects": Engendering the Modern Body,* edited by Helen Deutsch and Felicity Nussbaum. Ann Arbor: University of Michigan Press.

HEALTH

The concept of health is the most central concept in medicine and in the health sciences in general. Health is, indeed, the foremost goal of medicine (Pellegrino and Thomasma 1981; Callahan and Hanson 1999). Health also has a prominent position in many life contexts and is a crucial condition for maintaining and executing a profession, for enjoying leisure activities, and indeed, for living a good life in general. For example, health is a formal prerequisite for performing certain tasks or taking up certain occupations, such as that of soldier, police officer, or firefighter. More compelling is the place of mental health as a condition for moral and criminal culpability.

It is significant that, in modern secular society, health has gained an extremely high position in many people's value hierarchies. A Swedish group of researchers (Kallenberg, Bråkenhielm, and Larsson 1997) asked a representative sample of Swedes what are the highest values in their lives. A vast majority of these people put health at the top of their lists, which also contained such values as wealth, high social status, and good family relations. This social judgment can be contrasted with the ancient Platonian more restricted evaluation of health. According to Plato, it is an unsound condition in a society when people concentrate on their health and want to consult a physician anytime and about any question (*The Republic*).

Etymologically, health is connected with the idea of wholeness. This is evident in the verb *heal*, with the sense of regaining wholeness. The healthy person is a person who is whole in the sense of having all the properties that should pertain to a human being. Health has thus traditionally been viewed as an ideal notion, a notion of perfection that very few people, if any, can completely attain. Today, health also sometimes functions as an ideal notion. This is, indeed, the case with the formulation of health by the World Health Organization (WHO) in its initial declaration, published in 1948: "Health is a state of complete physical, mental and social well-being and not only the absence of disease or injury."

The notion of health is the object of scientific study from several points of view and within several disciplines. Besides research by those in medicine, public health, nursing, and other paramedical disciplines, other investigations are based in anthropology, psychology, sociology, and philosophy. In some of these disciplines, the focus is on a particular aspect of the notion: for example, in psychology, the experience of health and illness, and in anthropology and sociology, health and illness as factors of social importance. Philosophical analyses of health have often involved an attempt to formulate global definitions of the idea. Thus, in the following, many references will be taken from philosophical theories of health.

THE VARIETIES OF HEALTH

Health, thus, is a notion primarily applicable to a human being as a whole. On the other hand, there are more specific derivative notions. Ever since antiquity, and reinforced by the Cartesian distinction between body and mind, it has been natural to separate somatic health from mental health. The interpretations of mental health have varied over time. The ancient notion of mental health was closely connected to morality, whereby the mentally healthy person was a person who lived a virtuous

life, but this idea has lost most, though not all, of its significance today. The idea of spiritual health is also current in the health sciences although it is not systematically recognized. Bernhard Häring (1987:154) is a leading spokesman for a notion of health including a spiritual dimension: "A comprehensive understanding of human health includes the greatest possible harmony of all of man's forces and energies, the greatest possible spiritualization of man's bodily aspect and the finest embodiment of the spiritual."

The various categories of health have connections to each other. Sometimes bodily health has been given priority in the sense that it has been viewed as a prerequisite for mental health. Galen (AD 129–ca. 199/216) in some of his writings attempted to explain mental properties of the person in terms of specific mixtures of the bodily parts (Galen 1997). Consider also the ancient proverb: *mens sana in corpore sano* (a healthy mind in a healthy body). In the modern discussion about mental illness, one position, favored in particular by medical doctors, is that all mental illness has a somatic background, that is, all mental illnesses—if they exist at all—are basically somatic diseases (Szasz 1974). The customary view, however, also in Western medicine, is that a person can at the same time be somatically healthy and mentally ill, or vice versa.

HEALTH AS ABSENCE OF DISEASE

Although health is often described in nonmedical terms and with reference to nonmedical contexts, it has its primary place and function as a medical concept. Health in the medical arena is contrasted in particular with disease, but also with injury, defect, and disability. Culver and Gert (1982) have coined the term *malady* to cover the negative antipodes of health. In many medical contexts (Hesslow 1993), and in some philosophical reconstructions of the notion of health (Boorse 1977, 1997), health has been defined as the absence of diseases or the absence of maladies. The perfectly healthy person therefore is the person who does not have any diseases or maladies.

If one looks at the relationship between the concepts in this way, the burden of definition lies on the negative notions. Christopher Boorse (1997), for instance, defined disease in the following terms: "A disease is a type of internal state which is either an impairment of normal functional ability, i.e. a reduction of one or more functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agents." The notion of functional ability, in this theory, is in turn related to the person's survival and reproduction, namely, his or her fitness. From this analysis follows that we need not use the notion of disease to define health. The same idea can be formulated in the following positive terms: A person is completely healthy if, and only if, all his or her organs function with at least typical efficiency (in relation to survival and reproduction).

This idea of natural function is similar to, but not identical with, the one proposed by Jerome Wakefield (1992 and later), where the platform for analysis is biological evolutionary theory. The natural function F of an organ is, according to this idea, the function for which it has been designed through evolution. This means that the species in question (e.g., the human being) has been able to reproduce through history with the genetic setup for the function F. This idea has been criticized partly because it relates the idea of health in the present context to developments in the past.

HEALTH, DISEASE, AND ILLNESS

In many contributions to the theory of health, a distinction is made between the concepts of disease and illness (Boorse 1975; Twaddle 1979; Fulford 1989). The general idea behind this distinction—although it has been made in different ways by different authors—is that a disease is a deranged process in the person's body, whereas an illness is the person's negative experiences, for instance, pain or anguish, as a result of the disease. In addition, some theories include disability in illness; see below. The distinction between disease and illness has proved useful in several contexts, including the clinical one (Hellström 1993), for separating the disease as a pathological phenomenon from its impact on the person as a whole. (For a criticism of the distinction between disease and illness, see Sundström 1987.)

HEALTH AS BALANCE

An extremely powerful idea in the history of medicine is the one that health is constituted by bodily and mental balance. The healthy person is a person in balance, normally meaning that different parts and different functions of the human body and mind interlock harmoniously and keep each other in check. The Hippocratic (428–347 BCE) and Galenic schools were the first Western schools to develop this idea in a sophisticated way. They stated that a healthy body is one where the primary properties (wet, dry, cold, hot) of the body balance each other. In the medieval schools, following Galen, this idea was popularized and formulated in terms of a balance between the four bodily humors: blood, phlegm, yellow bile, and black bile (cf. humoral pathology).

The idea of balance is strong in several non-Western medical traditions. The *yahurveda* tradition in India, for instance, declares that there are three humors acting in the body, the breath (*vata*), the bile (*pitta*), and the phlegm (*kapha*). The proportions of the three humors vary from person to person, and their actions vary according to the season, the environment, the lifestyle of the individual, and his or her diet. In good health, the humors are in equilibrium. Disease is the result of their imbalance (Singhal and Patterson 1993).

Balance is a powerful idea also in modern Western thought, in particular, within physiology. The idea is often recognized under the label of *homeostasis* (the Greek word for balance). Walter Cannon's (1871–1945) classical work on homeostasis (1932) described in detail how the various physiological functions of the body control each other and interact in feedback loops to prevent major disturbances.

The idea of balance or *equilibrium* (the Latin word for balance) has a rather different interpretation in the writings of Ingmar Pörn (1993). Here balance is a concept pertaining to the relationship between a person's abilities and his or her goals. The healthy person, according to Pörn, is the person who can realize his or her goals and thus retain a balance between abilities and goals (cf. health as ability, below).

HEALTH AS WELL-BEING

It is an important aspect of health that the body and mind are well, both in order and function. But we may ask for the criteria of such well-functioning. How do we know that the body and mind function well? When is the body in balance?

A traditional answer is that the person's subjective well-being is the ultimate criterion (Canguilhem 1978). Simply put, when a person feels well, then he or she is healthy. This statement certainly entails problems, since a person can feel well and still have a serious disease in its initial stage. The general idea can, however, be modified to cover this case too. The individual with a serious disease will sooner or later have negative experiences such as pain, fatigue, or anguish. Thus, the ultimate criterion of a person's health is his or her present or future well-being. (For a different approach suggesting that complete health is compatible with the existence of disease, see Nordenfelt 1995 and 2000.)

It is a difficult task to characterize the well-being constituting health. If one includes too much in the concept, there is a risk of identifying health with happiness. It is, indeed, a common accusation directed against the WHO definition that it falls into this trap. Health cannot reasonably be identical with complete physical, mental, and social well-being, many critics say. The absurd conclusion of this conception could be that all people who are not completely successful in life would be deemed unhealthy.

Some authors (Gadamer 1993; Leder 1990) have pointed out that phenomenological health (or health as experienced) tends to remain as a forgotten background. Health is in daily life hardly recognized at all by its subjects. People are reminded of their previous health first when it is being disrupted, when they experience the pain, nausea, or anguish of illness. Health is "felt" only under special circumstances, the major instance being after periods of illness when the person experiences relief in contrast to the previous suffering.

Thus, although well-being or absence of ill-being is an important trait in health, most modern positive characterizations of health have focused on other traits. One such trait is health as a condition for action, that is, ability.

HEALTH AS ABILITY

A number of authors in modern philosophy of health have emphasized the place of health as a

foundation for achievement (Parsons 1972; Whitbeck 1981; Seedhouse 1986; Nordenfelt 1995; Fulford 1989). In fact, they argue, in partly different ways, that the dimension of ability/disability is the core dimension determining whether health or ill health is the case. A healthy person has the ability to do what he or she needs to do, and the unhealthy person is prevented from performing one or more of these actions. There is a connection between this conception and the one that illness entails suffering. Disability is often the result of feelings such as pain, fatigue, or nausea.

The formidable task for these theorists is to characterize the set of actions that a healthy person should be able to perform. Parsons (1972) and Whitbeck (1981) refer to the person's wants, that is, the healthy person's being able to do what he or she wants, Seedhouse (1986) to the person's conscious choices, and Fulford (1989) to such actions as could be classified as "ordinary doings." Nordenfelt settles for what he calls the person's vital goals. These goals need not be consciously chosen (babies and people with dementia have vital goals). The goals have the status as vital goals because they are states of being that are necessary conditions for the person's happiness in the long run. Health in Nordenfelt's theory is thus conceptually related to, but not identical with, happiness.

Although it is evident that health, as ordinarily understood, is connected with ability and ill health with disability, one may still doubt whether the dimension of ability/disability can remain the sole criterion of health/ill health. An important argument concerns those disabled people who are not ill, according to common understanding, and who do not consider themselves to be ill. These people are to be classified as unhealthy according to the ability theories of health.

One answer to this question (Nordenfelt 2001) is that disabled people (given that their disability is assessed in relation to their individual vital goals) are all unhealthy. However, they are not all ill and they do not all have diseases. Another answer, proposed by Fredrik Svenaeus (2000), is that there is a phenomenological difference between the disabled unhealthy person and the disabled healthy person. The unhealthy person has a feeling of not being "at home" with regard to his or her present state of body or mind. This feeling is not present in the case of the disabled in general.

HEALTH AND VALUE: NATURALISTS AND NORMATIVISTS

A crucial theoretical problem in the characterization of health is whether this notion is a scientific one. One can ask whether health and its opposites can be given a neutral, rather than value-laden, description, or whether it follows by necessity that health is to be characterized as a "good" bodily or mental state. Proponents of the former view are often called naturalists, whereas proponents of the latter view are often called normativists.

Different theorists have arrived at different conclusions with respect to this issue. Boorse (1977, 1997) claimed that there is a value-neutral definition of the basic notion of disease. Donald Broom (1993), who analyzed the notions of animal health and welfare, came to the same conclusion. Wakefield (1992) argued for the thesis that the notion of disease has two parts, one of which is value neutral, namely, the one that refers to the natural function of organs. The other part of the concept refers to the value-laden notion of harm. Most other theorists, however, think that the notion of health and its opposites are with necessity value laden. Some argue that these values are universal (Pellegrino and Thomasma 1981), others that the values determining the concepts of health and illness are connected to the background cultures (Engelhardt 1996). The physician/philosopher Georges Canguilhem (1978), who wrote one of the most significant treatises of human health and illness of the twentieth century, though he drew almost exclusively on medical data, came to the conclusion that health is an evaluative concept in a strong sense. The healthy organism, says Canguilhem, is not an organism whose functions are normal in a statistical sense. The healthy organism is one that is "normative," that is, one that is capable of adopting new norms in life.

One can discern further differences in the contention that the notion of health is value laden. Some theorists (e.g., Khushf 2001) claim that the notion is value laden in the strong sense that its descriptive content can vary over time. As a result of this, the only element common to an ancient and a modern concept of health is that health is a "good" state of a person's body or mind. Others, like the ability theorists above, would claim that there is a common descriptive content, namely, the fact that health has to do with a person's abilities but that one needs to make an evaluation

in order to specify what aspect or level of ability is required for health.

HEALTH AND CULTURE RELATIVISM

If health is a value-laden concept, then, as we have seen, some would argue that there are differences in the interpretation of health between cultures both historically and geographically. It is important to note that these differences can be more or less profound.

The concepts of health can vary from culture to culture because there are fundamental differences in the basic philosophy of health and health care, as between Western medicine and traditional Chinese medicine or the traditional Indian ayurveda medicine. Western medicine, which is to a great extent based on a naturalistic philosophy of people, arrives easily at a naturalistic understanding of health, whereas oriental schools with a holistic understanding of people in a religious context derive a notion of health that incorporates forces and developments that are partly supernatural.

The ways of and reasons for ascribing health to people may, however, vary even if there is a basic common theory of health and disease. Consider a particular physiological state, the state of lactase deficiency, which has the status of disease in a Western country but not in most North African countries. Lactase deficiency causes, in combination with ordinary consumption of milk, diarrhea and abdominal pain. Thus, in Western countries where people ordinarily drink milk, lactase deficiency will typically lead to illness. Therefore, this state ought to be included in a list of diseases in these countries. In North Africa, however, people rarely drink milk. Therefore, lactase deficiency seldom leads to illness. Consequently, it would be misleading to consider lactase deficiency a disease in this part of the world.

What makes the difference between the Western and the African cultures in this example is not different concepts of health and disease. It is a question of different lifestyles and different environments.

HEALTH AND ILLNESS AS GENDER DEPENDENT

Some theorists contend that the way we define and in general look at health and health care is dependent on our gender (Oakley 1993). This difference is well reflected in the traditional health professions. The traditional doctor is a man who is basically concerned with the physical condition of his patients. He sees his primary task as being to cure the diseases of the patient by use of well-established treatments often in the form of surgery and drugs. The traditional nurse is a woman who is basically concerned with the general well-being of the patient. She sees her primary task as being to care for the person as a whole. Caring, for her, means above all "relating to the ill person as a whole person whose psyche is equally involved with her or his soma in the illness in question" (Oakley 1993:40).

HUMAN BEINGS VERSUS ANIMALS AND PLANTS

Health, disease, and the other central medical concepts are not used only in the human context. We ordinarily ascribe health and disease also to animals and plants. Do we then apply the same concept of health?

In this case, the answers differ. The naturalists, who relate health solely to survival and reproduction, can easily transpose their concept to the world of animals and plants. The same could hold for balance theorists. It is more problematic to use the idea of health as ability or, even more, the idea of health as well-being all over the world of animals and plants. This can serve as an argument in favor of the naturalistic account. On the other hand, it can be argued that there is an enormous difference between the human context and the context of other living entities. Human beings live in complex societies with complex demands and with a system of health care that is supposed to serve the demands. It is no wonder that the concept of human health has evolved in directions quite different from the concepts of health concerning animals and plants.

WORLD HEALTH ORGANIZATION CLASSIFICATION

The WHO has issued roughly every 10 years a version of the International Classification of Diseases, Injuries, and Causes of Death (ICD) (the latest version from 1992 having the changed title "International

Classification of Diseases and Related Conditions"). The purpose of this classification is to provide an international taxonomy and nomenclature for the whole range of diseases and injuries. In the present version, there are 17 classes of diseases and injuries. In addition to this, there is a special heading for external causes of injury and poisoning. This classification plays an important role in medical statistics, in particular the statistics of causes of death.

The ICD fails, however, to reflect the full range of problems that lead people to seek medical help. It stops short at the consequences of disease, such as disabilities and handicaps. The latter are factors that intrude on everyday life and are directly observable by the bearer himself or herself. To fulfill the need for a theory and classification of consequences of disease, the WHO issued a tentative proposal for such a classification in 1980. This was the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), renewed and finally accepted in 1993.

This classification is firmly placed in a health context. The key phenomena classified, impairments, disabilities, and handicaps, are viewed as typical consequences of diseases. This is clearly seen in the definition of the concepts. Disability, for instance, is defined in the following way: "In the context of health experience, a disability is any restriction or lack . . . of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO 1980:28).

As a result of extensive testing and investigation, the ICIDH was finally (in 2001) replaced by a completely new taxonomy. This is the recently adopted International Classification of Functioning, Disability, and Health (ICF). Here the notion of health and its negative counterparts play a different and somewhat diminished role. Health is mentioned as a relevant category, and the ICF proposes definitions for concepts such as health states, health domains, and health conditions. However, since the classification is intended for several uses outside health care, the notions of health and ill health do not play a crucial role in the construction of the classification.

—Lennart Nordenfelt

See also Georges Canguilhem; Galen; Health Promotion; Hippocrates; International Classification of Functioning, Disability, and Health (ICF/ICIDH).

Further Readings

Boorse, C. 1975. "On the Distinction between Disease and Illness." *Philosophy and Public Affairs* 5:49–68.

———. 1977. "Health as a Theoretical Concept." *Philosophy of Science* 44:542–573.

———. 1997. "A Rebuttal on Health." In *What Is Disease? Biomedical Ethics Reviews,* edited by J. Humber and R. Almeder. Totowa, NJ: Humana Press.

Broom, D. M. 1993. "A Usable Definition of Animal Welfare." *Journal of Agricultural and Environmental Ethics,* pp. 15–25.

Callahan, D. and M. J. Hanson. 1999. *The Goals of Medicine: The Forgotten Issues.* Washington, DC: Georgetown University Press.

Canguilhem, G. 1978. *On the Normal and the Pathological.* Dordrecht: D. Reidel.

Cannon, W. B. 1932. *The Wisdom of the Body.* New York: Norton.

Culver, C. M. and E. Gert. 1982. *Philosophy in Medicine: Conceptual and Ethical Issues in Medicine and Psychiatry.* Oxford, UK: Oxford University Press.

Engelhardt, H. T., Jr. 1996. *The Foundations of Bioethics*, 2d ed. Oxford, UK: Oxford University Press.

Fulford, K. W. M. 1989. *Moral Theory and Medical Practice.* Cambridge, UK: Cambridge University Press.

Gadamer, Hans-Georg. 1993. *Über die Verborgenheit der Gesundheit.* Frankfurt am Main: Suhrkamp Verlag.

Galen. 1997. *Selected Works.* Translated with an introduction and notes by P. N. Singer. Oxford, UK: Oxford University Press.

Häring, Bernhard. 1987. *Medical Ethics.* Middlegreen, Slough, UK: St. Paul.

Hellström, O. 1993. "The Importance of a Holistic Concept of Health for Health Care: Examples from the Clinic." *Theoretical Medicine* 14:325–342.

Hesslow, G. 1993. "Do We Need a Concept of Disease?" *Theoretical Medicine* 14:1–14.

Kallenberg K., C. R. Bråkenhielm, and G. Larsson. 1997. *Tro och värderingar i 90-talets Sverige* (Beliefs and Evaluations in Present Day Sweden). Örebro, Sweden: Libris.

Khushf, G. 2001. "What Is at Issue in the Debate about Concepts of Health and Disease? Framing the Problem of Demarcation for a Post-Positivist Era of Medicine." In *Health, Science, and Ordinary Language,* edited by L. Nordenfelt. Amsterdam: Rodopi.

Leder, Drew. 1990. "Clinical Interpretation: The Hermeneutics of Medicine." *Theoretical Medicine* 11:9–24.

Nordenfelt, Lennart. 1995. *On the Nature of Health: An Action-Theoretic Approach*, 2d rev. ed. Dordrecht: Kluwer Academic.

———. 2000. *Action, Ability and Health: Essays in the Philosophy of Action and Welfare.* Dordrecht: Kluwer Academic.

———, ed. 2001. *Health, Science, and Ordinary Language.* Amsterdam: Rodopi.

Oakley, Ann. 1993. *Essays on Women, Medicine and Health.* Edinburgh: Edinburgh University Press.

Parsons, T. 1972. "Definitions of Health and Illness in the Light of American Values and Social Structure." In *Patients, Physicians, and Illness*, edited by E. G. Jaco. New York: Free Press.

Pellegrino, E. D. and D. C. Thomasma. 1981. *A Philosophical Basis of Medical Practice*. Oxford, UK: Oxford University Press.

Plato. 1998. *The Republic.* In *Complete Works,* edited by J. M. Cooper. Indianapolis, IN: Hackett.

Pörn, I. 1993. "Health and Adaptedness." *Theoretical Medicine* 14:295–304.

Seedhouse, D. 1986. *Health: Foundations of Achievement.* Chichester, UK: Wiley.

Singhal, G. D. and T. J. S. Patterson. 1993. *Synopsis of Ayurveda.* Based on a translation of the Treatise of Susruta. Delhi, India, and Oxford, UK: Oxford University Press.

Sundström, P. 1987. *Icons of Disease.* Linköping, Sweden: Linköping Studies in Arts and Science.

Svenaeus, F. 2000. *The Hermeneutics of Medicine and the Phenomenology of Health.* Dordrecht: Kluwer Academic.

Szasz, T. 1974. *The Myth of Mental Illness,* rev. ed. New York: Harper & Row.

Twaddle, A. R. 1979. *Sickness Behavior and the Sick Role.* Boston: G. K. Hall.

Wakefield, J. C. 1992. "The Concept of Mental Disorder: On the Boundary between Biological Facts and Social Values." *American Psychologist* 47:373–388.

Whitbeck, C. 1981. "A Theory of Health." In *Concepts of Health and Disease: Interdisciplinary Perspectives,* edited by A. L. Caplan, H. T. Engelhardt Jr., and J. J. McCartney. Reading, MA: Addison-Wesley.

World Health Organization. 1980. *International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Disease.* Geneva: World Health Organization.

———. 1992. *International Classification of Diseases and Related Conditions.* Geneva: World Health Organization.

———. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

HEALTH CARE AND DISABILITY

The highest objectives of health care systems throughout the world can be framed within the context of the World Health Organization's (WHO) definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." The WHO Constitution (2004) further states that "enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" and that "extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health."

In addition to the obvious barriers created by issues of loss of mobility and communication deficits, research has established that individuals with disabilities have finance-related problems with access to health care. People with disabilities are more likely to put off or postpone medical care because they cannot afford it (28 vs. 12 percent in a recent U.S. survey). The same survey determined that persons with severe disabilities are almost four times more likely to cite lack of income as the number one reason why they were not able to get care when it was needed versus people with slight disabilities. Individuals with disabilities are four times more likely than people without disabilities to have special needs that are not covered by their health insurance. Meeting the health care objectives of the WHO faces steep barriers for persons with disabilities.

In the context of caring for persons with disabilities (e.g., physical, developmental, cognitive), health care providers' tasks can be described in the following distinct areas: physical access to health care, functional access to health care, fiscal access to health care, effective prevention of health care issues that create or worsen disabilities, effective intervention in the general health care needs of individuals who happen to have disabilities, effective provision of rehabilitation services to address the special needs of persons with disabilities, and equal employment opportunity for professionals with disabilities.

BACKGROUND

Since World War II, emerging social and scientific developments have improved the potential for individuals with disabilities and have had great impact on the provision of health care to this population. There are large, and growing, numbers of persons with disabilities in all parts of the world. While the consequences of disability vary throughout the world, variations in the health care available to persons with disabilities are the result of different socioeconomic circumstances and of the different provisions that nations make for the well-being of their citizens as well as the ignorance, neglect, superstition, and fear that greet such individuals throughout the world. Also, having disabilities is

broadly associated with poverty, and poverty compounds the barriers to participation in the routine activities of the general population of a nation.

Since the 1960s, a new concept of addressing both the social and health issues associated with disabilities started to gain ground. The new thinking pointed to the correlation of the limitations experienced by those with disabilities, and the effect of the social and physical environment on those limitations. This thinking expanded during the UN Decade of Disabled Persons (1983–1992) to recognize the necessity of addressing both the individual needs (such as rehabilitation and technical aids) and the shortcomings of the society (various obstacles for participation). In 1975, the UN General Assembly adopted the Declaration on the Rights of Disabled Persons, which included a specific provision establishing the right to medical, psychological, and functional treatment.

In the United States, the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990 brought the force of the federal government into the effort to establish a clear and comprehensive prohibition of discrimination on the basis of disability.

The 1973 Rehabilitation Act, which covered all providers who were above a certain size and were receiving federal funds, was not as aggressively applied as it could have been and did not stretch to routinely extend the benefits of American health care to all persons with disabilities. Yet it did assert that in providing health, welfare, or other social services or benefits, a provider that is a recipient of federal health care dollars may not, on the basis of handicap,

> Deny a qualified handicapped person these benefits or services
>
> Afford a qualified handicapped person an opportunity to receive benefits or services that is not equal to that offered to nonhandicapped persons
>
> Provide a qualified handicapped person with benefits or services that are not as effective as the benefits or services provided to others
>
> Provide benefits or services in a manner that limits or has the effect of limiting the participation of qualified handicapped persons
>
> Provide different or separate benefits or services to handicapped persons except where necessary to provide qualified handicapped persons with benefits and services that are as effective as those provided to others.

In addition, the Rehabilitation Act mandated the use of assistive aids for those with impaired sensory, manual, or speaking skills, where necessary to afford such persons an equal opportunity to benefit from the service in question.

The ADA had significant impact on the provision of health care to persons with disabilities in the United States. The ADA continues to evolve through regulation and court decisions that extend the determination to make health care accessible to Americans with disabilities, and U.S. health care providers continue to evolve in their efforts to make health care seamlessly available to individuals with disabilities. Today, U.S. health care can be viewed as a leader in the effort to make health care services available to all regardless of disabilities. The effect of these changes in health care for the disabled can be described in several specific areas.

EQUITY: EQUAL ACCESS TO HEALTH CARE

The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies, and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. This also applies to the provision of health care services.

Physical Access

Most licensed health facilities in the United States are operated under state and local regulations (as well as accreditation rules) that require clinical facilities that are physically designed for accessibility in wheelchairs or carts. The ADA imposed new thinking that required wheelchair accessible entry to all public and common areas, accessibility to public toilets, barrier-free entry, and improvement of access and navigation for the visually impaired. Wheelchair lifts, automatic doors, power-assist examination tables, Braille labeling of elevator instructions, audible signals on elevators, and Braille directional signs are all commonplace in U.S. health care facilities today.

Functional Access

Simple physical access does not ensure that individuals with disabilities will be able to make use of health care services in any useful way. Visually and hearing-impaired individuals have long been left outside the mainstream of much routine activity. This barrier to full participation is even greater in times of medical crisis. Section 502 of the Rehabilitation Act covering providers of care as "public accommodations" mandated that adaptive devices and access to signing interpreters be available for hearing-impaired patients. Section 504 of the Rehabilitation Act regulates providers of health care as recipients of federal funds through the Medicare and Medicaid programs. Numerous court cases in the United States have served to define the underlying policy of functional access, and expand the application of it through the regulation of those providers that participate in such federally funded programs. Such cases not only have a direct regulatory impact but also serve to create a "community standard of care" that has great impact on potential financial liability in the courts if the provider of care is accused of harming the patient as a result of withholding these services.

Financial Access

Even in the presence of accessible facilities with appropriate functional adaptations to provide adequate care for persons with disabilities, ability to pay for that care may remain a significant barrier to service. The UN addresses financial support for assistive devices in its Rules on the Equalization of Opportunities for Persons with Disabilities. The rules specify "that this may mean assistive devices and equipment should be provided free of charge" or at a lowered price to ensure affordability. The U.S. Rehabilitation Act requires that communications assistance be provided at the expense of the health care provider. In the absence of a universal health care plan in the United States, many persons with disabilities would still be confronted with affordability barriers given the substantial portion of the population lacking private health insurance. Many of these persons are, however, covered under the U.S. Medicare and Medicaid health insurance programs by virtue of their defining disability.

Additional barriers have historically existed for employed and insurance-eligible individuals. Persons with chronic diseases and disabilities often found themselves confronted with rejection by insurers, or exclusion from coverage of their specific health problems. The passage of the Kennedy-Kassebaum Act of 1996 placed some limitations on the exclusions that insurance companies can impose on accepting coverage of employee group members.

One specific area of broad exclusion has been private insurance coverage for mental health needs. In the United States, mental and developmental disabilities remain largely overlooked problems. There is evidence indicating that such coverage is affordable and that substantial savings are possible in reduced medical costs, crime, homelessness, increased worker productivity, and increased employment taxes. Yet several efforts to create federal statute or regulation requiring parity of mental health coverage with existing somatic illness coverage have repeatedly failed to gain passage. As a result, significant barriers to obtaining such services remain.

EFFECTIVENESS

Health care aimed at the issues of persons with disabilities must pursue the same broad goals of health care for any population, with the added burden of addressing the specific risks of disability.

Prevention

The reduction in incidence of disabling diseases and injuries is the first goal for the health care system. The term *prevention* means action aimed at preventing the occurrence of physical, intellectual, psychiatric, or sensory impairments (primary prevention) or at preventing impairments from causing a permanent functional limitation or disability (secondary prevention).

Primary prevention may include many different types of action, such as primary health care, prenatal and postnatal care, education in nutrition, immunization campaigns against communicable diseases, genetic testing, measures to control endemic diseases, safety regulations, programs for the prevention of accidents in different environments including adaptation of workplaces to prevent occupational disabilities and diseases, and prevention of disability resulting from pollution of the environment or armed conflict.

Secondary prevention may include early detection of, and intervention in, potentially disabling diseases. It may also include the development of more sophisticated diagnostic and interventional techniques and technology to enable more successful reduction of adverse outcomes of chronic diseases and critical injuries.

Health Maintenance

Persons with disabilities may have special needs related to their disabling condition that can cause specific challenges to their continuing overall health and well-being. In addition, loss of mobility or ability to communicate effectively can increase the likelihood of secondary failures of health providers to manage the continuing health of such individuals. While there has been a trend toward the development of generalists or primary care specialists to improve the coordination of health care services for the general population, it may be argued that the special needs of populations with disabilities require special understanding to fruitfully provide such continuing care. Several special efforts have produced noteworthy results. There has been some demonstration that focused efforts to care for those with severe developmental disabilities can result in reduction of adverse outcomes and hospitalizations when compared to mainstreaming the care of such persons. Rehabilitation specialists delivering continuing care to disabled patients exhibit greater focus on the corollary problems of mobility loss (e.g., spasticity, decubiti, infection) that can lessen the quality of health.

Rehabilitation

The term *rehabilitation* refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric, and/or social functional levels, thus providing them with the tools to change their lives toward a higher level of independence. Rehabilitation may include measures to provide and/or restore functions or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance, vocational rehabilitation.

EFFICIENCY

Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment, and social services to maximize their ability to lead a productive life. Providers of health care cannot lose sight of the need to optimize the value of the provision of the care and to maximize the value of the outcome for an individual with disabilities. Certainly, keeping an individual within a local community and maximizing the possibility of a normal productive life is one of the needs that must be accommodated to achieve these goals.

Olmstead Decision

In the United States, several court decisions have served to define and expand expectations under the ADA. Key among these has been the court ruling known as the *Olmstead* decision, in which the U.S. Court of Appeals held that decisions regarding services and where they are provided must be made on the basis of the appropriateness for each particular individual and further that services should be provided in the most community-integrated setting possible. This and other cases have broadened the requirements to maintain the care of individuals with disabilities close to home and within the routine of a productive life. Largely applied to persons with mental disorders and developmental disabilities, the decisions have recently been applied to the deinstitutionalization of care for persons with spinal cord injury and other mobility deficits.

CONCLUSION

Health care has historically been driven by developments in technology and science. Health care for persons with disabilities brings to the formula the critical need for understanding the driving forces of ethics, philosophy, and social commitment. In this arena, the role of government regulation will surely play a continuing role.

—Benn Greenspan

See also Americans with Disabilities Act of 1990 (United States); Rehabilitation Act of 1973 (United States).

Further Readings

Arizona Center for Disability Law. 2001. "The Duty of Health Care Professionals to Provide Sign Language Interpreters." Retrieved September 3, 2001 (www.acdl.com).

National Mental Health Association. 2001. "Mental Health and Substance Abuse Parity Fact Sheet: Introducing or Amending Parity Laws in 2001." (www.nmha.org/state/parity_fact_sheet.cfm).

National Organization on Disability. 2001. "Access to Health Insurance." Retrieved July 25, 2001 (www.nod.org/content.cfm).

Olmstead v. L. C. (98-536) 527 U.S. 581 (1999).

United Nations. 1975. "Declaration on the Rights of Disabled Persons, G.A. res. 3447 (XXX), 30 U.N. GAOR Supp. (No. 34) at 88." U.N. Doc. A/10034.

———. 1993. "The Standard Rules on the Equalization of Opportunities for Persons with Disabilities Adopted by the United Nations General Assembly, forty-eighth session, resolution 48/96, annex, of 20 December 1993, Rules 2, 3 and 4." Appendix 1, pp. 31–34.

U.S. Department of Health and Human Services. June 3, 2004. News release. (www.hhs.gov/news/press/20040603.html).

U.S. Department of Health and Human Services Health Care Finance Administration. August 4, 1998. "HCFA Letter Regarding Individuals with Disabilities." (www.healthlaw.org/pubs/Alert980804.html).

———. January 14, 2000. "HCFA Dear State Medicaid Letter Provides Guidance on *Olmstead* Decision Regarding Individuals with Disabilities." (www.healthlaw.org/pubs/Alert000114.html).

United States Title 104 Stat. 327. Americans with Disabilities Act of 1990.

United States Title 34 Education, Subtitle B Regulations of the Offices of the Department of Education, Chapter I—Office for Civil Rights, Department of Education, Part 104—Nondiscrimination on the Basis of Handicap in Programs or Activities Receiving Federal Financial Assistance.

World Health Organization. 2004. "Constitution." (http://www.who.int/about/en/).

Websites

National Rehabilitation Hospital, Project Shield, www.nrhrehab.org/researchstatic.cfm

Olmstead decision, http://www.cms.hhs.gov/olmstead/default.asp

HEALTH CARE SYSTEMS

In the early twenty-first century, the number of disabled persons continues to rise and their health care needs persist and multiply. At the same time, the health care systems they interact with are also constantly changing, reflecting responses to economic, political, and social forces. Those systems, composed of health care professionals (physicians, therapists, researchers), structural elements (hospitals, clinics, professional schools), and systems of payment for services (government, managed care organizations, insurers, voluntary organizations and other private sources) occur in different arrays, with subsequent differences in suitability and ease of access for persons with disabilities.

THE DISABLED AND MEDICAL CARE

Persons with disabilities depend on interaction with doctors and medical institutions. Even when well, the disabled must look to health care professionals for equipment, certification of disability and capability, rehabilitation or maintenance of status, eligibility for private and governmental supports, and entry to education and public services.

The professionals, however, are embedded in systems—both formal and implicit—that permit or constrain their abilities to perform effectively on behalf of their disabled clients. The systems in which they work and on which the disabled are dependent are the products of history, cultural norms and practices, national and local priorities, and legislative initiatives and rule, and these all determine the resources available to disabled persons.

Most people with disabilities are well, that is, not requiring acute medical care or interventions most of the time. The real continuing needs of the disabled in their everyday lives are for social and family supports, access to education and work, transportation, and living and working environments adapted to their disabilities; these are not areas in which health professionals necessarily have expertise or interest. Yet the dependence of disabled persons on medical and related systems for legitimation and entry to social and personal services requires that they understand and turn to the health care systems.

When problems are medical, the care of the disabled is rarely accomplished quickly; time required for their care is greater than that for nondisabled patients. Often physicians and other health care personnel are

uncomfortable with patients with chronic problems that do not respond to acute care protocols. In addition, disabled persons often complain that medical professionals are eager to apply new and sophisticated technologies but overlook "low tech" interventions that might aid daily living.

While there has been significant movement in developed countries toward assessing the quality of medical care by looking at outcomes, almost all of the established outcomes and "best practice" protocols measure the success of acute illnesses and injuries. The desired outcomes for non-sick disabled persons are much less concrete and much more individual; even those who have degenerative diseases or periodic acute care needs spend most of their lives outside of hospitals and rehabilitation facilities. Thus, persons with disabilities do not fit well into either the standard treatments or the standard measures of quality used in acute care medicine.

HEALTH CARE SYSTEMS

Health care systems may be monolithic and governmentally structured, as in Canada, the Scandinavian countries, and the British National Health Service, or pluralistic and loosely organized, including both public and private sector components, as in the United States.

Systems begun in the 1980s organized around the concept of managed care at first offered great promise for comprehensive approaches for the disabled. However, the commercialization of such programs in the United States, with emphasis on cost containment and standardization of treatment, has led, in general, to disappointment for those with disabilities and chronic illness. Disabled persons often find their care needs are not met in health care programs and systems that depend on prescribed standards of care or "disease management" protocols for defined populations and illnesses. Wide variations in functional impairment and, thus, of the multiple health care services needed make generalizations about both services and reimbursement risky; each disabled person conforms only to a personal profile and, thus, challenges standardized programs of care. The service needs of most disabled people will continue for a lifetime; no defined period of treatment or financial coverage exists. Planners, policy makers, and insurers are reluctant to build or fund programs for individuals whose life expectancy, treatment duration, and intensity cannot be submitted to standard actuarial analysis, with predictable costs. State governmental forays into managed care in the Medicaid program in the United States have suffered from rising costs, often leading to restriction of the benefits and services most often needed by the disabled.

The training of health professionals, especially physicians, has not necessarily prepared them for the special needs of the disabled. The absence of such specific training puts physicians at a disadvantage in advocating for their patients in the health care systems. Medical care for the disabled often falls to the small group of physicians trained in physical medicine and rehabilitation, and a few generalists who choose to work with disabled and chronically ill patients. Within the medical care system, the disabled often confront fragmentation and lack of communication among medical specialists and between tertiary care centers, community agencies, and primary care physicians.

APPROACHES AND CHALLENGES

There are several promising alternatives that respond to the complex needs of the disabled and the inadequacies of acute care systems. Some centers have developed model comprehensive care programs with a case manager (really a care manager), whose responsibility is coordination and transmittal of information between medical professionals and community agencies on behalf of the patient and family. It is within such medical care programs that the disabled are likely to receive the most attentive and appropriate care. Unfortunately, this is not the dominant practice. Despite demonstrations that show improved outcomes, in both reductions in hospitalizations and in long-term costs of care, most medical organizations in the United States have not adopted the care manager model. Thus, disabled persons and their families or caretakers must de facto become their own care managers, an enterprise that can deplete already compromised reserves of energy, time, and funds.

In some states in the United States and in some countries (Sweden, the Netherlands), comprehensive programs for the disabled have grown out of integration of medical and social service programs; there are a few

(usually academic) centers in the United States that have assembled such integrated approaches, using a combination of private, state, and federal funds.

Another trend that has benefited the disabled has been the growing practice of early discharge from hospital to long-term care at home and in the community. The home care movement has been propelled by a variety of factors, some well motivated, some suspect, including control of inpatient costs (the most expensive part of health care); improved technology allowing relatively complex interventions and treatments to be done in a home setting; recognition of the hazards of extended hospital stays (particularly infections), and acknowledgment of the psychological and social benefit of being in one's familiar surroundings. Where medical institutions and systems have extended their services and oversight into the home ("hospitals without walls"), there has been marked success in terms of recovery, maintenance of function, and patient and family satisfaction.

While there are clear benefits, home or independent care for the disabled and chronically ill creates new challenges for health care systems, many in previously unexplored territory. In choosing care at home, there is a transfer of responsibility and risk from the inpatient institution to the patient and family, which leads to important questions: What are the limits of the institution's (or health care system's) liability? What are the system's moral and legal responsibilities for adequate preparation and support of the home caretakers? Should the institution or system initiate a home care program in the face of inadequate continued funding and assistance from society and its formal (e.g., in the United States, local state and federal programs) and informal supports? Does the system's obligation to the patient and family end when they leave the hospital or rehabilitation facility?

The appropriate services for a disabled person at home may involve many agencies and organizations: physical, occupational, and speech therapies; vocational and educational services; the provision and maintenance of equipment and supplies; respite for caretakers; and modifications of the environment for accessibility and safety. Most of these are not attended to in traditional health care systems but (at least in the United States) are fragmented among many public and private agencies, a situation that demands constant initiative and vigilance from the caretakers, family, and the disabled persons themselves, adding to their already heavy logistical and psychological burdens. Advocates for the disabled note another paradox confounding home care: Both public and private insurance systems may pay for outsiders (e.g., nurses, therapists, attendants) to care for disabled persons at home or in school but do not recognize or reimburse for the large financial and emotional sacrifices made by family members when they perform the same tasks.

Some planners, looking from the perspective of system costs and pursuing efficient use of resources, propose the establishment of congregate facilities or the clustering of disabled persons around (or in) a central facility or a defined geographic area. Indeed, in larger cities with ample medical and social resources, one can imagine a virtual community of the disabled served by an organized system of care extending seamlessly from health care institutions to the communities and homes of the disabled. Pilot programs of this sort for the elderly, for children with continuing technological needs (e.g., ventilators), and for developmentally disabled children and adults have been successful. However, the initiative and continuing support for target populations has usually not come from health care systems, but from private or public service organizations. Such comprehensive approaches require sophisticated information and transportation systems, and a reservoir of professionals and support personnel. In rural areas and in small towns, such a network of services is difficult or impossible to construct, and disabled children and adults may have to travel great distances to engage with the needed health care and social services.

The development of congregate facilities for disabled individuals has been tried in several forms in Western Europe (e.g., Het Dorp in the Netherlands, a town of disabled individuals in which dedicated medical and social services are built around the daily lives and work of its residents). However, in the individualistic United States, the dominant philosophy is to support the integration of disabled individuals into everyday life. Many organizations (e.g., centers for independent living) work to connect individual disabled persons with accessible and appropriate health care and to find suitable living arrangements for them, including adapted housing.

For the more severely disabled who cannot live independently, there are several types of institutions that provide various programs of partial independence and sheltered workshops, some with permanent living arrangements. For those, the means of provision of health care services to clients vary; some have good working arrangements with local facilities, other negotiate on a case-by-case basis for adequate medical and health care services. Many of these organizations are private charities and work to mobilize additional available public funds (Medicaid, Social Security, Developmental Disability, Special Education) for their clients' health care and social service needs.

There is an understandable tension between philosophies promoting independent living and those supporting the various forms of congregate care. The greater efficiencies and access, especially to health care, gained by clustering disabled people is countered by restrictions on independence, social and physical mobility, and integration into the greater society. In the United States and other countries where geography and distance from centers of optimal medical care is a reality, those tradeoffs are sometimes seen as necessary. In more compact countries where medical care systems are regionalized (e.g., Sweden) and integrated with social service systems, the disabled may find less incentive to cluster around urban medical centers. Many disabled people say they find comfort and recognition in settings dedicated to people like themselves, with important psychological and social rewards. Especially for the majority who do not have continuous medical care needs, the real benefits deriving from congregate or clustered communities of the disabled may outweigh the potential benefits of independent living and the uncertainties about ongoing health care that go with it.

An encouraging trend has been the relatively recent development and growth of the specialty of geriatric medicine. The need for comprehensive care for the growing numbers of elderly persons, with and without disability, has brought attention to the need for integration of medical, social, and financial resources for all vulnerable populations. There are increasing numbers of demonstration projects and comprehensive programs for the elderly, from which models for the care of all disabled people, young and old, are emerging.

ISSUES IN FINANCING SERVICES

The ability to pay for medical services for the disabled in those countries without a comprehensive publicly funded universal health care system (most prominently, the United States) is very uncertain. Many of the services and therapies needed by the disabled are required for *maintenance* of present functional status, not for cure or even improvement of the primary causal illness or injury. Thus, they lie outside the benefits of most private insurance plans, and even of Medicare; they do not meet the criteria for "medical necessity." In the private insurance market, previously able-bodied persons who become disabled will usually find that their health insurance has a lifetime maximum benefit limit that can be quickly exhausted with high-cost medical procedures and specialized inpatient care. Those persons or their families must then seek support from public funds (Medicaid, Social Security) for continued access to medical care systems, some of which reject or refuse care to those supported by public funds. Because each state in the United States has different Medicaid, developmental disability, and special education programs, there is significant disparity in the services available across the country. This diversity of benefit packages sometimes leads disabled persons or their families to move from one state to another to improve their access to health care benefits.

Private insurance also limits access to coverage for "prior existing conditions"; such restrictions make it difficult or expensive to obtain private insurance (especially for those with congenital or early-acquired disabilities) and limit families' ability to relocate or change employment, where the change would require a new insurer.

While some advocates for the disabled have proposed that public and private funds available for their care be given directly to the patient or family, others are concerned that many families are not sufficiently informed or prepared to act in the disabled person's best interests. In addition, those disabled persons who are not part of a comprehensive medical care system may miss important therapeutic advances.

The future of disabled people in medical care systems is uncertain. It will be determined by the political and economic evolution of health care systems and

will require vigilance and assertive participation of the disabled and their advocates.

—Arthur F. Kohrman and Claire H. Kohrman

See also Health Care and Disability; Health Management Systems; Independent Living.

Further Readings

Arras, J. D., ed. 1995. *Bringing the Hospital Home.* Baltimore: Johns Hopkins University Press.

Barresi, C. M. and D. E. Stull, eds. 1993. *Ethnic Elderly and Long-Term Care.* New York: Springer.

Corbin, J. M. and A. Strauss. 1988. *Unending Work and Care: Managing Chronic Illness at Home.* San Francisco: Jossey-Bass.

Kohrman, A. F. 1994. "Financial Access to Care Does Not Guarantee Better Care for Children." *Pediatrics* 93:506.

Lantos, J. D. and A. F. Kohrman. 1992. "Ethical Aspects of Pediatric Home Care." *Pediatrics* 89:920.

Mitchell, D. 1999. *Managed Care and Developmental Disabilities.* Homewood IL: High Tide.

Perrin, E. C., P. Newacheck, et al. 1993. "Issues Involved in the Definition and Classification of Chronic Health Conditions." *Pediatrics* 91:787.

Starr, P. 1984. *Social Transformation of American Medicine.* New York: Basic Books.

Swedish Institute. "The Health Care System in Sweden." Retrieved January 24, 2004 (http://www.sweden.se/templates/FactSheet6856.asp).

U.S. Department of Health and Human Services. 2004a. "The Disabled: Their Health Care and Health Insurance." Retrieved January 24, 2004 (http://aspe.hhs.gov/daltcp/reports/disabled.htm).

———. 2004b. "Office of Disability, Aging and Long-Term Care Policy (DALTCP) Reports." Retrieved January 24, 2004 (http://aspe.hhs.gov/daltcp/reports.shtml).

Zola, I. K. 1984 (reissued 2003). *Missing Pieces: A Chronicle of Living with a Disability.* Philadelphia: Temple University Press.

HEALTH MANAGEMENT SYSTEMS

Management is an increasingly important component in the health and social care systems that provide services for people with disabilities. The rise of management science and specialist managers has coincided with a profound shift in the way organizations are run. Older forms of administration have been displaced by forms of active management that focus more clearly on economic efficiency, cost control, performance review, and accountability. Management thinking has influenced professional and policy networks so that it has been incorporated in the political, bureaucratic, and scientific discourses that affect health care organizations. The ranks of the specialist managers have been augmented by management-oriented physicians and other supporting experts. This has transformed the environment in which health professionals work and disabled people receive care.

Although there are cross-national variations in management philosophies and practices, differences appear to be diminishing as management science becomes a global phenomenon. In sociological terms, this may be linked to the spread of rational bureaucratic organization, which has helped to shape both private and public sector work. But from the 1980s onward, a new array of management technologies and practices emerged that made the micro-management of organizations more feasible. This has coincided with the creation of processes of regulation and control that permeate downward within organizations and introduce new forms of surveillance and accountability.

The management of health care affects disabled people in manifold ways. Aging populations and the increased burden of chronic illness in many countries mean that disability services have moved nearer the top of the policy agenda in both state and market-dominated health care systems. At the strategic level, senior managers play a leading role in planning the future shape of services and how consumers can access them. Planning decisions affect matters such as the volume and range of services, the degree of coordination of health and social care, the scope for patient choice, and how services are paid for. At the operational level, managers oversee the operation of the system, enforce the rules, and try to resolve emergent problems that arise in delivering services. Managers function as mediators or translators of policy fixed at a higher level in a public bureaucracy or corporation. Sometimes they actively shape policy as they adapt it in the course of implementation.

Much management work involves passing between high-level civil servants or corporate board members

and the professional staff who provide frontline services. Managers liaise with professionals to determine the detailed procedures and practices that must be worked out as organizations are reformed and restructured. In many countries, better management systems have led to increased efficiency and also have provided a counterbalance to institutionalized professional power and the skewing of status and resources toward acute medicine. But this has also meant that managers are drawn into difficult decisions about priorities and the provision or nonprovision of services.

Precisely how managers undertake these tasks will depend on the nature of the health care system in which they work. There is a marked difference between a private market-based system, where managers remain at arms length from state regulators and work with owners or their representatives to determine corporate strategy, and a publicly funded/publicly provided system, where managers interact with civil servants and politicians to implement public policy.

The rise of management ideas is well illustrated by the global influence of U.S.-style managed care. The United States has a mixed, though mainly private, system comprising a range of organizations that purchase, provide, or coordinate health and social care services. *Managed care* is an umbrella term for a variety of systems and techniques used to control costs and quality. It typically involves review of patterns of utilization and the medical necessity of treatments, and the steering of patients toward certain providers and care pathways. Since the 1980s, against a background of rising health expenditures, there has been a drift away from traditional health insurance plans toward alternative products sold by managed care organizations (MCOs), such as health maintenance organizations. Some MCOs sought vertical integration by supplementing acute hospital provision with the buying up of outpatient clinics, nursing homes, home health care, and specialist psychiatric facilities, with the aim of creating large networks which could achieve economies of scale and force prices down. Largely for cost control and marketing reasons, other MCOs adopted the strategy of separating benefits for chronic illness or disability from the rest of their health plans. For example, mental illness, alcohol, and drug services were contracted out to specialist providers who would treat members who had purchased this coverage from the MCO. Because these arrangements often offered more limited benefits than indemnity insurance plans, they had the potential to reduce adverse selection and reduce costs.

Although MCOs have reduced the cost of health care, they have been criticized for limiting patient choice and excluding certain treatments from coverage. Managers play a key role in determining what plans will cover, and they consider issues such as cost and litigation risk alongside the question of the medical necessity of treatments. While research shows that denial of treatment for acute conditions is a relatively rare phenomenon in the United States, there are indications that exclusions may have more impact on people suffering from chronic illness and disability. For example, in a recent special issue of *Sociology of Health & Illness,* Gary Albrecht describes the constant battles faced by disabled people in securing access to desired forms of care, usually conducted via contact with middle managers in MCOs. Others have criticized the failure of specialist providers to liaise with cognate organizations and provide appropriate care networks. Recent efforts by some purchasing alliances to use buying muscle as a lever to drive up quality tend to focus on acute services and have so far had little impact on services for disabled people.

In a predominantly public service such as the British system, the role of managers centers more on the implementation and translation of government policy. The splitting of the National Health Service (NHS) into purchaser and provider divisions in 1991, together with the creation of a market in social care, led to significant changes in managerial roles. The interests of purchaser and provider organizations became more sharply differentiated, often leading to increased tensions between their respective managers.

Purchasing was regarded as part of a wider commissioning function, involving needs assessment and judgments about strategy and priorities, and better coordination between health and social services. Continued problems at the interface of health and social care have been partly blamed on continuing organizational barriers to collaboration, and an inability to move from communication at senior management level to effective team working on the ground. The heavy burden of work associated with the new system of

contracting for clinical services resulted in growing numbers of managers, but along with new power came pressure to meet government-imposed "costs savings" and performance targets. Some commentators have argued that contracting became a financially driven exercise that paid insufficient attention to quality. There was also criticism from doctors who argued that managerial concentration on the key target of reduced surgical waiting times meant that clinical priority became less important than time on the waiting list.

The NHS reforms initially seemed set to improve the situation of people with disabilities because the quasi-market system was designed to end the system of historically based budgets, which had channeled money toward high-profile acute specialties and away from the so-called Cinderella services (long-stay hospitals and community services that had traditionally suffered from underfunding). However, in practice, spending patterns did not change as much as predicted, and there was little reallocation of resources to community and continuing care services that would meet the needs of disabled people. The concentration of spending on acute services was reinforced by the weight given by the government to surgical waiting times targets, and the way these were presented as a key indicator of the success of the reforms. Many district health authorities operated "exclusions" policies, usually formulated jointly by public health physicians and managers, which listed treatments that would not normally be purchased. This "postcode lottery" affected some high-cost drugs for disabling conditions, such as beta interferon for multiple sclerosis, anti-TNF medication for rheumatoid arthritis, Riluzole for motor neuron disease, and Memantine for Alzheimer's disease.

The Blair reforms introduced after 1997 marked a step away from the language of the market but retained the purchaser/provider split and the basic framework of service contracts. The burden of administration was reduced by a shift from annual to multiyear contracts. However, the government imposed new arrangements for "performance management" based on target setting and review, which increased providers' accountability for outcomes.

There were also new policies on "clinical governance," which aimed to achieve improvements in quality and safety. In practice, this involved the creation of clinical guidelines for a range of medical conditions, recommendations about whether new and controversial treatments should be provided on the NHS, and the development of a series of National Service Frameworks (NSFs), which defined expected care pathways for different condition groups. Several of these clinical guidelines affect disabling conditions such as chronic heart failure, chronic obstructive pulmonary disease (COPD), multiple sclerosis, diabetes, and "supportive and palliative care," and the NSFs include frameworks for older people, renal services, and diabetes. Sections of the British medical profession have helped shape these developments, but they go beyond professional self-regulation. Rather, they have emerged from a coalition of political, managerial, and professional groups, and they encapsulate a form of scientific/bureaucratic rationality that sets limits on the discretional decision making of individual professionals.

Although this short entry has focused on only two systems, most of the issues discussed have more general applicability. Converging trends in the health care systems of almost all developed countries ensure that management will continue to be a central component of disability services. Changing patterns of health and disease and the rising proportion of budgets directed toward chronic illness and disability must be considered alongside continuing technological advances and resource pressures. Disabled people will expect more, and it will be the management systems that are charged with finding ways of maximizing outputs for a given level of expenditure and placing limits on what a health or social care system can reasonably provide.

—David Hughes

See also Health Care Systems; Managed Care.

Further Readings

Birenbaum, A. 1997. *Managed Care: Made in America.* Westport, CT: Praeger.

Harrison, R. and W. I. U. Ahmad. 2000. "Medical Autonomy and the UK State: 1975–2025." *Sociology* 34:129–146.

Kronenfeld, J. J., ed. 1998. "Changing Organisational Forms of Delivering Health Care: The Impact of Managed Care and Other Changes on Patients and Providers." In *Research in the Sociology of Health Care*, Vol. 15. Greenwich, CT: JAI.

Light, D. and D. Hughes, eds. 2001. "The Sociology of Rationing." *Sociology of Health & Illness* 23(5, monograph issue).

HEALTH PROMOTION

Health promotion is defined as the process of enabling individuals to increase control over their health and to improve their quality of well-being by engaging in a socially, physically, and spiritually fulfilling life. This definition applies to people with and without disabilities. The process of achieving good health depends on the synergy of personal engagement and commitment, and a supportive environment that includes ample opportunities for maintaining and improving health.

Research has demonstrated that the more supportive an environment is in terms of access to quality health promotion (e.g., available transportation to obtain good medical care, close proximity to a grocery store that sells fresh fruits and vegetables, sidewalks to walk or push a wheelchair in the neighborhood), the more likely the person is to engage in these health-enhancing behaviors. The primary goal of health promotion is to empower people with disabilities to engage in their own successful health-promoting strategies with as minimal assistance as possible, and with the freedom to make choices appropriate to their needs and desires.

There is growing awareness in the public health community of the need for more knowledge and awareness of effective health promotion programs for persons with disabilities. Innovative strategies for improving health, preventing complications associated with a disabling condition, and adequately preparing individuals with disabilities to better understand their own health has emerged as an important public health priority. While people with disabilities account for only 17 percent of the noninstitutionalized population of the United States, they constitute 47 percent of total medical expenditures. On average, their medical expenditures are more than four times those of people without disabilities. Many health experts believe that access to quality health promotion programs can reduce medical costs while improving quality of life in persons with disabilities, who are generally underserved and vulnerable to the effects of poor health.

OVERVIEW OF HEALTH PROMOTION

Prevention of Secondary Conditions

The paradigm shift from disability prevention toward the prevention of secondary conditions is still a relatively new and emerging concept. One of the primary goals in disability and health is to encourage health professionals to become aware of the growing needs of people with physical, cognitive, and sensory disabilities. Another goal is to recognize that people with disabilities can achieve similar health benefits as the general population provided they have equal access to health promotion services/programs that are offered to the general community.

The term *prevention* has a different connotation for people with and without disabilities. For people without disabilities, primary prevention starts with a person being absent of disease and includes efforts to eliminate or reduce the risk of disease or disability. Although primary prevention of disabilities remains a high priority for public health agencies and intervention specialists, prevention of secondary conditions in people with disabilities is beginning to receive more attention. In people with disabilities, primary and secondary prevention include initiatives to prevent secondary conditions in addition to preventing conditions associated with poor health behaviors (e.g., smoking, physical inactivity, poor nutrition). The term *secondary conditions* relates to any physical, medical, cognitive, emotional, or psychosocial consequences of a primary disability. This may include weight gain or weight loss, pressure ulcers, pain, fatigue, advanced osteoporosis, depression, social isolation, orthopedic changes, and reduced physical function such as loss in aerobic capacity or strength. Secondary conditions have a tendency to exacerbate a primary disability and can limit physical and social independence and reduce participation in important health-enhancing behaviors such as employment and recreation.

Healthy People 2010

During the late 1970s, the United States began monitoring the health of the nation in its *Healthy People* agenda. The most recent document, *Healthy People 2010*, targets people with disabilities as a subgroup of the population. A chapter titled "Disability and Secondary Conditions" has been added to the document to reflect various health disparities found in people with disabilities. This document will serve as an important benchmark for supporting the development of health promotion initiatives for people with disabilities in the coming years.

Barriers to Health Promotion

People with disabilities often experience health disparities because of the many environmental barriers that they are confronted with when trying to improve their health, including poor physical access, societal attitudes, and lack of quality medical care. Research has demonstrated that the more supportive an environment is in terms of access to health-promoting behaviors, the more likely the person is to engage in these health-enhancing activities.

While there is substantial information on health promotion for the general population and for people with chronic conditions (e.g., diabetes, arthritis, asthma), much of this information does not provide important adaptations or modifications to be engaged in by individuals with physical, cognitive, or sensory disabilities. Barriers to health promotion for people with disabilities include inaccessible materials and programs, lack of transportation to get to an exercise facility, lack of financial resources to purchase healthy foods or medication, and lack of access to good medical care. Materials in standard curriculums or textbooks are, for the most part, not available in alternative formats (i.e., large print, audio), and information is often too generic for individuals with specific types of disabilities who may have several secondary conditions (i.e., pain, fatigue, urinary incontinence) and/or impairments (lack of vision/hearing, low cognition, paralysis). These secondary conditions and/or impairments require specific adaptations to standard health promotion programs to ensure successful integration and outcomes.

An additional barrier to health promotion involves the lack of training among health care providers regarding the needs of people with disabilities. Most health promotion specialists are not trained to modify or adapt existing programs for people with various types and severities of disabilities. For example, many professionals will recommend walking as the primary mode of physical activity because it can be conveniently done in various settings (i.e., mall, outdoors), and it does not require expensive equipment or a membership to a fitness center. However, individuals with lower extremity disabilities may not be able to walk or may have difficulty walking. An alternative to walking would be to recommend hand cycling, wheeling, or performing chair exercises.

KEYS AREAS OF HEALTH PROMOTION

Physical Activity and Disability

The health benefits of an active lifestyle that includes moderate amounts of medium to vigorous physical activity on a regular basis have been detailed in the Surgeon General's report, *Physical Activity and Health* (U.S. Department of Health and Human Services 1996):

> Regular physical activity greatly reduces the risk of dying from coronary heart disease, the leading cause of death in the United States. Physical activity also reduces the risk of developing diabetes, hypertension, and colon cancer; enhances mental health; fosters healthy muscles, bones, and joints; and helps maintain function and preserve independence in older adults. (Foreword of the Executive Summary)

Unfortunately, the vast majority of people with disabilities are not obtaining the recommended amount of physical activity needed to confer health benefits and prevent secondary conditions associated with a sedentary lifestyle (e.g., heart disease, type 2 diabetes, obesity, and osteoporosis). The *Healthy People 2010* report notes that significantly more people with disabilities reported having no leisure-time physical activity, 56 versus 36 percent, compared to people who did not have a disability.

As persons with disabilities age, they often experience increasing difficulty performing activities of daily living (ADLs) (e.g., dressing, showering) and instrumental activities of daily living (IADLs) (e.g., ambulation, doing laundry, grocery shopping). Persons with disabilities also must overcome various physical obstacles during the day as a result of environmental barriers that require greater energy expenditure to perform certain physical tasks (e.g., wheeling up and down ramps and curb cuts, performing transfers). And various secondary conditions that often accommodate a disability (e.g., increased weight gain, pain, spasticity, weakness, fatigue, loss of strength and function) make it more difficult to sustain these physical tasks. When combined with the natural aging process, the likelihood of requiring assistance to perform various ADLs and IADLs is likely to increase.

Based on evidence from studies conducted with various disabled populations, deconditioning in the form of reduced strength, flexibility, and aerobic capacity

result in an earlier onset of reduced health and function. There is a substantial amount of health improvement that can be obtained by people with disabilities with minimal increases in physical activity. Finding ways to overcome environmental barriers to physical activity participation is an important priority in public health.

One example of a primary barrier to physical activity participation among several groups of individuals with disabilities is the lack of information on where or how to exercise at home or in the community. Much of the general literature and public health messages promoting physical activity encourage Americans to walk more often, with the goal of 30 minutes a day most days of the week. While this recommendation may be appropriate for the general population, it is often inappropriate for people who have difficulty walking (e.g., cerebral palsy, multiple sclerosis, stroke) or who are unable to walk (e.g., spinal cord injury, polio) or must be supervised while walking (e.g., severe mental retardation or mental illness, Alzheimer's disease). A more inclusive message would have a greater likelihood of reaching a more diverse population.

National Center on Physical Activity and Disability

Through a grant from Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Disability and Health Division, the National Center on Physical Activity and Disability (NCPAD) was established to collect, synthesize, and disseminate information on various programs and services related to physical activity and disability. This web-based research and information center has many unique features that can assist health professionals in developing appropriate physical activity programs for people with disabilities. The website (http://www.ncpad.org) contains a national directory of accessible recreation and fitness facilities along with a listing of equipment vendors that manufacture or sell adaptive equipment. There is also an extensive database on physical activity and disability that allows the user to search for information by disability or activity. The toll-free telephone number (800-900–8086) allows end users to consult with an information specialist if they do not have access to a computer.

Nutrition and Disability

While government agencies responsible for nutritional information emphasize optimum levels of nutrients for the general population, specific guidelines for people with physical and cognitive disabilities are lacking. Although having a disability does not necessarily require a significant alteration from national dietary guidelines (e.g., low fat, low cholesterol, high fiber), certain modifications to the nutritional component of a health promotion program may need to be tailored to people with various types of disabilities. For example, individuals with cerebral palsy, Down syndrome, and spinal cord injury are more susceptible to osteopenia (reduced bone mass) and osteoporosis (significant bone loss). While there are no specific guidelines for daily calcium intake in younger, disabled populations with osteopenia or osteoporosis, it is plausible that a higher calcium intake may be required at an earlier age to slow or reduce the progression of bone loss.

Individuals with stroke who are taking the blood thinner Coumadin to prevent blood clots and a recurrent stroke may need to avoid a high intake of vitamin K. Vitamin K has an essential role in blood clot formation and counteracts the effects of Coumadin. A comprehensive nutrition program for stroke survivors would include food choices that have a low concentration of vitamin K while still maintaining adequate levels of other important vitamins and minerals.

Fluid intake is another area of nutrition that may need to be tailored to individuals with certain types of disabilities. For example, individuals with spinal cord injury (SCI) may require higher amounts of fluids to avoid dehydration. However, many individuals with SCI are reluctant to drink large amounts of fluids because of the difficulty with catheterization and/or the greater frequency of having to perform this task. Yet, without adequate hydration, people with SCI are more susceptible to urinary tract infections, syncope, and impaired thermoregulation. Constipation is another secondary condition found in various subgroups with disabilities, and increased fluid intake would help improve motility and evacuation of bowel contents.

Many individuals with disabilities have large increases in weight often related to medication use, lack of physical activity, and poor nutrition. For example, one of the major side effects of psychotropic

medications is excess weight gain. Health professionals must be aware of the impact that various medications can have on nutritional status and take appropriate action to avoid large increases in weight through reductions in caloric intake and increased physical activity.

Good nutrition that is tailored to the needs of individuals with disabilities can have a dramatic effect on improving health and reducing various secondary conditions. In general, nutrition recommendations for the general population should be followed by people with disabilities. However, in cases where the individual's impairment may alter certain metabolic processes, specific nutritional guidelines must be included for that individual.

Health Behavior and Disability

Health behavior can have a significant impact on empowering people with disabilities to manage their own health. The current state of practice in most health behavior programs is to educate participants about the benefits of the various components of health promotion, which can include anything from cancer prevention screening (e.g., breast and prostate exams), to spirituality, stress management, exercise, and proper nutrition.

The transtheoretical model is one of the most widely used behavioral models in health psychology. The model uses the phrase "stages of change" to integrate change processes through a variety of intervention strategies. There are five primary stages that range from people who are not even thinking about making a change (precontemplation) to people who have changed a behavior and are working to maintain the new behavior and prevent relapse (maintenance). In between, people can be thinking about making a change in the next six months (contemplation), getting ready to make a change in the next 30 days (preparation), or be in the first six months of a behavior change (action).

Implementation of the transtheoretical model in health promotion programs for people with disabilities is a viable approach to ensuring better outcomes. Intervention strategies should be tailored to the stage of change that the person is currently in and that will serve as a useful guide for moving the individual to the final stage of maintenance. It is becoming increasingly clear that there is a greater likelihood of successful adherence to health promotion programs when the program is tailored to the needs, interests, and comprehension level of the individual learner.

—James H. Rimmer

See also Activities of Daily Living (ADLs); Disease; Exercise and Physical Activity; Health; *Healthy People 2010*.

Further Readings

Lollar, Donald J., ed. 1994. *Preventing Secondary Conditions Associated with Spina Bifida and Cerebral Palsy: Proceedings and Recommendations of a Symposium.* Washington, DC: Spina Bifida Association of America.

McGinnis, Michael J., Pamela Williams-Russo, and James R. Knickman. 2002. "The Case for More Active Policy Attention to Health Promotion." *Health Affairs* 21:78–93.

Ravesloot, Craig, Tom Seekins, and Quincy-Robyn Young. 1998. "Health Promotion for People with Chronic Illness and Physical Disabilities: The Connection between Health Psychology and Disability Prevention." *Clinical Psychology and Psychotherapy* 5:76–85.

Rimmer, James H. 1999. "Health Promotion for Persons with Disabilities: The Emerging Paradigm Shift from Disability Prevention to Prevention of Secondary Conditions." *Physical Therapy* 79:495–502.

———. 2002. "Health Promotion for Individuals with Disabilities." *Disease Management and Health Outcomes* 10:337–343.

Smith, Richard D. 2000. "Promoting the Health of People with Physical Disabilities: A Discussion of the Financing and Organization of Public Health Services in Australia." *Health Promotion International* 15:79–86.

Stuifbergen, Alexa K. and Heather A. Becker. 1994. "Predictors of Health-Promoting Lifestyles in Persons with Disabilities." *Research in Nursing and Health* 17:3–13.

U.S. Department of Health and Human Services. 1996. *Physical Activity and Health: A Report of the Surgeon General.* Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease and Prevention.

———. 2000. "Healthy People 2010: Understanding and Improving Health." Retrieved April 10, 2003 (http://www.health/gov/healthypeople/document/html/volume1/opening.htm).

Websites

National Center on Physical Activity and Disability, http://www.ncpad.org

HEALTH RESOURCE RATIONING

THE NEED FOR A SYSTEM OF RATIONING

Health care is uniquely important. Modern medicine has been extremely successful in discovering new kinds of health care and improving the old kinds. But medical innovations have come at increasingly high prices. The cost both of the best health care and even moderately good health care is rising much faster than our ability to pay for it. This creates a problem. If a society wishes to provide health care to its citizens, some form of rationing has become a necessity.

The very idea of health care rationing is objectionable to many people. Citizens of the United States are especially opposed. This is partly because the United States has no universal health care system. The two national U.S. health programs (Medicare and Medicaid) cover only 26 percent of the population, those who are elderly, poor, or significantly disabled. Health care for the remaining 74 percent is left to the marketplace. This is seen as desirable by many, who believe that a free market will ensure freedom of choice in health care. But the effect of this "free market rationing" by the year 2002 was that 15 percent of the population—more than 43 million people—had no health insurance at all, and that number is increasing. Some public system involving rationing is likely to be required in the future. It is already used in the U.S. national systems and in private health maintenance organizations, so U.S. citizens will have to accept the concept of rationing in some form. Most other developed countries have universal health care programs. Because rationing decisions are always made within these programs, the concept is seen as less objectionable.

Health care rationing is a genuine necessity within any publicly funded system. It is easy to argue that national health care systems are underfunded. Nevertheless, the funds that would be necessary to purchase unlimited health care for everyone are beyond any nation's capacity. Increases in funding can produce better health care but not unlimited health care. If health care must be limited, then both fairness and efficiency demand that it must also be rationed in some way. We should spend health care funds *wisely,* so that expensive procedures are funded only when they are worth the expenditure in comparison to other procedures. This follows from the fact that an expenditure on any one patient reduces the funds available to other patients. But we should also spend funds *fairly,* so that everyone gets a just share of the benefits of the system. Crafting a health care rationing system that is both efficient and fair is a tremendously complex process. But it is also a necessity.

Both the efficiency and the fairness of a system of health care rationing are difficult to establish. The simplest programs are easy to apply, but they have serious moral flaws. These flaws have been recognized, and attempts have been made to circumvent them. One group of people is especially vulnerable to disadvantage from rationing systems: people with impairments and chronic illnesses. Even systems that are intended to fairly and efficiently distribute health care resources can discriminate quite seriously against disabled people, as we shall see. This discrimination results from questionable moral assumptions about the goals of health care, from questionable factual assumptions about quality of life, and even from disagreements about the nature of disability itself.

Conflicts between the medical community and the disability rights community are almost inevitable, for one simple reason. The medical community considers disability to be a medical problem, to be solved (if at all) by medical means. The disability rights community considers disability to be a social problem, to be remedied by social changes that make environments more accessible and integrate disabled people with the rest of society. These activists consider disabled people to be similar to an ethnic minority, harmed by discrimination from mainstream society. The so-called medical model of disability is a basic assumption of the medical community, but it is a misconception according to disability rights activists. This is one source of conflict over the relation between disability and health care policy.

SOME SYSTEMS AND THEIR PROBLEMS

One might think that statistical analyses of health care efficiency would result in simple statistical facts, not in

moral problems. But statistical analyses often begin with hidden assumptions that infect their outcomes. One early analysis of health care efficiency was called cost-benefit analysis (CBA). The goal was to determine the costs of nationally funded health care in terms of its impact on economic productivity. The analysis indicated that health care expenditures on workers who were young, productive, and highly paid would repay the costs by increased productivity. But other expenditures did not produce the same payback. Health care for unemployed and elderly people was a bad investment. The use of these results to prioritize public health care was immediately recognized as unfair. The moral goal of health care is not only to maximize the nation's economic production but also to make its citizens healthier whatever their economic contribution.

It is not difficult to calculate the relative cost-effectiveness of different treatments when they are aimed at producing the same outcome. The calculation of the cost-effectiveness of certain screening tests for colon cancer, for example, is merely the cost of one test multiplied by the number of such tests it would take to detect a single tumor. This kind of analysis can lead to useful results. But this kind of analysis, alone, cannot compare different kinds of outcomes; it cannot compare treatments that extend life with those that control pain, or improve function. A way had to be found to compare the different health-related outcomes with each other. This would allow cost-effectiveness analysis to be applied to *health itself,* instead of being limited to individual kinds of outcomes. It would also remove the unfairness of CBA's focus on the economic consequences of health. The health of unemployed and elderly people would receive equal consideration as that of high-wage earners. This was surely a moral improvement. But how can one measure health itself? The concept has proven surprisingly problematic.

The first step in measuring health itself was the recognition that the goal of health care was not only to extend lives but also to make lives better. The relief of pain and discomfort and the improvement and maintenance of function are legitimate goals of health care even if lives are not lengthened. Life extension and life improvement were seen to be distinct dimensions of health care. To compare two distinct dimensions of health, a measure had to be constructed that incorporated them both. Some amount of life extension must be seen to be comparable to some amount of life improvement. This would be possible if health itself were seen to be the product of multiplying the *length* of life produced by a medical treatment (the longer the better) by the *quality* of the life produced (the better the quality, the better the outcome). But now we see another problem. One of those goals is easily measurable but the other is not. Length of life is simply a number of years. But how does one measure the "goodness" of life?

THE INVENTION OF "QUALITY OF LIFE"

In the 1970s, this problem led to the coinage of the expression "quality of life" (QOL). The expression rapidly became a buzzword. But it is important to remember its origin. Even though *quality of life* has entered ordinary language, it retains its specialized meaning among those who deal with health care rationing systems. In ordinary speech, quality of life refers to the subjective satisfaction and fulfillment that an individual experiences. But in its original technical sense, quality of life refers to *everything except life extension* that is a beneficial outcome of health care. Subjective satisfaction is irrelevant. The technical concept is quite problematic, as we will see. One of its ironies is that the technical term *quality* of life was invented only because of the need for *quantification.* Health care economists had to be able to quantify—to measure, count, add up, and compare—the valuable outcomes of health care. For the purposes of health care rationing, QOL is a quantity.

With QOL understood as a quantity, an amount of goodness, health care economists believed that they could calculate the total amount of *health itself* in an individual or in a population. Total health is a length of time multiplied by the QOL during that time. The quality adjusted life year (QALY) became the standard measure of total health. Numerical comparisons can now be made. One QALY is one year of life at its maximum quality (set at 1.0 by convention), or two years of life at the QOL of 0.5, or four years of life at the value of 0.25. The number of individuals involved does not matter: Four years of one person's life at a given QOL is equivalent to two years of two people's lives at the

same QOL. Health care can now be rationed with the help of objective measures. A system called cost-utility analysis (CUA) was devised by applying cost-effectiveness analysis to the production of QALYs. (*Utility* is a term used by economists and philosophers to designate an amount of welfare or happiness. In the case of CUA, utility is measured in QALYs.)

To illustrate the use of CUA in health care policy, imagine a decision between two programs of life-extending treatment. Program A and Program B have the same costs and the same size patient groups (say, 1,000 patients), and each program extends the lives of its patients for one year. The patient group for Program A has the highest possible QOL of 1.0. The group for Program B has a lower QOL of 0.8. Which program should be funded? Clearly, Program A. It produces 1,000 QALYs (1,000 people with a one-year life extension at 1.0 QOL), while Program B produces only 800 QALYs. A greater amount of *health itself* is purchased for the same price. CUA shows that the QALYs produced by Program B cost 1.25 times as much as those produced by Program A. Given this choice, it would be a financial waste to fund Program B.

QOL AS A THREAT TO HEALTH CARE FOR SOME

We are very close to the point at which health care rationing discriminates against people with permanent impairments or chronic illnesses. One further step is needed, and it is almost always taken. It is this: People with impairments are determined to have a lower QOL than nondisabled people merely because of their impairments. The overall goal of maximizing QALYs implies that, under certain circumstances, people whose QOL is permanently low will receive a lower priority for certain kinds of health care than people whose QOL is high. This will not happen in every circumstance, of course. If two individuals with different QOLs contract a disease that lowers each of their life qualities an equal amount, then the treatment for the disease would result in the same QOL increase for each person, whatever their baseline QOL. Because each treatment results in the same increase, they have an equal priority for treatment even though they began at different QOLs. But consider life-saving treatments. Saving the life of a person with a high QOL produces a larger number of QALYs than an otherwise similar person who has a permanent impairment (and therefore a lower QOL). For treatments like these, disabled people will have a lower priority for health care than otherwise similar nondisabled people.

This version of CUA is beginning to sound like CBA, with its focus on economic outcomes. Instead of discriminating against non–wage earners, we discriminate against people who have a low QOL. One would think that the same objections would apply. Many non–wage earners have a lower QOL than wage earners, and so would be disadvantaged by a QOL-based CUA just as much as by the old income-based analysis. Presumably, many poor people, elderly people, lonely people, and people who have lost a loved one have a low QOL, and so would also be subject to discrimination. Shouldn't fairness dictate that health care not discriminate against these groups of people? Should all sad people be classified in the same category as disabled people, and have their access to health care reduced by their low quality of life? Is health care only for happy people?

Not according to the actual rationing systems that have been developed. Advocates of CUA are not interested in maximizing overall QOL, in the ordinary sense of the subjective enjoyment or fulfillment that individuals experience in their lives. Keep in mind the original purpose of the concept of QOL. It was meant to quantify non-life-extending health care so that it could be compared and traded off with life-extending health care. Unhappiness-causing characteristics such as poverty and loneliness are not treated by the health care system. So they are ignored by CUA advocates. The term *health-related quality of life* (HrQOL) is now used to call attention to this difference. CUA advocates insist that disability is health related and that loneliness and poverty are not. So a person whose life is made unhappy by disability receives a lower priority for health care. But a person whose life is made unhappy by widowhood or unemployment does not. All sadnesses are not equal.

But are these generalizations even true? Are the lives of people with impairments significantly lower in quality than nondisabled people? It depends on whom you ask. When people with impairments are asked about

their lives, they report a QOL only slightly lower than that reported by nondisabled people about their own QOL. But when nondisabled people are asked about the QOL of disabled people, they report (or estimate, or guess) that it is extremely low. Even more paradoxically, health care workers have a lower estimate of the QOL of disabled people than does the general public. Gary Albrecht and Patrick Devlieger (1999) have reviewed the literature on this paradox.

WHO SHOULD WE BELIEVE ABOUT QOL?

So the question arises: Whose reports should be used in the rationing system? Should we incorporate the high-QOL reports of disabled people themselves, or the low reports that are given of disabled lives by nondisabled commentators? Biomedical ethicists have shown a strong tendency to trust only the nondisabled reports (or, more likely, their own intuitions). They dismiss the reports of disabled people as a mere lowering of personal standards. On the other hand, social psychologists have known of this discrepancy for much longer than the ethicists. Psychologists such as Daniel Kahneman and his colleagues (Kahneman, Diener, and Schwarz 1999) have taken the reports of disabled people seriously. The phenomenon fits into other psychological knowledge about how people find happiness in life. Ask yourself this: How happy would you be a year after you won a fortune in a lottery? You probably expect that you would be extremely happy. But the empirical facts do not fit your prediction. After an initial exultation, lottery winners almost always return to their original level of life satisfaction. The same happens with most people who experience major difficulties, whether from disability or the loss of a loved one. Nondisabled commentators *expect* that disability would cause them to have permanently low QOL, and lottery winning permanently high QOL. Both expectations are mistaken. This implies that people who are living with impairments (and those who are living with lottery fortunes) are the best judges of their own QOL. The contrary assessments of the nondisabled public, biomedical ethicists, and health care economists are clouded by a prejudice well known to psychological researchers.

So there is good empirical reason to doubt that the lives of most people with impairments have much less subjective satisfaction or fulfillment than the lives of nondisabled people. Insistence that they do would be seen as mere bigotry by disability rights advocates. But the CUA advocates have an additional argument to use in support of the lower QOL of people with impairments. They claim that it is logically incoherent to accept reports of high QOL from disabled people.

According to the principles of CUA, logical consistency requires us to link any expenditures dedicated to cures and prevention of a given condition with the QOL of a person who lives with that condition. If Condition A is regarded as extremely mild, then Condition A will have a low priority placed on it for purposes of prevention or cure, and people who live with Condition A will have a very high QOL. Conversely, if Condition B is one that is very important to cure and prevent, then a life with Condition B must involve a seriously reduced QOL. For example, if you consider it important to spend health care funds to prevent or cure blindness, then you are logically required to believe that people who are blind have a low QOL. If they did not, then why should we devote health care funds to prevent or cure blindness? The mere fact that we want to prevent disabilities logically implies that disabled people have a low QOL. What they report about their own QOL has no relevance to the matter.

This appearance of logical necessity is a consequence of the assumptions behind CUA accounts of rationing. CUA presupposes a utilitarian moral theory. Utilitarianism asserts that morality is a matter of the production of *consequences:* The rightness of an act is the amount of happiness it produces. A well-known shortcoming of utilitarianism is that it is unable to account for certain moral intuitions involving fairness, justice, and rights. Utilitarianism often seems to give the correct moral answers only when one assumes that no preexisting rights are involved in the question. CUA advocates make this assumption. The purpose of health care rationing is to maximize the amount of *health itself* that is created by the rationing system. No individual has any particular right to health or to health care. The only claim that any citizen has on health care comes from that citizen's ability to convert the expenditure of health care funds into high amounts of HrQOL.

Citizens who can "reimburse" health care expenditures with high HrQOL will receive health care. Those who cannot, will not. The status of an individual person within this system is merely to represent a potential health outcome, a contribution to the overall sum of *health itself.*

The utilitarianism behind CUA presupposes that the maximization of HrQOL is the categorical goal of health care, and therefore of health care rationing. But this assumption is challenged by many biomedical ethicists, and independently by the general public. Tom Beauchamp and James Childress (2001) have reviewed the ethicists' critiques. Peter Ubel (2000) and Erik Nord (1999) have conducted studies on how the general public perceives the importance of various kinds of health care. Ordinary citizens consider the strict application of pure CUA analysis to be unfair and would prefer systems that would actually produce a lower HrQOL than the maximum. For example, they would spend more funds on extremely ill patients than would be justified by CUA analysis. This "rule of rescue" requires that funds be spent on extremely ill patients even when the costs of their treatment are unlikely to be compensated by large improvements in their QOL. Ordinary citizens are also reluctant to give nondisabled people a higher priority than disabled people for life-saving treatments *even though they believe* that disabled people have a lower QOL. So the prejudice of the general public against the high QOL of disabled people seems to be compensated by their refusal to go along with CUA in its implication that disabled people should have a lower priority for health care than their nondisabled peers.

The utilitarianism of CUA is inconsistent with the concerns for fairness that are expressed by many biomedical ethicists and the general public. It is unclear which values will be reflected in future rationing schemes. With respect to life-saving measures at least, the general public seems to consider people with impairments to be similar to ethnic minorities—disadvantaged groups that should be protected from further discrimination. This matches nicely with the views of disability rights advocates. But the assumption that disability implies low QOL is shared by the general public and by CUA advocates.

The artificial notion of HrQOL is potentially hazardous to disability rights. HrQOL is a special form of quality of life that links disability and health care. But it artificially separates disability from other life experiences that can cause unhappiness—experiences such as sudden unemployment and the loss of a loved one. It reinforces the deep prejudice that the disadvantages of disability are a special curse from nature itself. A person's biology (not an inaccessible environment) is the cause of the person's unhappiness. This is merely a modernized reincarnation of the same old stigma that disability has always held. Unlike other causes of sadness that can be accommodated and learned from, disability is seen to be a permanent loss of life's goodness.

An important principle of the disability rights movement is the exact opposite. The disadvantages of disability arise not from biology but from social arrangements, such as inaccessible environments. Technical rationing concepts such as the HrQOL misrepresent the causes of disadvantage for disabled people. Even if disabled people are able to resist the loss of access to health care that would result from a CUA rationing system, they may be equally harmed by the assumption (shared by biomedical policy makers and the general public) that they "by definition" have a lower QOL than their nondisabled peers. If this were true, then improvements to environmental accessibility could benefit them only in small ways. Why bother trying to improve the life of a person who "by definition" has a low QOL anyway? If the technical concept of HrQOL reinforces the public's belief that disability is unavoidably associated with a low QOL, it may undercut the disability rights arguments for greater inclusion and more accessible environments.

—Ron Amundson

See also Ethics; Health Care and Disability; Health Care Systems; Health Management Systems; Outcome Measures; Quality of Life.

Further Readings

Albrecht, Gary L. and Patrick J. Devlieger. 1999. "The Disability Paradox: High Quality of Life against All Odds." *Social Science and Medicine* 48:977–988.

Beauchamp, Tom. L. and James F. Childress. 2001. *Principles of Biomedical Ethics,* 5th ed. New York: Oxford University Press.

Kahneman, Daniel, Ed Diener, and Norbert Schwarz. 1999. *Well-Being: The Foundations of Hedonic Psychology.* New York: Russell Sage Foundation.

Nord, Erik. 1999. *Cost-Value Analysis in Health Care: Making Sense out of QALYs.* Cambridge, UK: Cambridge University Press.

Ubel, Peter A. 2000. *Pricing Life: Why It's Time for Health Care Rationing.* Cambridge, MA: MIT Press.

Wasserman, David, Robert Wachbroit, and Jerome Bickenbach. Forthcoming. *Quality of Life and Human Difference.* Cambridge, UK: Cambridge University Press.

HEALTHY PEOPLE 2010

Healthy People is the term used to identify the agenda for improving the health and safety of Americans. The publication of *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention* in 1979 set the initial objectives addressing the reduction of mortality across four age groups—children, adolescents, young adults, and adults. A fifth objective aspired to increase independent functioning among senior adults.

The second decade of Healthy People commenced in 1990 with *Healthy People 2000.* This agenda included 316 health-related objectives in 21 chapters. During deliberations about areas to include, disability was discussed during the late 1980s. Little data were available, however, to monitor the health and well-being of people with disabilities. Therefore, no specific emphasis was given to disability and health as the specific objectives were created. Throughout the 21 chapters of *Healthy People 2000,* 16 objectives referenced disability-related themes. Seven focused on the primary prevention of conditions associated with disability, and nine addressed health issues of people with disabilities. These seven included "people with disabilities" as a subpopulation in the analyses. The areas included leisure activity, weight, stress, mental health treatment, and clinical preventive services. The major emphasis for subpopulations was to assess differences with the general population. In the final review of *Healthy People 2000,* results indicated that of the six objectives that could be measured, half showed the disparities between people with and without disabilities to have been reduced or eliminated, and the remaining three to have stayed the same or moved away from the overall target.

In the mid-1990s, the U.S. Department of Health and Human Services began a dialogue with the Centers for Disease Control and Prevention to include people with disabilities in the third edition, *Healthy People 2010.* Disability has become an emerging public health issue due to the increased survival of children and adults experiencing limitations due to aging, chronic illness, traumatic injuries, and developmental disabilities. Two opportunities for inclusion were provided. First, "people with disabilities" was proposed as a demographic variable, alongside age, ethnicity, sex, and education level, for example, as subpopulations to describe the health of Americans. Second, a chapter specifically focusing on issues that are more specifically related to people with disabilities. The overarching goals of *Healthy People 2010* were to increase quantity of quality of life for all Americans and to eliminate health disparities. These goals were then able to be monitored for people with disabilities. The development of objectives took six years and included 250 individuals representing 75 advocacy, professional, university, and governmental entities. From the 28 chapters in *Healthy People 2010,* more than 100 objectives included "people with disabilities" as a subpopulation for data gathering. This will provide badly needed information that will allow health disparities among people with disabilities to be identified and monitored.

Chapter 6, "Disability and Secondary Conditions," is the disability-directed chapter and includes 13 objectives. There are several core issues addressed by the chapter:

- Challenging two commonly held false equations: that disability equals illness and that health equals medical intervention
- Affirming the role of the environment as critical to improving health and well-being
- Acknowledging the need for a standard definition of *disability* for use in surveys
- Establishing a common conceptual and coding framework for science, program, and policy—the World Health Organization's International Classification of Functioning, Disability, and Health

The 13 objectives are as follows:

- 6–1 Include in the core of all relevant *Healthy People 2010* surveillance instruments a standardized set of questions that identify "people with disabilities."
- 6–2 Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy, or depressed.

6–3 Reduce the proportion of adults with disabilities who report feelings such as sadness, unhappiness, or depression that prevent them from being active.

6–4 Increase the proportion of adults with disabilities who participate in social activities.

6–5 Increase the proportion of adults with disabilities reporting sufficient emotional support.

6–6 Increase the proportion of adults with disabilities reporting satisfaction with life.

6–7 Reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles.

6–8 Eliminate disparities in employment rates between working-aged adults with and without disabilities.

6–9 Increase the proportion of children and youth with disabilities who spend at least 80 percent of their time in regular education programs.

6–10 Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.

6–11 Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed.

6–12 Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities.

6–13 Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

Workshops were convened in 2000 and 2002 to develop strategies to initiate new activities or encourage already-existing strategies to achieve the objectives. Workgroups are currently convened in five areas—data, policy, program, training, and children—to implement the strategies that were developed. *Healthy People 2020* should provide opportunities for furthering the objectives for which work has begun.

—Donald J. Lollar

See also Health Promotion; Quality of Life.

Further Readings

Lollar, Donald J. 2002. "Public Health and Disability: Emerging Opportunities." *Public Health Reports* 117(March-April): 131–136.

Lollar, Donald J. and John E. Crews. 2003. "Redefining the Role of Public Health in Disability." *Annual Review of Public Health* 24:295–208.

National Center on Birth Defects and Developmental Disabilities. 2003. *Healthy People 2010 Disability and Secondary Conditions Focus Area 6 Reports and Proceedings.* Atlanta, GA: Centers for Disease Control and Prevention, June.

Websites

Healthy People 2010, http://www.healthypeople.gov

National Center on Birth Defects and Developmental Disabilities, at the Centers for Disease Control and Prevention, http://www.cdc.gov/ncbddd/dh

HEARING IMPAIRMENT

The central issue for people with hearing impairments is that they cannot hear. While that seems totally obvious, its importance cannot be overlooked. Whether people with hearing impairments can hear some sounds; which sounds they can hear; when they can hear; and whether they can talk, use a telephone, read lips, or sign are all variable, but the fact of not being able to hear is not. Thus, one can make few assumptions about people with hearing impairments other than that they cannot hear some or all of the sounds in the environment. Hearing impairments make communication difficult; thus, the most disabling result of hearing loss can be isolation.

The physical nature of hearing impairment is also extremely varied. Hearing impairments may be genetic or environmentally caused, usually by illness. They may be accompanied by other conditions or they may not: Some hearing impairments coexist with other conditions, but often a person with a hearing impairment is otherwise perfectly healthy. Thus, the assumption that a person with a hearing impairment is ill is unwarranted without further information.

People with hearing impairments who know sign language can communicate effectively and at as high a level as their education will permit—but only with other people who know how to sign. People who can read lips are able to interact with speaking people, but lipreading itself is problematic. In English, for example, lipreading is about 25 percent successful for the average user and 50 to 75 percent for really skilled lipreaders.

Various types of assistive technology can provide remedies for the communication impairment that results from hearing losses, but none remedy the hearing impairment itself. Hearing aids can attenuate the hearing loss, but they work better for some people and in some situations than in others—primarily in one-to-one situations in quiet rooms. Cochlear implants also appear to be variably successful; although the predictors of success or failure are not fully established at this writing, people with previous knowledge of sound seem to do better than people without. Assistive listening systems, captioning systems, and computer technologies can be useful in ameliorating the communication impairment, although they are expensive and depend on more advanced technology than is likely to be available in developing countries. Several types of telephone substitutes can be used successfully where adequate phone systems exist.

Sign language, cued speech, or oral interpreters are available in some situations, as are phone relay systems that use operators as intermediaries. All are expensive and are not sufficiently available, even in developed countries, and they are of no use to someone without the requisite skills.

The variability in causes, presentation, amelioration potential, and results means that people with hearing impairments are not homogeneous. Some feel they are members of a deaf community, although many do not.

Deaf communities have tended to form whenever a sufficient "critical mass" is achieved. In the United States, where schools for deaf children began in 1817, deaf people tended to stay in the area after they graduated, sometimes finding jobs at the same school. Other deaf communities formed in localities where a concentration of deaf people worked in a specific industry. For example, deaf workers were "drafted" for work in tire plants in Akron, Ohio, during World War I, so a large deaf community formed there. In the United States, the fact that many deaf men worked as printers facilitated the growth of newspapers for the deaf community and contributed to its solidarity. In many countries in Europe and Africa, deaf communities formed around residential schools. Sometimes the communities were so separated that, because transportation was difficult and interacting unlikely, each had its own sign language. For example, in Zimbabwe, four sign languages had grown up around the residential schools, but the National Association of the Deaf was only formed (officially) in the late 1980s.

With the founding of the World Federation of the Deaf in 1951, the deaf community became international. Its goals at this time are improving the status of national sign languages, attaining better education, improving access to information and services, and improving human rights for those in developing countries.

Members of a deaf community may refer to themselves as "Deaf, not deaf." The capital *D* indicates a political or ideological stance that includes a strong preference for the use of sign language, an acceptance of deafness as a normal condition and not a disability, an unwillingness to accept the idea of becoming hearing, a desire for deaf children, and a desire to see the deaf community continue (and thus may include objections to mainstreaming and the closing of residential schools for deaf children).

People who live in deaf families or deaf communities or spend time among other deaf people have very different experiences from those who spend most of their time with hearing people, since they are unlikely to experience the communication barriers and consequent isolation experienced by people who cannot communicate with those around them.

There are two major dimensions that have a large impact on the experience of hearing impairment: age of onset and severity of hearing loss. Combined, these two dimensions create four categories, which are shown in Figure 1 and discussed below.

Cell 1: People with severe, prelingual hearing losses. Early-onset deafness can cause major problems in learning to speak, read, and write. These problems can lead to subsequent problems in education and employment. Children in this situation are at high risk for educational impairments unless they can develop an early linguistic foundation. Some children do succeed in developing that linguistic base through lipreading, but many do not. The earlier linguistic interaction starts, the more likely a child is to develop the necessary linguistic base, whether the interaction is spoken or signed. People in this category are most likely to consider themselves to be culturally deaf.

	Severity of Hearing Loss	
Age of Onset	more severe	less severe
prelingual	Cell 1	Cell 3
postlingual	Cell 2	Cell 4

Figure 1 Conditions of Hearing Impairment

Cell 2: People with severe, postlingual hearing losses. For some people, postlingual hearing impairment emerges slowly, over months or years, while others may literally wake up deaf after an illness or injury. For some, this happens in their teens or young adulthood, and for others it happens in later life. People who develop postlingual hearing impairments have very different experiences from those with prelingual impairments, because they can talk and can interpret speech if it is mechanically amplified. Their deafness may be as isolating as it is for earlier deafened people, but some of their communication modalities, such as speaking and writing, may remain useful. But with postlingual deafness comes the necessity for resocialization. That is, formerly hearing people must "become" deaf. Not only may they need to learn a sign language or another form of communication, but they may also need to overcome a cultural stigma against deaf people, since now "they" are "me." They may need to reorganize family relationships, occupational situations, and social networks.

Cell 3: People with less severe, prelingual hearing losses. People in this category may be even more marginalized than those with more severe impairments. Children may be considered to be "hard of hearing" and taught to speak and lip-read (often to the detriment of academic subjects), or they may be considered just to have "a little hearing problem." Some may succeed in developing a linguistic base through lipreading, but many do not. They are more likely to be sent to mainstreamed educational programs, where they may get a better education than those in "deaf" schools, but they are likely to be more socially isolated. As adults they may find themselves not able to function well with hearing people and so may need or want to move toward the deaf world. But the deaf community may not accept them because they are "not deaf enough." Especially if they do not know how to sign, they may find themselves between two worlds.

Cell 4: People with less severe, postlingual hearing losses. People in this category are likely to have lost their hearing at a later age than people in the other three categories. In developed countries, such people make up by far the largest proportion of people with hearing impairments. However, they are the group that is least likely to identify with other deaf people and/or to have any desire to learn a sign language. They are the most likely to experience the isolating consequences of hearing loss, although newer technological remedies may provide some assistance.

Overall, the variability of the condition of hearing impairment as discussed above is reflected in the polarizations within the deaf population. Some of the divisive issues are oralism (speech and lipreading) versus signing, assimilation (to the hearing world) versus separation, segregated versus integrated education, and Deaf versus deaf. These issues have led to contentious political actions, including the "Deaf President Now!" protest at Gallaudet University in 1988 as well as many others in all parts of the world. These polarizations make the possibility of one unified deaf community unlikely.

—Sharon Barnartt

See also Deaf, History of the; Deaf Culture; Sign Language.

Further Readings

Barnartt, S., K. Seelman, and B. Gracer. 1990. "Policy Issues in Communications Accessibility." *Journal of Disability Policy Studies* 1(2): 47–63.

Benderly, Beryl L. 1990. *Dancing without Music.* Washington, DC: Gallaudet University Press.

Christiansen, J. B. and S. N. Barnartt. 1995. *Deaf President Now: The 1988 Revolution at Gallaudet University.* Washington, DC: Gallaudet University Press.

Foster, S and G. Emerton. 1991. "Mainstreaming the Deaf Student: A Blessing or a Curse?" *Journal of Disability Policy Studies* 2(2): 61–76.

Higgins, P. and J. E. Nash, eds. 1987. *Understanding Deafness Socially.* Springfield, IL: Charles C Thomas. (2d ed., 2001).

Jankowski, K. A. 1997. *Deaf Empowerment: Emergence, Struggle and Rhetoric.* Washington, DC: Gallaudet University Press.

Journal of Deaf Studies and Deaf Education. Various issues.

Kisor, H. 1990. *What's That Pig Outdoors? A Memoir of Deafness.* New York: Hill and Wang.

Nash, Jeffrey E. and Anedith Nash. 1981. *Deafness in Society.* Lexington, MA: Lexington Books.

Neisser, A. 1983. *The Other Side of Silence.* Washington, DC: Gallaudet University Press.
Sign Language Studies. Various issues.

HEATH, JEFF 1955–2004

Australian activist and author

Jeff Heath was a self-described social entrepreneur, who gained public recognition for pursuing innovative projects aimed at social change for people with impairments. Heath had a significant physical impairment and was a wheelchair user from childhood. He was a Paralympian and sailor, who loved family life and cooking. Throughout his 30 years as a disability and antiwar activist, he was a persistent lobbyist who became a force in access campaigns, opposing economic rationalist dogma and euthanasia.

Heath subscribed to the belief that knowledge is power. Professionally, he was a writer, journalist, and editor of Australia's leading disability magazine, *Link*. He was a founder of the Disability Information Resource Centre in Adelaide, a prolific contributor to mainstream media, and a popular motivational speaker.

Heath had allies in countless forums in many countries was a member of many advisory structures. From 1988 to 1993, he was executive director of Disabled Peoples' International (DPI) South Australia. However, all who worked with him knew his impatience with group processes. Heath was at his energetic best when focused on tasks, analyzing public policy and hassling for positive change for people with impairments and subsequently the wider Australian community.

—Lorna Hallahan

See also Activism; Paralympics.

Further Readings

Heath, Jeffrey S. 2003. "Before, during and after—War Is Inextricably Linked with Disability." Retrieved April 29, 2004 (http://www.jeffheath.com.au/nowar.htm).

Websites

For cartoons about Jeff Heath's 2001 Senate election campaign for the Australian Democrats, see http://www.sphosting.com/webcartoons/heath/cartoons.html

HIP FRACTURE

In the United States, approximately 300,000 people fracture their hip every year, and half of them are age 80 or older. The incidence of fracture has increased as people are living much longer, and elderly people's unsteadiness on their feet can be affected by medication, dementia, and general frailty. Often the reason for the hip fracture is a fall, either in the home or on the street, and it is the way that elderly people fall that makes them particularly vulnerable to this type of fracture. For the younger patient, hip fractures are often caused by accidents, often involving motor vehicles and to a lesser extent sporting activities. Studies have shown that it is essential that treatment be carried out quickly, within 24 hours. Treatment usually consists of surgery to insert a bone plate or, in some cases, a hip replacement. The average cost to the health services for a patient with a hip fracture estimated in 1990 was US$20,000, and the entire cost to both private and public providers is estimated to be about US$5 billion per year.

The prognosis for very elderly people surviving hip fracture is poor in the immediate to long term. Complications for elderly people include thrombosis, pneumonia, and infections after surgery. Even with ever improving medical and surgical techniques, the long-term prognosis for the older person is still poor. In a study in six New England states, 24 percent of hip fracture patients died in the first year following surgery. Class and gender affect rates; for example, women have better survival rates than men, and those from lower socioeconomic groups have the worst.

To aid recovery after surgery, ward off potential complications, and increase the likelihood of survival, patients are encouraged to move and begin to walk with aids as soon as possible. Generally, for the younger patient this presents few difficulties. However, many elderly people are not able to take advantage of the rehabilitation programs due to their frailty, so sometimes their ability to improve after surgery is limited. In some cases, rehabilitation programs are not available so many elderly people who have fallen endure a diminished quality of life due to the disabling effect of a hip fracture and the loss of confidence that it can cause. As to be expected, younger people have better rates of recovery, although total hip replacement may be required as the patient gets older.

Since the results following surgery remain mixed, it seems that prevention of hip fractures for elderly people may be the best way to ensure that they do not have to endure surgery, the threat of complications, the potential for long-term disability, and a reduction in their quality of life. Charities in Britain run fitness training courses particularly for elderly people in order that they retain some flexibility and strength. Engineers are developing aids that reduce the potential for a fractured hip if an elderly person does fall. These include hip guards that are inserted in pockets in a special undergarment and act as a type of body armor to protect the hip. As research into preventive strategies improves, it can be hoped that the incidence of hip fracture and its disabling effects, which can cause a significant reduction in the quality of life of individuals, can be limited.

—Julie Anderson

See also Aging; Frailty.

Further Readings

Audit Commission Report. 2000, February. "United They Stand: Co-ordinating Health Care for Elderly Patients with Hip Fracture." London: HMSO.

Websites

National Institutes of Health, Osteoporosis and Related Bone Diseases National Resource Center Fact Sheet, http://www.osteo.org

Scottish Hip Fracture Audit report, http://www.show.scot .nhs.uk/shfa/AnnualReport/Main.htm

HIPPOCRATES (428–347 BCE)

Greek physician

Hippocrates was a physician, teacher, and author on the island of Cos in Greece. Little is known of his life. A corpus of roughly 60 Greek works (written between 420 and 350 BCE) has been associated with his name, though no text is certainly attributed to his hand. The sweep of the Hippocratic corpus includes texts on disease, deontology, therapy, and physiology among others. A cardinal feature of the corpus is its emphasis on natural, rather than divine or religious, etiologies of disease, often an imbalance of one of the four humors. The clearest evocation of this feature is in the case of epilepsy, which in other ancient sources was considered a religious or magical phenomenon. In the Hippocratic text *The Sacred Disease,* epilepsy was categorically identified as having "specific characteristics and a definite cause," namely, a surfeit of the humor phlegm. Similarly, paralysis, the Hippocratic *Aphorisms* tell us, is a sign of melancholia, or too much black bile.

By and large, the Hippocratics were more interested in generating a *prognosis*, or description of the past, present, and future of a condition (particularly its likelihood of improving) rather than theoretical etiologies and even diagnoses, though both are manifest.

The Hippocratic corpus includes references to scoliosis, limb fractures and lameness, epilepsy, paralyses, congenital conditions, sexual dysfunction, general debility, autoamputation, pain, and sensory impairments. Deafness was often seen more as a diagnostic sign than as a disability. Etiologically, the bowels were linked to deafness, which connection was used by later authors as a therapeutic mandate. Therapy within the corpus includes fracture reduction, crutches, orthoses, and humoral management. Psychiatric and cognitive conditions are also well represented.

The power of the Hippocratic corpus exists in large measure because of the emphasis that later authors placed on it, particularly Galen (AD 129–ca. 199/216); the first university professors of the Middle Ages; and eighteenth-century Western clinicians. To this day, a form of the "Hippocratic Oath" is still taken by many graduating medical students, thus demonstrating the long influence of authors more than 2,400 years ago on the medical model.

—Walton O. Schalick III

See also Galen; Humors, Theory of.

Further Readings

Littré, Émile. 1839–1861. *Oeuvres complètes d'Hippocrate* (Complete Works of Hippocrates). Paris: Baillière.

Nutton, Vivian. 2004. *Ancient Medicine.* London: Routledge.

Rose, Martha L. 2003. *The Staff of Oedipus: Transforming Disability in Ancient Greece.* Ann Arbor: University of Michigan Press.

HISTORY OF DISABILITY: ANCIENT WEST

The "ancient West " is a difficult term, calling into question cultural and geographic perception (*whose* west?). For the purposes of this entry, the term will refer to the ancient Graeco-Roman world, which was itself a shifting amalgamation of cultures, often distinctly "non-Western" cultures. The ancient Graeco-Roman world spans several millennia, from the third millennium BC through the fall of Rome in the fourth or fifth century AD. In short, the generalizations presented here do not necessarily apply to all places and phases of Graeco-Roman society.

Ideas about disability in the ancient world are part of our common consciousness. Images of Homer, Oedipus, and the Emperor Claudius—along with the phenomenon of Spartan infanticide of deformed infants—are often the first images that come to mind.

Greek civilization, especially fifth- and fourth-century classical Greek civilization, is generally considered the cultural and philosophical ancestor of the West. Current scholarship, though, is quick to qualify the view of antiquarians such as Johann Winckelmann, the eighteenth-century foundational scholar of art history, who viewed classical Greece as the pinnacle of human achievement and who assumed that Greek people themselves were the embodiment of perfection. As Charles Freeman wrote in *The Greek Achievement* (1999), "This was certainly a sanitized version of the original Greece and one could be forgiven for believing that ordinary human beings did not exist in ancient Greece at all." Indeed, people with disabilities are simply omitted in the earliest accounts of daily life such as Jerome Carcopino's *Daily Life in Ancient Rome* (1940).

But people with a wide variety of somatic and psychiatric variations did inhabit both the Greek and Roman worlds, and disability is one of the most recent categories of ancient social history to be examined. Interpreting disability has been influenced both by the romanticized vision of a heritage of perfect Western antiquity and by modern assumptions about what disability means. If one assumes a medical model of disability, in which disability is an individual misfortune to be corrected as far as possible by medical technology, the picture is indeed bleak. Howard Haggard's *The Lame, the Halt, and the Blind* (1932) tells dramatic tales about societies that lack rational medicine.

There has been a growing scholarly interest during the past decade in variations of the human body in the ancient world. Veronique Dasen couched her 1995 iconographic study, *Dwarfs in Ancient Egypt and Greece,* as a study of physical minorities. Daniel Ogden published *The Crooked Kings of Ancient Greece* in 1997. In addition, interest in the study of the human body in the ancient world is represented by a special volume of *Arethusa*, titled "Vile Bodies: Roman Satire and Corporeal Discourse" (Braund and Gold 1998). In 1999, the University of Michigan Press published *Constructions of the Classical Body*, a collection edited by James Porter.

A few scholarly works explicitly employ the perspective of disability studies, which is based on the tenet that disability is at least in part a socially constructed phenomenon—that is, no matter how real a missing limb or a psychiatric disorder might be, the meaning that any given society applies to the condition shifts over time and between cultures.

Among scholars of disability studies, there is no static or intrinsic universal assumption about what the human body should look like. Robert Garland, in *The Eye of the Beholder* (1995), transcends the understanding of disability in the modern, developed world and considers deformity from the perspective of the ancient Graeco-Roman world. Garland considers not only familiar categories of disability such as blindness, but he goes on to discuss emaciation and obesity and points out that baldness was a "serious and inhibiting social handicap." Nicholas Vlahogiannis also transcends the medical model by exploring the formation of attitudes in the discourse of social constructions of disability. Vlahogiannis looked at the disempowerment of disabled people through such systems as punishment and social positioning. Vlahogiannis's essays can be found in *Changing Bodies, Changing Meanings* (1998), edited by Dominic Monserrat, and in the collection *Health in Antiquity* (2005), edited by Helen King. My own work, which examines the intersection between ancient Greek and modern, Western portrayals of disability, is summarized in *The Staff of Oedipus* (Rose 2003).

Disability studies includes all types of disability, including cognitive and psychiatric. While there is no

shortage of writing on mental illness in the ancient world, such as Bennett Simon's *Mind and Madness in Ancient Greece* (1980), most works focus on the interaction between Greek mythology and Freudian psychology. Allen Thither's *Revels in Madness* (1999) is refreshing in that it treats "madness" as a shifting concept. Patricia Clark's dissertation, "The Balance of the Mind" (1993), is the only work that examines the effects of mental health and illness on ordinary human beings, in the context of ancient daily life. This work is, unfortunately, not yet published. Even less scholarly material exists for cognitive disability, but quality makes up for quantity in the work of Chris Goodey's essays such as "Politics, Nature, and Necessity" (1999); Tim Stainton, too, has examined the phenomenon in essays such as "Reason and Value" (2001).

Some disabilities are mentioned in the ancient medical texts, most notably epilepsy, the standard work on which is Oswei Temkin's *The Falling Sickness* (1971). Many other disabilities are not even mentioned in the ancient medical literature, as disabilities were not seen as the categorizable medical phenomena that they are today. The evidence for physical disability is scattered, scant, and often contradictory. No discussion of disability survives that is composed by a person who identifies himself or herself as disabled. Nevertheless, literary, papyrological, and archaeological primary sources contribute to our knowledge about disability. Following are sketches of three impairment categories: mobility impairment, deafness, and blindness. These are modern categories, not ancient; many other disabilities existed; and people would have had multiple disabilities, not necessarily one at a time. Still, this sketch provides a sample and an overview of a few issues of disability studies in the Graeco-Roman world.

The ancient landscape included a wide variety of human variation, far more varied than portrayed in images of Graeco-Roman perfection that is the Renaissance and neoclassical artistic legacy. Some people acquired disabilities in the womb or in infancy; an ancient physician writing in the Hippocratic tradition observed that lameness lies in heredity. Impairments such as spinal malformation and clubfoot can be acquired in the womb regardless of genetic configurations. A mother's inadequate nutrition was a significant factor in the ancient world in terms of producing offspring with physical anomalies, and even if a fetus were to grow unharmed in the womb, its birth might be premature. Prematurely born babies are at risk for disability such as cerebral palsy and motor incoordination.

Children born without a handicap could acquire one from a variety of circumstances later in life. Permanent physical disability could result from injured, diseased, and lost limbs; from diseases such as arthritis; and from several other conditions. Even the most minor injury could have permanent consequences. Accidents or events causing fractures were common. Whether as a result of improper healing or as the result of infection, fractured and dislocated bones were likely to result in a permanent physical handicap in the ancient world. In the developed world, we take for granted that, with medical attention, even the most severe fracture will be undetectably repaired. Without medical attention, fractures sometimes spontaneously and completely heal, but not always.

While it is assumed in the developed world that medical attention to a broken bone will result in its healing, a visit from a doctor in the ancient world could have a range of possible results. In the ancient world, a doctor's training was not standardized, licensed, or necessarily respected. There was no standard medical treatment for any given malady, but rather a variety of treatment methods. Some treatments seem sound; others seem of dubious value to the modern eye. For example, the second-century AD Roman physician Galen was in favor of letting blood as a remedy for injured limbs.

Even if a bone is tended to and set properly, it must remain immobilized to effect complete healing. While animals with broken bones do this by instinct, the need to tend a shop or a field would probably override any human instinct to remain idle. The paleopathologist Srboljub Živanović, in *Ancient Diseases* (1982:27), wrote that "the morphological deformities that arose are really beyond imagination at the present time."

Ancient material about deaf people in the ancient world is even more limited than that about people with mobility impairments, but the evidence that exists suggests a grim life for the deaf person who did not speak. There is no suggestion of any sort of formal sign language. Muteness went beyond a physical condition in ancient perception. An inability to speak went hand in

hand with an inability to reason, hand in hand with stupidity, embodied even today in the obsolete expression "deaf and dumb." Deafness was indeed a curse, sometimes literally. The word *deaf* appears in the surviving Greek inscriptions almost exclusively as a curse, and a powerful one. Deprivation of hearing, because it meant a deprivation of verbal communication and perceived intelligence, meant separation from the political and intellectual arena. A curse of deafness was appropriate not only for one's political opponents, whose speech could harm, but also for anyone who had too much power—many curse tablets are aimed at litigants.

In trying to reconstruct the daily realities of deaf people from scraps of information, it is worth considering that issues of speech and intelligence were different for the literate elite than they were for the bulk of the population but that we rely on the literate elite for almost all our information about deafness. The elite valued the very skills—such as fluency in communication—that they thought deaf people lacked. The deaf child of a farmer or shepherd, even if considered utterly stupid and incapable of political activity, could certainly carry out any number of tasks. Life in the ancient Graeco-Roman world for anyone who did not speak must have been frustrating occasionally. But while the consequences of deafness are synonymous with exile or death in the literature, it is important to remember that more people in the ancient world were interested in farming than in rhetoric; that is, the majority of the population was composed of peasant farmers, not politicians. Limited conversational ability among peasants might have been a frustration, but not an insurmountable condition.

In contrast to the dearth of deaf people in ancient literature, several blind archetypes are household names. The blind bard Homer, the blind seer Tiresias, and Oedipus Rex, who was blinded by divine punishment, dominate most discussions of blindness in the ancient Greek world. By supplying an apparent historical precedent, generalizations made from the tales of these figures support modern attitudes toward blindness and blind people, such as the idea that blind people are special but horrifying. It is fallacious, though, to transfer attitudes seen in the grand sweep of legend and tragedy to everyday life and to generalize that Greeks and Romans viewed blindness as a fate worse than death. In fact, the ancient concept of vision had little to do with the modern one. There was no measured scale of vision, from perfect sight to legal blindness. One was able to see, even if only a little, or one did not see at all.

No one in the ancient world was immune to blindness. Most of us in the developed world live in the luxury of assuming that we will not—among other fates—become blind. In the ancient world, it was perhaps more reasonable to assume that one would lose at least some of one's sight. It follows that in the ancient world, sighted people knew blind and sight-impaired people well enough to understand the abilities and limitations of failing vision and that there was not the cultural gulf between the sighted and the blind that exists today.

Ancient myths and tales reflect truths and anxieties about sight and blindness in the ancient world. The tales of blind people come from the ancient, contextual understanding of what blindness meant. Blindness meant adapting one's life and activities to the individual's unique condition. In contrast, measurements and categories for degrees of vision determine one's legal status as a sighted or blind person in the modern, developed world. Blindness itself, regardless of individual circumstances, is seen as pitiful and tragic, and, like any evident disability, overrides any other physical characteristic.

In conclusion, and in general, disability in the ancient world was treated as a family and civic issue, rather than a medical one, in which what was conceived of as a "problem" was inherent in the individual. Disability status was defined and negotiated between individuals on a case-by-case basis within a community. On one hand, this does not suggest a utopia; indeed, the lack of a recognized disability status negates the possibility of systematized accommodation and service. On the other hand, people with what we call disabilities were not discriminated against as a group.

—M. Lynn Rose

See also Blind, History of the; Emperor Claudius; Deaf, History of the; Galen; Homer.

Further Readings

Braund, Susanna Morton and Barbara K. Gold, eds. 1998. "Vile Bodies: Roman Satire and Corporeal Discourse." *Arethusa* 31(3) (Special issue).

Carcopino, Jerome. 1940. *Daily Life in Ancient Rome: The People and Their City at the Height of the Empire.* New Haven, CT: Yale University Press.

Clark, Patricia. 1993. "The Balance of the Mind: The Experience and Perception of Mental Illness in Antiquity." Dissertation, University of Washington, Seattle, WA.

Dasen, Veronique. 1995. *Dwarfs in Ancient Egypt and Greece.* Oxford, UK: Clarendon.

Freeman, Charles. 1999. *The Greek Achievement: The Foundation of the Western World.* New York: Viking.

Garland, Robert. 1995. *The Eye of the Beholder: Deformity & Disability in the Graeco-Roman World.* Ithaca, NY: Cornell University Press.

Goodey, C. F. 1999. "Politics, Nature, and Necessity: Were Aristotle's Slaves Feeble Minded?" *Political Theory* 27(2): 203–223.

Haggard, Howard. 1932. *The Lame, the Halt, and the Blind: The Vital Role of Medicine in the History of Civilization.* New York: Blue Ribbon Books.

Ogden, Daniel. 1997. *The Crooked Kings of Ancient Greece.* London: Duckworth.

Porter, James, ed. 1999. *Constructions of the Classical Body.* Ann Arbor: University of Michigan Press.

Rose, Martha. 2003. *The Staff of Oedipus: Transforming Disability in Ancient Greece.* Ann Arbor: University of Michigan Press.

Simon, Bennett. 1980. *Mind and Madness in Ancient Greece: The Classical Roots of Modern Psychiatry.* Ithaca, NY: Cornell University Press.

Stainton, Tim. 2001. "Reason and Value: The Thought of Plato and Aristotle and the Construction of Intellectual Disability." *Mental Retardation* 39(6): 452-460.

Temkin, Oswei. 1971. *The Falling Sickness: A History of Epilepsy from the Greeks to the Beginnings of Modern Neurology.* Baltimore: Johns Hopkins University Press.

Thiher, Allen. 1999. *Revels in Madness: Insanity in Medicine and Literature.* Ann Arbor: University of Michigan University Press.

Vlahogiannis, Nicholas. 1998. "Essays." Pp. 13–36 in *Changing Bodies, Changing Meanings: Studies on the Human Body in Antiquity,* edited by Dominic Monserrat. New York: Routledge. (Essays also in Helen King, ed., 2005. *Health in Antiquity.* New York: Routledge.)

Živanović, Srboljub. 1982. *Ancient Diseases: The Elements of Paleopathology.* Translated by L. Edwards. New York: Pica.

HISTORY OF DISABILITY: EARLY MODERN WEST

In the early modern West (1500–1800), *disability* was commonly defined as the inability to work sufficiently to take care of life's necessities. Physically disabling conditions that were recognized by contemporaries included chronic illness, maims, deafness, blindness, mental problems (illness and intellectual impairment), and infirmity brought on by age or service. Several disabling conditions were understood via reference to the Christian religion and the dominant humoral theory of medicine, especially early in the period. Charitable and state provision became increasingly important, with the origins of disability benefits emerging as military pensions. That disability is a social and political construct is clear in its origins, with medicine being brought in only later merely to serve certain functions in the administration of benefits. In the seventeenth and eighteenth centuries, there were efforts to educate those with certain disabling conditions. Special institutions were created for that purpose.

During the medieval period, there were institutions for lepers (a disease that receded from the fourteenth century in Europe, but not in other places such as Brazil), almshouses, and hospitals for the sick poor. Institutions became more significant from the late sixteenth century for many disabled people, and they grew in number and size (madhouses; workhouses; hospitals for the poor, orphaned, aged; as well as veterans' and military hospitals). The emergence of these institutions was a result of a change in policy. Whereas in the medieval period the disabled poor were free to wander and beg, this was curtailed from the early sixteenth century on, with begging criminalized. Increasingly, efforts were made to force the able-bodied to work. Efforts were also made to create pensions and to house those disabled to work in institutions. The old English poor law largely emphasized relief outside institutions in the parishes, paid for from compulsory local taxes from 1598 on. This system was influential to a greater or lesser degree in colonial North America. In much of continental Europe, private institutions run by religious confraternities or municipalities were created and grew in size. By 1591, Rome, with a population of nearly 120,000, had nearly 4,000 hospital residents, for example.

In seventeenth-century France, the Catholic Church reformed its charitable institutions, with the Company of the Holy Sacrament creating the Hôpital Général in Paris, housing and detaining thousands of disabled

people. By 1700, more than 100 hôpitaux généraux existed in France, with over 100,000 inhabitants, including the insane, the chronic sick, alongside petty thieves, prostitutes, and single mothers. Some scholars have termed this development "the great confinement" (Michel Foucault). Large city hospitals—the Hôtel Dieu—treated the sick and disabled poor and became more medicalized in the eighteenth century, hiring surgeons and appointing physicians. Nursing orders such as the Daughters of Charity (1633) provided practical nursing skills and hospital labor.

Institutional treatment became increasingly important for those afflicted with a disease that was new to the West in the early modern period: venereal disease. Classic secondary symptoms of this disabling disease include terrible pains in bones leading to limited mobility and skin disruptions resulting in disfiguring scars, and for some, collapse of the nose. Although it had previously been believed that sufferers afflicted with this disease could not gain access to a hospital place, recent scholarship has proven that, on the contrary, hospital provision was widespread and a significant factor in the lives of those most affected. For example, up to 30 percent of patients in St. Thomas's Hospital in late-eighteenth-century London were victims of venereal disease (known as "foul" patients).

The origins of disability as a social and political category emerged with military pension schemes. The first state disability benefits were created in England in 1593, when Parliament enacted Europe's first national system for those disabled in war. Initially, the system had a very strong basis of entitlement: Disability experienced in military service entitled men to lifelong pensions. Poverty and financial assets were not criteria. Soldiers and sailors wounded in the service of the realm were treated as members of the community of honor, with hospitality extended to them in a way reminiscent of traditional noble hospitality. Even though the veterans were economically and socially inferior, they were nevertheless to be treated as part of the social world of the host (to enquire too closely into their financial resources would have been dishonorable). Governed (veterans) and governors (council and Parliament) in Elizabethan England thus agreed that disabled ex-servicemen were entitled to statutory relief. This strong conception of entitlement was not, it should be noted, rooted in modern notions of equality or citizenship but in premodern ideals of hierarchical social obligation based on status. In time, this entitlement basis was challenged in practice and later in law by developing, contemporary, poor law notions of disability that were based on the belief that only those disabled to work should be accorded benefits.

From the late sixteenth century, pension evidence from the disabled themselves shows the influence of the humoral understanding of the body on the disabled and those who administered pension schemes, military, and later, poor law. The disabled would narrate their service or life history, their wounds, describing the ways in which their wounds disabled them physically. Some also cited colds and disease, violent fevers and fluxes, which they had contracted in service or domestic life. These continued to plague them for a long time afterward, so as to make labor difficult. Several of the citations of cold and disease correspond to contemporary understandings of the humoral theory of the body, a theory that was understood and accepted by laypeople of different social classes as well as medical practitioners. Thus, the diagnosis was offered by the disabled veterans or domestic poor themselves, and it was generally accepted by those administering the pension systems.

Within the medical theory of humoralism, the human body was believed to be a semipermeable, irrigated vessel in which moved the four humors (blood, phlegm, yellow bile, and black bile). Health was maintained by the preservation of internal stability—balance—through evacuation of bodily fluids and the avoidance, if possible, of environments and conditions of life that upset one's internal stability. The humors moved with differing degrees of fluidity. And they left with varying degrees of efficiency. Heat was believed to promote solubility, cold to hamper it. Several disabled petitioners demonstrated a keen awareness of the permanent effect of heat and, especially, cold in military service and life upon their physical state.

In their general descriptions of wounds, men sometimes mentioned their loss of blood and bruises (the extravasation of blood) suffered on the battlefield. This was often combined with citing old age. It is clear that people believed that a significant loss of blood, or its being forced from its proper vessel in the case of serious bruising, could have permanent effects on the

human body. The blood was believed to carry the humors, and as such an inordinate loss of it could irreparably upset one's internal balance. As one got older, the loss of a great deal of blood on one or more occasions would have a greater effect on one's health and strength. This was because it was believed that the bodies of the aged contained less blood than the bodies of younger adults. Aging was understood as a process of people gradually drying out. Thus, although in 1628 William Harvey revealed that blood circulated and that more of it flowed through the heart than could be created as a result of digestion, people continued to believe for some time that the body's production of blood was related to consumption and other factors such as age.

The meaning of some illnesses, as with wounds, was thus cast in historical terms by petitioners. What we would deem medically insignificant events triggered long-term chronic disability. It is clear from the petitions that although age was important in contemporary notions of pensionable disability, one had to be old and disabled to be considered: People were expected to work as long as possible.

By the late eighteenth century, petitions from the war disabled exhibit a marked decline in explanations founded in humoral theory, with mention of the effect of bad humors, as well as cold and heat in service, disappearing. Instead the surgeon's opinion is cited much more than it was in the seventeenth century, and explanations tended to be based more on physical diagnosis rather than the patient narrative. It may be that the decline of humoral medical theory in midcentury among elite physicians—the body as a machine—was filtering through, entering popular culture. In addition, developments in military medicine were influential, with an increasing emphasis on identifying diseases as entities and the development of standardized diagnosis and treatment. These developments contributed to the gradual decline in practice and importance of the disabled patient's story within a humoral context. Within pension systems, medical practitioners gradually became influential as functionaries from approximately the mid-seventeenth century on, after which they were gradually brought in to assist with the assessment of disability.

Some illnesses and disabling conditions in individuals (e.g., madness, epilepsy) and society (e.g., the plague) were linked traditionally to supernatural causes—fate, the devil (i.e., witchcraft), or more commonly, God's will (divine providence). This declined from the late seventeenth century. Contemporary links between illness, disability, and divine providence did not arise within the context of veterans' and old age benefits. Maims experienced in military service were the work of other men, and not God (no matter which side He fought on), and it was accepted that the elderly were more susceptible to disabling conditions.

Over the course of the early modern period, developments in science, philosophy, and medicine had a significant impact on understandings of disabling illnesses. This was particularly the case with respect to mental illness. Cartesian mind/body dualism fundamentally challenged the previous view that mental illness was caused by disturbances in the immortal soul or the mind. Instead, it gradually became accepted that such illnesses were caused by material, corporeal, problems within the body and brain. Thomas Willis (1621–1675) studied the pathology of the brain and the nature of the nerves, developing ideas about the physical origins of problems that had previously been assigned supernatural causes (e.g., epilepsy, narcolepsy). This shift occurred at the same time as a move away from the belief in an interventionist God to one that was much more distant and respectful of universal scientific laws. In addition, scientists became more careful to distinguish between mental illness and intellectual disability. With these intellectual changes over time madness lost much of its stigma, and new ideas about humane and scientific care and treatment developed.

Technological changes also had an impact on the way disabled people were perceived. With the invention of printing, for example, society saw a very gradual movement away from a primarily oral culture in which there was a link between civilization and deafness. Printing brought increased literacy and interest in improving eyesight, with the common use of eyeglasses by the sixteenth century.

From the sixteenth century on, there was increasing interest in understanding the nature of a number of disabling conditions. First deaf people and later the blind were studied and educational methods were developed. Education for the deaf is believed to have begun in Spain in response to inheritance laws that prevented deaf males from inheriting if they could not speak

(early legal codes of nearly every European country did not allow a disabled person to make a deed, contract, or will or to testify in court). Aristocratic sons were taught to read and speak by a Benedictine monk, Pedro Ponce de Leon (1520–1584).

This work was continued by Jean Pablo Bonet (1579–1629), who used a hand alphabet and lipreading in his educational methods, an account of which he published in 1620. Seventeenth-century developments in England were influenced by the Spanish experience, with Sir Kenelm Digby (1603–1665), John Wallis (1616–1703), and others in and outside the Royal Society studying practical ways to teach the deaf. Attention was also devoted to the blind. John Bulwer (*bap.* 1606–1656) suggested a special school for the mute in the mid-seventeenth century, and later, Henry Baker (1698–1774) made his living educating the deaf. The British commonly used finger alphabets, likely with some use of signs, whereas in Europe teachers such as Johann Conrad Amman (1669–1724, Swiss) focused on teaching the deaf to speak. In the eighteenth century, deaf schools were established throughout Europe, with a dozen up and running by 1789.

Eighteenth-century developments in the education of the deaf and blind were influenced by intellectual changes. John Locke's *Essay Concerning Human Understanding* (1690) was significant in this regard. Locke (1632–1704) argued that the mind developed as a result of sensory perception and reflection (rather than innately). Accordingly, new experiences could develop new faculties: The deaf and blind could be taught.

The National Institute for Blind Youth was opened in Paris in 1784, founded by Valentin Haüy (1745–1822), who was one of the first to employ embossed print. Similar institutions were later founded in Berlin, Liverpool, and elsewhere. During the seventeenth century, an Italian, Francesco Lana-Terzi (1631–1687), recommended a system of lines and dots representing letters of the alphabet. In 1825, Charles Barbier, a sighted military officer, invented a raised-dot system intended to allow officers to communicate with one another in the dark. This system was refined by Louis Braille (1809–1852).

The growth of institutions for particular disabilities included the development of specialized treatments and educational services. Although positive in many ways, this process also reinforced existing, and created new, boundaries between the normal and those perceived as abnormal in society.

—Geoffrey L. Hudson

See also Blind, History of the; Deaf, History of the; Humors, Theory of; Poor Laws (United Kingdom).

Further Readings

Braddock, David L. and Susan L. Parish. 2001. "An Institutional History of Disability." Pp. 11–68 in *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury. Thousand Oaks, CA: Sage.

Brockliss, Laurence and Colin Jones. 1997. *The Medical World of Early Modern France.* Oxford, UK: Clarendon.

Fissell, Mary E. 1991. *Patients, Power, and the Poor in Eighteenth-Century Bristol.* Cambridge, UK: Cambridge University Press.

Gray, Louise. 2002. "The Experience of Old Age in the Narratives of the Rural Poor in Early Modern Germany." Pp. 107–123 in *Power and Poverty: Old Age in the Pre-Industrial Past,* edited by Susannah R. Ottaway, L. A. Botelho, and Katharine Kittredge. Westport, CT: Greenwood.

Hudson, Geoffrey. 2000. "Disabled Veterans in Early Modern England." Pp. 117–144 in *Disabled Veterans in History*, edited by D. Gerber. Ann Arbor: University of Michigan Press.

Pelling, Margaret. 1998. *The Common Lot: Sickness, Medical Occupations and the Urban Poor in Early Modern England.* London: Longmans.

Porter, Roy. 1997. *The Greatest Benefit to Mankind: A Medical History of Humanity from Antiquity to the Present.* London: HarperCollins.

Siena, Kevin P. 2004. *Venereal Disease, Hospitals and the Urban Poor: London's "Foul Wards," 1600–1800*. Rochester, NY: University of Rochester Press.

Winzer, Margaret A. 1997. "Universalizing Marginality: Disability and Society before the Eighteenth Century." Pp. 75–109 in *The Disability Studies Reader,* edited by Lennard J. Davis. New York: Routledge.

Wright, David. 2001. "Developmental and Physical Disabilities: The 'Blind,' 'Deaf and Dumb,' and 'Idiot.'" Pp. 507–516 in *Encyclopedia of European Social History from 1350 to 2000,* edited by Peter N. Stearns. New York: Scribner's.

HISTORY OF DISABILITY: KOREA

Disability is *jang-ae* in Korean, which means barrier or hindrance, and *jang-ae-in* is the widely used term to

call disabled people. The term for disabled people has been changed over time from *byeongsin*, *bulguja, jang-hae-ja, simsinjang-ae-ja*, and *jang-ae-ja* to *jang-ae-in*.

Historical studies of disability in Korea, which mostly emerged in special education, rehabilitation, and social welfare policy, have focused on legislation and state policies for people with disabilities. Traditional attitudes toward disability have been explored through the examination of proverbs, ancient folklores, religious scriptures, royal chronicles, and literature. Some explorations of disability history in Korea find parallels with the Western histories such as the experience of stigma, the interpretation of disability as moral punishment, and widespread and institutionalized exclusion of disabled people. Through modernization and Western influence, disability policies have been thought to enhance disabled people's lives. Others sought to read Confucian, Taoist, and Buddhist principles regarding body and disability as the indicators of traditional attitudes toward disabled people before modernization and generalized them as "humane," "benevolent," and "holistic" in comparison to Western maltreatment of disabled people.

ANTIQUITY AND MIDDLE AGE

The alleged earliest reference to disability is in *Samguk Sagi* (*The History of Three Kingdoms*, 1145). This book documents King Yuri Isageum of Silla (a kingdom that existed from 57 BC to AD 935), who provided food to widows, widowers, orphans, people without families, the elderly, the diseased, and people who were unable to support themselves in the winter of AD 25. Similar records appear regarding Goguryeo (37 BC to AD 668) and Bakje's (18 BC to AD 660) relief policies around the fourth century. The stories of disabled people in the text of *Samguk Yusa* (*The History of Three Kingdoms*, complied approximately in the 1280s by Ilyeon) provide rich texts in which one can explore the meaning of disability within ancient Korea from the fourth century BC to the seventh century AD. It contains stories about a disabled person being exorcised and receiving eyesight and being healed from an illness by the power of Buddhism. These stories show that disability was appropriated to expand the power and influence of Buddhism. In parallel, there is a story where the state rewards a daughter who sold herself as a slave to support her blind mother, and this story is also used to emphasize Confucian value of filial piety (Ji'eun story in *Samguk Sagi* and a filial daughter in *Samguk Yusa*). Similar stories have appeared later including "Sim Cheong Jeon" ("The Story of Sim Cheong"), which deals with a blind father whose disability is eventually cured through the sacrifice of his daughter. Disabled figures in other Confucian tales often provide moral challenges to nondisabled characters by becoming obstacles to overcome. For example, Tomi's story from *Samguk Sagi* is about chastity of a wife after her husband was made blind as a punishment.

It is common to interpret ancient texts presenting disability as a punishment of moral wrongdoing, as well as reflecting karma from a previous life. Disability is often positioned as a sign of sin or as dishonor of the family in this context and is often blamed on the parents, mothers in particular. Interestingly, however, disability is also presented as a sign of being more likely to reach spiritual transcendence in some ancient texts, such as in the Chinese Taoist scripture *Chuang-Tzu* (or *Zang-Za*) and often considered as vantage point due to the possible exemption of labor conscription and military services.

Later, in the Goryeo Dynasty (936–1392), there is a record in *Goryeosa* of blind people, shamans, and blind monks as having superstitious power. In *Dongsagangmok* (1778), there is a reference to a guide dog for a blind orphan who managed to survive when the parents died in a disease epidemic. In this period, oriental medicine facilities were developed to provide relief care and shelters to people who suffered from poverty and diseases through Dongseo Daebiwon and Hyeminguk. King In-Jong gave people with disabilities and minors reduction of the punishment, and King Won-Jong required that a person be designated to support each sick person in the village. Disabled people and their caregivers began to be exempted from army service and labor draft (Im An-Su 1993). Seonghyun wrote in *Yongjechongwha* that blind people were hired and educated in Myeongtongsa as prognosticators for royal governance.

In the Chosun Dynasty (1392–1897), blind people continued to receive royal education in prognostication studies (Myeonggwahak), yin and yang studies

(Eumyanghak), and music education in Seowungwan until the fifteenth century. Gwanhyeon Maeong'in refers to royal blind musicians. Royal chronicle shows a record of the official position and promotion given to blind musicians (Chosun Wangjo Sillok, 1431). Specialization of blind people as musicians appeared in the *Analects of Confucius* (when Sagwang made himself blind to sharpen his hearing sensibility and Confucius taught how to accommodate blind musicians). There were legislations and vocational trainings to provide poverty assistance for people with disabilities (especially blind people) to assist their independence (An Byeong Zeup and Jeong Jae Gweon 1983). Some folklores tell that blind people in this period were farmers and teachers in addition to fortune tellers, and the origins of their blindness vary from the ancestor's sin, punishment of heaven, fung sui, violation of taboo, and aging. Rules of decorum, *Sasojeol*, written in the eighteenth century taught that it was unfair and dangerous to call disabled people pejorative names. Military exemption became systematized in the constitutional law *Kyeongguk Daejeon* (1485) for the eligible group of people including minors below age 16 and people with epilepsy; blind in two eyes; who had amputations of more than two limbs; who were mute, deaf, or dwarf; or who had paralysis in more than one limb.

PREMODERN LITERARY REPRESENTATIONS

"Nocheonyeoga" ("Song of an Old Spinster") appeared in *Samseolgi* and introduces a first-person poetic narrative that addresses how the narrator's "deformed" status causes her singleness in the traditional kasa form (Choi 2001). It consists of a narrator's prose preface and epilogue and the spinster's soliloquy and shows that the disabled spinster attempts to address her abilities and effort to get married. In addition, this story demonstrates the normalization of disabled people through marriage by showing that the spinster's disability disappears after the marriage; this transformation also appears in the folk tale "The Half Man." There is another nineteenth-century short reference in "Heungbu Jeon" ("The Tale of Heungbu"), in which a party of blind men came out of a gourd, picking their way with their longsticks, while their sightless orbs were raised toward the unseen heavens and offered them to tell the fortunes of the family. They were employed in order to chastise the brother of Heungbu for his stinginess and greediness and to extort money from him with other groups of people such as shamans, kisaeng, Buddhist priests, a jester, and officials.

In the premodern period, disabled people were called *byeongsin,* which means sick body as an overall term. There were individual terms referring to specific disabilities such as *jeolleumbari* (a lame person); *anzeunbang'i* (a quadriplegic); *jangnim*, *sogyeong*, *chambong,* or *bongsa* (a blind person); *beong'eori* (a mute person); *kwimeogeori* (a deaf person); *kopchu* or *kopsadeung-i* (a person with a humpback) and *kombaepari* (a person with a short arm); and *babo*, *cheonchi*, and *meojeori* (a person with cognitive disability). It seems that there were less terms for cognitive disability in this era, which is read to be due to the emphasis placed on physical ability by the primarily agricultural society. *Byeongsin* is still used today often as a curse word. Bak Hee Byeong traces the usage of this term in premodern literature and concludes that it was used in a descriptive way referring to a sick body but started to have pejorative meaning implying inferiority of the persons in the late eighteenth century. According to Bak, in the late nineteenth century during the Enlightenment period, this word started to be employed as a symbol of the old customs that must be eliminated in order to build a strong nation.

In the Patriotic Enlightenment period (1905–1910), disabled characters were culturally employed to represent Korean identity amid the conflicts between traditional values and customs and modernization. Kyeong-Hee Choi argues that the trope of disability surfaced largely within a sociopolitical perspective that emerged in response to a sense of national crisis. The newspaper *Daehan Mae'il Sinbo* presented the unique genre of a serialized story in 21 installments with two disabled characters, "Sokyeong'gwa Anzeumbang'i Mundap" ("Questions and Answers between a Blind Man and a Quadriplegic") from November 17 to December 13, 1905. The anonymous writer's dialogue style satire subjects able-bodied people and the social situation to the scrutiny of two disabled characters; however, two characters signify old value and custom.

MODERN SPECIAL EDUCATION

Modern special education and institutions for disabled people were first introduced in Korea by the imperial inspectors Sinsayuramdan, sent to Japan to learn modern civilization, and Yu Gil Jun, who traveled Japan and Western countries. Yu Gil Jun introduced asylums in the West and special education facilities in his book *Seoyugyeonmun* (1895). With the arrival of American missionaries, modern special education is believed to have begun in Pyeongyang in 1894 by Rosetta S. Hall when she first started teaching a blind girl. Western missionaries fed imperialism in the form of medical and educational practices without making evident the Christian mission in order to get permission to start their activities. Missionaries especially focused on disabled people and women. Jung Keun Sik (2002) argues that missionaries "rediscovered" lepers in Korea in the process of implanting modern medicine and Protestantism. Jung also argues that missionaries maintained competitive relationships with Japanese colonial management for disabled bodies.

It is possible to see the effects of the Christian origins of the special education system, particularly in its cultural positioning of such education as an act of mercy and because many private special education schools are affiliated with Christian organizations. Hall's first special education class was initially located in the Hospital for the Children and was directed toward teaching blind and deaf girls and also providing medical treatment to women. It developed into the special education school called the School for the Blind and Deaf in 1909. Other residential schools for the blind opened in different areas including the School for Blind Boys established by the Presbyterian missioner Alice Moffett in Pyeongyang (1903) and the Custodial Care Facility in Seoul established by the British missionary Jean Perry in 1914. In 1923, Pak Du Seong established the Korean Braille system, Hunmaengjeong'eum, when Hall's New York style Braille was found insufficient in the application to Korean letters.

Until the late 1960s, special education was mostly aimed at blind, deaf, and cognitively disabled children. Children with mobility impairments started to be educated in special schools in the late 1960s. In 1911, the Japanese colonial government opened Jaesaengwon to provide custodial care to orphans and deaf, blind, and other disabled children. Maeng'abu in Jaesaengwon was the first public school for the disabled and provided vocational training. After decolonization, Maeng'abu changed into the National School for Blind and Deaf. Paramedical vocational trainings such as acupuncture and massage therapy were set up as the curriculum for blind people. The first special education class was installed in a regular elementary school, Dondaemun gongnip gukminhakguo, in 1937 (Kim Byeong Ha 1983).

Special education was moved from the public health domain into the category of education after the Korean War. The war left many people disabled and led to the establishment of the rehabilitation institute and the growth of rehabilitation medicine. Postwar institutions for orphans and disabled children were usually connected in some way to church or charity organizations. The independent South Korean government set various laws and regulations with respect to mandatory education. However, Article 98 of the Education Act exempted certain children from elementary schooling. These children are "those with a disability, developmental delay, imperfection, illness or any other condition making school education impossible." The disability movement would later argue that this exclusion amounted to discrimination against disabled children. In the 1950s, legislation focused on supporting disabled veterans and their families, and in the 1960s, policies for compensating veterans were reinforced. Policies also started focusing on supporting industrial disability compensation insurance.

SURVEYS

In 1961, the first national-level survey of disabled children, *Hankuk Janghae Adong Josa* (Handicapped Children's Survey), was conducted and funded in part by the Pearl Buck Foundation and the U.S. Army. Categories of the survey include "paralytic or palsied, deaf and dumb, deaf only, blind in one eye, hunchback, stuttering, totally blind, hare lip or cleft palate, epileptic, partially blind, psychotic, clubfoot, and racially mixed." It is noteworthy that racially mixed children mostly born between Korean women and U.S. soldiers are included and labeled as "socially handicapped."

The 1966 census of people with disabilities, *Janghaeja josa,* by the Ministry of Health and Social Affairs was based on the 1961 survey and maintained the same categories. "Children of mixed racial parentage" disappears in later statistics and definitions of disability. Later categories appeared to have a more medically influenced definition system including mental retardation, mental disability, physical disability, visual disability, hearing disability, and language disability.

Saenghwalbohobeop (Social Security Law, 1961) allowed the establishment of rehabilitative institutions, and minimum social security was promulgated; 1961 marks an important beginning of governmental control over the disabled population by forwarding institutionalization under the banner of "protection." Mojabogeonbeop (Maternity and Child Health Law, 1973) started allowing abortion in case of "genetic or eugenic causes" or "contagious diseases." The government from this period drove an intensive economic development policy and the welfare of the citizens was left behind.

Statistical surveys on disability people continued in 1962 by the Institute for Economic Planning on injury rates, the 1966 census of disabled people, and the 1968 and 1975 national statistics on disabled people supplemented the population census. The effort to identify the realities and the magnitude of the disabled population was forwarded even more in the 1980s. National surveys of disabled people from 1980 and 1985 show this effort, and after 1990, it became required by law to conduct surveys every five years. The 1980 survey did not include disabled people who lived in the institutions. The term *jae-ga-jang-ae-in* referring to disabled people who reside in the domestic space started to be used in 1991 national statistics as a distinctive category as opposed to institutionalized disabled people, *si-seol-jang-ae-in*. In 1988, the government began to require that all disabled people register to be identified as having a disability to be eligible for benefits. It is common to see disabled people explain their gradients of disability given by this registration procedure and medical examination along with the types of disability. The gradient is entitled based on the degree of limitations, and the first degree of disability refers to the greatest limitations. These gradients reflect the categorization of disability according to functional limitations and its effect on disabled people's identities.

In 1973, there was an attempt to embark the Sterilization Law of Mentally Retarded People (Kim Mi-Ok et al. 2004). In addition, given that the competitive educational system allowed only six years of universal education and required entrance examinations for middle school and high school, which included physical fitness tests, people with post-polio syndrome—who were more frequently included in regular education in spite of its inaccessibility—were often subjected to this specific discrimination until the exemption of physical tests was enacted in 1972. Many people with post-polio syndrome born in the 1950s and 1960s attempted careers in medical or paramedical disciplines, pharmacies, and oriental medicine; this practice was in line with the public belief that those professions were appropriate for some disabled people—mostly those who could walk or had minimal physical disabilities—with less discrimination. However, in the 1970s universities often rejected them due to their disabilities. In 1967, Hanguk Ilbo forwarded a campaign reflecting the social attention to people with post-polio syndrome under the slogan "Let able-bodied people take care of children with polio" (Kim Mi-Ok et al. 2004).

Under the influence of the 1981 International Year of Disabled Persons, the Ministry of Health and Social Affairs developed the Welfare Law for Mentally and Physically Handicapped (Simsinjang'aeja Bokjibeop) under the military government's "Welfare State" propaganda. Paradoxically, the number of institutions grew in this period significantly and custodial care started to be supplemented by medical rehabilitation, therapies, and vocational trainings in the institutions. The Special Education Promotion Law was enacted in 1977. However, less than 20 percent of disabled people benefited from formal education until the early 1990s. The expansion of special education classes from the mid-1970s is also characterized by an effort to exclude students who are identified as below certain standards in school achievement or who are considered as interrupting the education of others. Economic support started to be provided to people with disabilities such as social security pensions and tax exemptions in the 1980s. The legal term for people with disabilities changed to *Jangae'in* from *Jangaeja* in this period.

The International Year of Disabled Persons in 1981 and the declaration of disabled people's human rights and the principles of antidiscrimination provided a background as the disability movement in Korea emerged during the mid-1980s. The discourse of social responsibility of disability rather than individual fault regarding the problems faced by disabled people emerged. The human rights of disabled people became the dominant rhetoric of the disability movement. In 1986, various disability groups such as National Union of Physically Disabled Students became very politically active, aiming at the presidential election the following year. In April 1988, the public protest of disabled people was held in front of the Myeongdong Catholic Church. The disability movement had opposed the hosting of the Paralympics in Seoul because it was believed to cloak the severe violations of the rights of disabled people in their everyday lives and extreme poverty. For instance, sterilization is still practiced on many women with cognitive disabilities as a form of contraception. Depo-Provera has been suggested by medical doctors to parents as a means of removing the menstruation of females with cognitive disabilities. Also, corrupt private institutions that exploit disabled people by using them to raise funds were also the targets of the disability movement. The shared goal of disability organizations was to amend the welfare law to enhance social status of people with disabilities, and to establish legislation for employment and affirmative action in higher education. Activists often viewed disability oppression mainly as a class and poverty issue under the capitalist system that considers disabled body as useless in terms of labor power.

The disability movement celebrated the passage of legislation of the Employment Promotion Act for People with Disabilities in 1990, which requires a 2 percent quota system for eligible workplace. The Accessibility Promotion Law for disabled people, pregnant women, and the elderly enacted in 2000. The amendment of the Welfare of People with Disabilities Act expanded the definition of disability. It includes physical disability, brain neurological impairment, visual impairment, hearing impairment, chronic illnesses, language disability, cognitive disability, mental disability, and developmental disability.

The emergence of the disabled women's movement illustrates the importance of gender in the experience of disability (Kim Eunjung 1999). Disabled women asserted their different needs and experiences from disabled men and nondisabled women during the late 1990s. For instance, sexual violence in institutions and communities especially against women with cognitive disabilities has been a neglected issue from both the women's movement and disability movement. Often staff and volunteer workers were responsible for this violence. Disabled female activists who encountered a male-centered atmosphere within disability movement started to organize feminist groups with an alliance of non-disability-identified women. The disabled women's movement came forward launching cultural celebration of different bodies and pride as women with disabilities and providing challenges and different perspectives on the body, sexuality, beauty, and femininity. There has also been increased awareness among disabled women of the needs of an alliance with marginalized groups such as lesbians and women laborers, and some links have been made with the organizations for women in the sex industry in which the exploitation of disabled women occurs as well. Enhanced penalties for sexual violence when the victim has a physical disability were expanded to include mental and cognitive disability in the Sexual Violence Act.

Access to public transportation has been an important issue in contemporary Korea. Prompted by the deaths of several disabled people while using unsafe devices such as a stair lift in the subway that had been employed as an expedient remedy for accessibility, the disability movement has undertaken militant actions such as hunger strikes, blocking public railroads, and delaying subway trains in 2001. Along with these protests, some organizations called for antidiscrimination legislation.

In spite of the efforts of disability organizations, many people in Korea continue to see assistance for disabled people as an act of kindness or a benefit, rather than an issue of human rights. The disability movement continues to raise important issues such as cultural invisibility, economic hardship, unemployment, insufficient medical services, lack or inaccessibility of education, inaccessible housing and transportation, institutionalization, and human right violations such as

forced sterilization, infanticide, and double suicide of parent and disabled child.

With regard to the North Korean situation of disabled people, very little information is available and only through the testimony of people who escaped or through international human right reports. It has been reported that in the 1960s, there was a massive forced migration of little people in one village in Hamgyeong-namdo by the command of Kim Il Seong. Pyeongyang, the capital of North Korea, has been kept from having disabled people in public by expelling disabled people to rural areas. It is allegedly known that due to city beautification and reproductive control, little people and people with hereditary diseases or physical disabilities are institutionalized. The 1998 North Korean Human Rights White Paper documented that there has been forced sterilization of disabled people practiced (Choi Eui Cheol et al. 1998).

—Eunjung Kim

See also Advocacy; Blind, History of the; Confucius.

Further Readings

An Byeong Zeup and Jeong Jae Gweon. 1983. *Jangaeineui I'hae* (Understanding People with Disabilities). Seoul: Hyeongseol Chulpansa.

An Jeong Bok. 1978. *Dongsagangmok*. Seoul: Gojeongukyeok chongseo.

Bak Hee Byeong. 2003. "'Byeongsin'-ea-eui Siseon" (Gaze toward Disabled People). *Gojeonmunhak Yeongu* 12:309–361.

Choi Eui Cheol et al. 1998. *Bukhan Ingwan Baekseo* (North Korean Human Rights White Paper). Bukhan Ingwan Saenteo.

Choi, Kyeong-Hee. 2001. "Impaired Body as Colonial Trope: Kang Kyong'ae's 'Underground Village.'" *Public Culture* 13(3): 430–458.

Ilyeon. 2002. *Samkuk Yusa* (History of Three Kingdoms). Translated by Kim Won Jung. Seoul: Eulyeumunhwasa.

Im An Su. 1993. "Teuksu Gyoyukeui Jeonsa" (Prehistory of Special Education). Edited by Gyoyukbu (Ministry of Education). Pp. 3–41 in *Teuksugyoyuk Baekseo* (White Book of Special Education). Seoul: Gyoyukbu.

Jung Keun Sik. 2001. "Jangae'eui Saro'un Insikeul Yeuihayeo: Munhwabipyeong-euroseoeui Jangae-ui Sahoesa" (Toward a New Understanding of Disability: Social History of Disability as Cultural Critiques). *Dangdaebipyeong* (Contemporary Criticism) 14:252–278.

———. 2002. "Tong'asia Hansenbyeongsareul Yuihayeo" (For the History of Hansen's Disease in East-Asia). *Bogeongwa Sahoi kwahak* (Public Health and Social Science) 12.

Kim Bu Sik. 1997. *Samguk Sagi* (History of Three Kingdoms). Translated by Yi Jae-Ho. Seoul: Sol.

Kim Byeong Ha. 1983. *Teuksu Gyoyukeui Yeoksajeok I'hai* (Historical Understanding of Special Education). Seoul: Hyeongseol Chulpansa.

Kim Mi-Ok, Kim Yong Deuk, and Yi Seon Wu. 2004. *Jangae'wa Sahoibokji* (Disability and Social Welfare). Seoul: Hakjusa.

Kim, Changyeop et al. 2002. *Naneun Nappeun Jangaein'igosipda: Dayanghan Momeui Pyeongdeunghan Salmeul Kkumkku myeo* (I Want to Be a Bad Disabled Person: Dreaming Equal Lives of Different Bodies). Seoul: Samin.

Kim, Eunjung. 1999. "Jeongsangseong'yeo Dojeonhaneun Yeoseongdeul" (Women Who Challenge Normality). In *Hankuk Yeoseong Ingeon Wundongsa* (The History of Korean Women's Movement), edited by Hankuk Yeoseong'eui Jeonhwa Yeonhap. Seoul: Hanwul Academy.

Korea Child Welfare Committee. 1962. *Handicapped Children's Survey Report.* Seoul: Korea Child Welfare Committee.

Kyeong-guk Daejeon. 1978. Seoul: Iljusa.

Seong Hyun. 1980. *Yongjechonghwa*. Seoul: Daeyangseojeok.

Yu Gil Jun. 1969. *Seoyu Gyeonmun*. Seoul: Kyeong In Munhwasa.

HISTORY OF DISABILITY: MEDICAL CARE IN RENAISSANCE EUROPE

The European Renaissance lasted roughly from 1400 to 1600, its period varying somewhat by region, but it had little effect on medical practice. The two events that influenced medical concepts significantly were the writings of Paracelsus (1493–1541) that opened the possibility of questioning Galenic dogma, and the two anatomical texts of Andreas Vesalius (1514–1564) that corrected some Galenic anatomical beliefs. Health care was practiced according to the 1,300-year-old traditions of Galen (AD 129–ca. 199/216) by a few university-educated physicians who largely served the clerical and secular nobility. There were a larger number of apprenticeship-trained barber surgeons, as well as itinerant quacks, while the peasantry in general cared for themselves. The little information there is regarding care for the chronically disabled pertains mainly to the institutional management of those diagnosed with leprosy. Some towns, Nuremberg, Bavaria, for example, made

a considerable effort to provide financial aid to the unemployable.

This entry presents a sampling of sixteenth-century medical opinions regarding some of the causes and treatments of psychiatric, neurologic, orthopedic, and gastrointestinal conditions that would now be considered potentially disabling. It is based on four books published between 1543 and 1596, each of which had earlier editions. The authors were Giovanni de Vigo, an Italian, who was surgeon to Pope Julius II; Felix Wirtz, a Swiss surgeon; Christoph Wirsung, a German physician; and Hieronymus Brunschwig, a German surgeon. The first three were texts for other practitioners, the last a home medical guide.

The symptoms these writers have provided frequently are inadequate to make a modern diagnosis, being lumped or split into diseases consistent with pathologic concepts of the time but inconsistent with ours. On the other hand, the modern reader may be tempted to make a diagnosis by interpreting an astute observation quite differently from the observer's belief. Pathologic explanations were based almost entirely on the imbalance of or obstruction by humors. A principal pathogenetic diagnosis was "aposteme" or its synonym, "impostume." This may be "hot" or "cold." Specifically, it is an abscess, a localized accumulation of pus. Any superficial swelling might have been so designated, as well as any localized internal symptom. Palpation and color could determine whether a superficial aposteme was hot or cold. Internally, this differentiation appears to have been arbitrarily made by the writer. Surgeons wrote less about humoral pathology than physicians because they dealt more with trauma.

Overall, more space was devoted to "effective cures" than to the description of diseases. The "cures" were largely botanical, and the descriptions were only occasionally accompanied by instructions for their preparation and administration. Actually, few people ever were treated by a physician, and there is no information about how extensively a particular medicine really was employed. Furthermore, a remedy may have appeared in numerous publications because of its reputation rather than its availability. Some circumstances were deemed incurable and some signs of imminent death were specified. However, descriptions of the duration of an illness were consistently lacking.

While medical symptoms had humoral explanations, behavioral peculiarities still were widely attributed to magico-religious causes. Wirsung addressed this unequivocally. In regard to phenomena that we might interpret as preconvulsive auras or hysteria:

> They are not signs of a pinching devil or witches . . . but in truth none other but a natural sickness. [Describing either coma or hysterical rigidity:] the common people [believe that] Satan mingles his wiliness, . . . but this numbness agrees with infirmities of the brain. There are three kinds of "altered disposition": [1.] Delirium, which when associated with fever is called frenzy, is caused by the admixture of phlegm to hot humors. [2.] Mania is caused by hot humors, mainly yellow bile. [3.] Dementia, in which the patient is "wholly out of his right mind" only results from cold humors.
>
> The brains are the uppermost and chiefest of all the inward members of man's body, a place and abode of the understanding, memory and judgment. . . . Hence do also spring all the sinews and spread themselves through the back over all the body, strengthening and conjoining it, making it movable and sensible. (p. 117)

In Wirsung's psychiatric discussion, nerves are "sinews," while in the musculoskeletal section "sinews" clearly are tendons and ligaments. Contrary to "sinews," tendons and ligaments lack sensation. The brain is "insensible," but "this precious and tender part is subject to many accidents which bring very great inconveniences. . . . When sinews become inflamed the brain is affected so that there is mental deterioration."

"Palsy is indeed a swift, grievous and terrible disease which has its offspring in the brain" (p. 134). This comprehensive designation includes a gradually developing lethargy (perhaps encephalitis); tremor or small palsy (perhaps including Parkinson's disease); epilepsy in old men and young children which occurs with or without motion, and is most severe if there is incontinence; sudden loss of motion and sensation without loss of consciousness; and the most severe, apoplexy. This may initially resemble death. The main indicator of its severity is the characteristic of the respiration.

Residuals of a stroke are not described, but "albeit that it were cured, yet it does turn to some other sickness."

Palsy may result from trauma: "If so be that one falls so hard, or is beaten or struck that thereby forthwith he is taken with the Palsy, then it is not to be helped; but if it comes slowly afterwards upon one." There are various medications. Facial palsy is considered separately. "[It] is a convulsion of the mouth and lips to the right or left side, at other times shutting one eye." (This probably includes Bell's palsy.) Lameness has many causes such as apoplexy, the pocks (possibly syphilitic arthropathy), hectic consumption (possibly tuberculous arthropathy), and chronic dislocations. It is associated with withering of limbs and contractures and is mainly treated with poultices.

De Vigo succinctly attributed various functions and dysfunctions to specific parts of the brain. Each of its four parts is controlled by a different humor: blood in the front, phlegm in the rear, bile in the right, melancholy (black bile) in the left. He conceived there to be three ventricles: The largest, in front, receives sensations; the rear houses imagination; and the middle, common sense. An aposteme in the substance of the brain is fatal. A cold aposteme in the middle ventricle causes forgetfulness. Vapors in this region cause vertigo or loss of vision, while obstructive humors cause a palsy. If all ventricles are blocked, the result is apoplexy. "The cure of the palsy . . . I will leave to my masters, the Physicians, for most often it has a physical cause and therefore its cure pertains to them." Nevertheless, since palsy may result from head trauma, some medicines will be described.

Three writers differed in their discussion of joint diseases, while Brunschwig ignored them. According to Wirsung, arthritis is "the pain of the joints, or an inflammation of the joints, which proceeds from within the body, and the Tendons be annoyed, hurt and pained. It is none other than a dispersed Podagra over the whole body." Tophaceous (genuine) gout is incurable. Wirsung and de Vigo agree that hot gout is indicated by erythema and is associated with blood. It has dire and potentially fatal consequences. Cold gout is indicated by pallor and mild discomfort, but it is the most protracted. Its cause is predominantly phlegm. Wirsung defined an intermediate severity caused mainly by the bilious humor, with sharp pain but no erythema. In addition to appearance, cold gout is differentiated from the most severe variety by the quality of the pulse.

Wirtz, like de Vigo, a surgeon, did not concern himself at all with etiology, but discussed trauma that causes drainage of synovial fluid from an injured joint. Normal synovial fluid, he believed, is produced by ligaments and is required for joints to function. It must be differentiated from pus, but in an improperly treated wound may become purulent. Prolonged loss of this fluid from a joint can destroy it, or can fatally drain moisture from the entire body. Such an injury must be treated by drying medicines and proper bandaging. The treatment of fractures by setting, splinting, and binding is primarily the responsibility of surgeons. However, advice is offered in regard to auxiliary medical remedies.

Worm infestation was the one medical ailment for which the pathogen did not require invocation of humors. Its causes included (presumably communal) bathing and eating pork. This suggests that trichinosis was recognized, but since muscle pain is not cited, this is unlikely. The association of worm infestation with children who eat much fruit suggests a belief that maggots in fruit become intestinal worms. Wirsung recognized three varieties: long worms (possibly tapeworms) that reside in the upper intestine, ascarids that reside in the stomach, and small worms "like maggots" (possibly pinworms) that reside in the rectum and cause severe itching. The surest sign of infestation is that the patient excretes in the stool small things resembling gourd kernels. The main symptoms in children are irritability and restless sleep. Adults experience severe abdominal pains. Treatment is necessary because obstruction and, last, painful death may occur. High-lying worms are best treated orally and low-lying worms by enemas or suppositories. The choice of vermifuges is particularly large. Some treatments were biphasic: the first potion to kill the worms, the second to expel them.

Wirsung warned in regard to blood letting: "Good heed is to be taken of the strength and power of the patient, for . . . the veins in the lower parts weaken the body more when they be opened than those in the uppermost parts." Compared to medications and bleeding, bathing was infrequently recommended, probably because this was less effective than bleeding or purging in eliminating noxious matter. One may bathe in seawater or sulfur water. Simply bathing in

lukewarm water after a stroke was permissible, but would be more effective if steeped cooling herbs were added. Baths that opened the pores and caused perspiration were more effective, but not necessarily by immersion in hot water. Alternatively, the patient might be exposed to a vapor created by spreading powdered herbs over hot irons over which scented water is poured. He is then washed with water after he leaves the steam. Since bathing opens the pores, it is potentially hazardous because it permits entry of "infection." In a communal bath "as well the pores of the [plague] infected as of the sound are opened, whereby the venomous vapor of the infected is let forth, and may easily be received of the healthy. . . . If one cannot sweat, heat bricks or other stones very hot and wrap them in a wet cloth. Place them under the feet, armpits, on his sides or between the legs. The vapor will cause the patient to sweat."

Little advice is given for convalescence, and none for the care of the disabled. According to Wirsung, when "sick folks begin to mend, and the disease wears away, the breath begins to be free, the pain to cease, the sleep to come, and have appetite for meat . . . the patient begins to recover" and a light diet is recommended. Above all else for the recovery from all diseases, the patient should relocate, "especially to draw near to mountains or hills where it is dry, far from the sea and stinking lakes." Brunschwig, writing for families rather than colleagues, did not describe signs of convalescence nor diets. He recommends baths "for them that have been long sick or whose bone marrow is corrupt, or whose blood is corrupt and deficient." Various ingredients should be put into as much water as is practical, and "bathe in the morning fasting so long as he can endure it," but do not add more water, presumably because this would dilute the effect of the additives.

Opinions about opium, one of the few botanicals having major pharmacologic effects (henbane, the source of atropine alkaloids, is another), varied. Wirtz was particularly positive. "It calms agitation, eases pain in the head, creates calm sleep, drives off visceral pain, strengthens the brain, stimulates the spirits, brings on happiness and a good appetite. . . . You must first evaluate the patient carefully because dosage depends on the circumstances." His only warning was not to prescribe opium in the presence of pulmonary symptoms. The authors leave the implication that apothecaries had ready access to opium.

Wirsung gave several receipts for oral or topical administration using seeds of the white poppy. Made into an oil, it "assuages all pain, cools, and by anointing the temples sedates and as the hot vapors draw to the head in any hot sickness it assuages throat pain, the heat of agues and nightmares." He stated that poppy seeds are used in almost all receipts for sleep, but if such receipts are not effective "then opium of necessity must be used" to obtain some rest, but not without the counsel of an experienced physician.

De Vigo believed that there are 15 kinds of pain, but three types of treatment: (1) external medicines that evaporate the cause by restoring normal heat; (2) altering the evil complexion (humoral imbalance); and (3) "suppressing the natural heat of the member and taking away its feeling, which is done by medicines of opium." De Vigo appears to have been the most reluctant to use opium. Opiate medicines palliate pain but should be used only "in great necessity." Although the pain will temporarily be suppressed, "it will return with greater vehemence." A purge should be given before administering opium, and opium should not be given to a weak patient. "The malicious nature of opium" is reduced by the addition of other herbs. Whether it may be used orally or only as a plaster is not clear. Among home remedies Brunschwig mentions neither opium or poppy seed concoctions, presumably because of their perceived danger.

A considerable amount of the clinical writings, both of physicians and surgeons, in the sixteenth century described proper behavior toward patients. The following example is unusual in that a surgeon (Wirtz) appears to hold physicians up as superior models:

> A surgeon for many reasons should guard against submitting to drunkenness. Would a complete physician rather be able to diagnose an injury or a wound if he is confused in his head and bereft of proper understanding? How can he examine a wound correctly, view the signs and decide on their significance while he is not sharp, or sharp enough, or sees everything double? And how can he grasp and palpate a fracture properly while his hands tremble and are in other ways clumsy and coarse? (p. 105)

The ideals of healers were the same as those of modern medicine, as Brunschwig indicated: "Let every Physician and Chirurgion follow this rule: to well and exactly know and search for the cause of the disease, so that he the more certainly know how to heal the patient."

—Thomas G. Benedek

See also Galen; Humors, Theory of; Medicine.

Further Readings

Brunschwig, Hieronymus. [1545] 1561. *A Most Excellent and Perfecte Homish Apothecarye. . . .* Translated by Jhon Hollybush. Collen (Cologne, Germany): A. Birckman.

de Vigo, Giovanni. [1520] 1543. *The Most Excellent Works of Chirurgerye. . . .* Translated by Bartholomew Trahern. London: E. Whytchurch.

Stiker, Henri-Jacques. 1999. *A History of Disability.* Translated by William Sayers. Ann Arbor: University of Michigan Press.

Strauss, Gerald. 1976. *Nuremberg in the Sixteenth Century.* Bloomington: Indiana University Press.

Wirsung, Christoph. [1568] 1598. *A Generall Practice of Physicke. . . .* Translated by Jacob Mosan. London: E. Bollifant.

Wirtz (or Wirz), Felix. 1596. *Practica der Wundartzney. . . .* Translation by Thomas G. Benedek. Basel, Switzerland: S. Henricpetri.

HISTORY OF DISABILITY: MEDIEVAL WEST

There is a medieval nursery rhyme,

> I saw three headless [people] play at a ball,
> A handless man served them all;
> While three mouthless men lay and laughed,
> Three legless [men] away them drew.

The fact that children might learn of disability in their crib and at play suggests how profoundly quotidian was medieval disability. However, disabilities in the Middle Ages are only now beginning to be investigated as a group. For the medieval child or adult, aggregating experiences and conditions, which we would consider disabling, would have been peculiar.

The period of the Middle Ages in the West, conventionally is held to run from roughly 500 to 1500 CE, although the nature of the medieval world shifts dramatically from the south of Europe, which experienced the Renaissance earlier, to the north of Europe from the extreme west to the extreme east. In general, the Middle Ages embraced social and intellectual changes from the fall of the Roman Empire to the rebirth of antique culture in the Renaissance and the origins of the nation-state.

Our view of disability during this period is still highly fractured. This entry presents an overview of several of the fragments. Ideas about and experiences of disability during the Middle Ages varied dramatically. The conceptualization and experience of disability by a serf with a lower-extremity paralysis in twelfth-century England was notably different from that of a fifteenth-century Italian duke with a speech impediment or an eleventh-century German nun with depression. In addition, the social expectations of medieval people were rather different from those today in the West. As a consequence, the following survey will be at best imagistic.

Medieval disability originated from many directions. Given that, some studies report, nearly 50 percent of children died before age 21, death was a fiercely regular occurrence in the home and community. Nearly a third of the inhabitants of a York cemetery were children during the Middle Ages. Parasites were frequent, suggested by archeological studies of cesspits. Accidents were a regular occurrence. Hunger and starvation were probably common in the full life of a medieval rural person; conditions of nutritional deficiency, such as rickets, were not uncommon. Still, infectious diseases were probably the most common cause of death. But death was only an extreme.

Owing to variable survival of sources, it is difficult to generate any kind of accurate epidemiologic statistics of disabling conditions from the Middle Ages. We know that tuberculosis, plague, and leprosy, among others, were infectious diseases, which could leave survivors with long-term disabilities as attested to by both archeological and textual evidence. Data derived from miracle records at the shrines of saints suggest a range of symptomatic/diagnostic conditions with disabling features, including blindness, deafness, mutism, a variety of paralyses, and leprosy. While we have only the barest sense of epidemiology for medieval disabling conditions, we can gather that disabilities were common enough both to provoke notice and yet often

to deny total "otherness" by the degree of accommodation and integration invoked by society at large.

The experience of disabilities by medieval people is only now beginning to be elucidated. Biographically, we know any number of figures with disabling conditions. Henry the Minstrel, fifteenth-century chronicler of William Wallace of Scotland, was known as "Blind Henry," though not all scholars agree to the veracity of that epithet. Some famous figures with disabling conditions, like Hermann von Reichenau (also known as Hermann "the Lame" because of a congenital lower-extremity impairment), were born into the nobility and went on to positions of great intellectual productivity denied to the poorest medieval peasant. Hermann was educated at an abbey and became a well-known chronicler, poet, musician, and mathematical astronomer. Teresa de Cartagena, who became deaf as a child in the fifteenth century, 20 years later, as a nun, wrote *Arboleda de los enfermos* (*Grove of the Infirm*), possible only because her family was wealthy enough to have her tutored. King Baldwin IV of Jerusalem was a child when he contracted leprosy, and yet he continued to fight in crusades before his death at around age 24. Another leper, this one very poor, lived in Venice and spent much of his life begging on the fourteenth-century streets. The Old Norse *Landnámabók* refers to a certain Bjargey Valbrandsdóttir, wife of Hávarðr halti ("the lame"). A famous woman with a potentially disabling condition, the mystic Hildegard of Bingen had visions, which have been postulated to be severe migraine headaches with scotoma. Rather than impairing her vision while toiling in the fields, these images became a religious experience, which transformed both her individual relationship to God and also those influenced by her writings. On the other hand, King Sancho the Fat (r. 955–958 and 958–960) of León in the eleventh century was driven from his throne for severe obesity. It was not until after he was successfully treated by the Jewish physician Hasdai ibn Shaprut, perhaps with opiates, that he was able to return to the thrown. As well as class, religion, race, and gender certainly altered the experience of disability.

The world around the medieval person was potentially disabling at all times. In one example, a medieval fisherman netting a torpedo fish became paralyzed in his upper extremities. The often-analyzed Hippocratic *Aphorisms* explained how winds from the south make one deaf. In addition to the vagaries of nature, accident, happenstance, and bad fortune were clearly agents of disabling etiology. More frequently, etiology was attributed to witchcraft or evil magic, as when King Alfred the Great was enjoying his wedding night and was attacked by a severe pain, which some attributed to witchcraft. But religious explanations were widespread and promulgated by ecclesiastical doctrine. As a consequence, the role of relics and saints' shrines in miraculous cures of disabling conditions is undeniable (see below).

Increasingly, into the thirteenth and fourteenth centuries, a process of "medicalization" provided another explanatory system. This was hardly to the extent of the medicalization of the nineteenth and twentieth centuries, but still significant. For many disabling conditions, a common medieval medical explanation was framed in terms of humoral theory. Having been propagated by Hippocrates and Galen in antiquity, the four humors were initially understood incompletely in the early Middle Ages prior to being recovered in the wave of translations from Greek and Arabic into Latin in the eleventh through fourteenth centuries. Thus, elite theories about disabilities may be divided in a bimodal fashion—the early medieval and the late medieval conceptualization. Characteristic of the early medieval is a vague understanding of the four humors; characteristic of the late medieval is a highly complex understanding. Where medical experts in antiquity were greatly interested in prognosis, the role of the late medieval physician increasingly fell to diagnosing conditions, and indeed in officially certifying them. That certification could become a tool for market competition. One thirteenth-century university physician, Jean de Saint-Amand, described a drug he prescribed for its special property of attracting phlegm from the head if scrubbed on the palate. In this way, he treated a patient who according to common wisdom was essentially dead because of her inability to talk and listlessness. Using the drug, he restored her ability to talk long enough for her to give her final confession then died. In this example, Jean not only displayed his ability to alter humors, relieve a disability, and assist a patient in her crucial religious function, but he also distinguished his refined knowledge

from that of the untutored. Jean also treated a patient with another drug to forestall leprosy; the therapy worked for three years, when the patient contracted the condition. In stories like these, elite physicians used the care, treatment, and prevention of disabilities to their marketplace advantage. As the physicians became more influential in social circles, surmounting surgeons, apothecaries, and barbers in their medical roles, the "lesser" disciplines tried to emulate the physicians and disabilities could play a role. Thus, Lanfranco of Milan, a thirteenth-century surgeon in Paris, treated a patient only after a lay healer admitted his ignorance of the condition.

For disabling conditions such as leprosy, medicalization was an important shift. As a consequence, the rise of institutions, previously devoted to charitable care like leprosaria, increasingly allowed for population-wide "social control" of some of those with disabilities. Disabilities could offer complications to the elite theoretician. At times, the presence of a disabling condition, such as epilepsy, could incite caution for doctors in the drugs they prescribed. Thus, Avicenna, an eleventh-century Arabic physician widely studied in Latin translations in Europe, noted that celery was contraindicated in epileptics as it could cause status epilepticus. On the other hand, one condition could induce another disabling one. According to Taddeo Alderotti, a thirteenth-century Bolognese physician, diarrhea could induce stuttering or stammering. Similarly, chronic, untreatable conditions of a disabling nature could be cause to withhold certain kinds of charity care. Thus, the Hospital of St. John the Baptist in Oxford did not accept people with those conditions, nor did it accept those with epilepsy or women pregnant out of wedlock. Simply taking mercury could cause paralysis in everyone. Occasionally, medical and technical interventions for disabilities have had long-standing consequences. The invention of eyeglasses in the fourteenth century, for example, has accommodated presbyopia ever since.

In addition to elite theories of disabling conditions, religious explanations helped people with disabilities and those caring for them to understand their conditions. Thus, the ill will of the devil could cause a crippling pain, the loss of faith in a patron saint could cause the reoccurrence of blindness, or unrepentant breakage of a Commandment could cause mania. Not surprisingly, the Catholic Church's role in ministering to the disabled was considerable; that role was even represented in religious symbology. Hence, the bishop's crosier was designed to indicate a support for the disabled and infirm. The Bible and its multiple exegeses are rife with metaphoric descriptions of intellectual and spiritual blindness and deafness, many of which were then cured through divine intervention.

The twelfth-century monk and pioneering biographer Guibert de Nogent tells how his mother became paralyzed after a devil's visitation. Even the divine could have disabilities. Angels, for example, were considered by some medieval theologians to have a kind of disability in lacking the bodies to experience sensory passions; they could only experience intellectual passions (cognition). Yet the divine was, in Bible and sermon, frequently the source of healing for disabilities. Appeals to saints for miracle-based cures were commonplace. In this role, religious healing was an economic competitor of lay medical "cures." Even those perceived as holy by laypeople, such as the flagellants during the Black Death, could generate healing imagery. So the blood of flagellants was sometimes collected by women on the street side and applied to the eyes for preventing or curing blindness.

At other times, the two certified systems of healing—religion and medicine—could team up to stave off the ministrations of the magical healer, of whom both the doctor and the priest disapproved. Such magical healing was based on "superstitious" notions of causation ranging from the evil eye to fear of a particular color to belief in malignant magical elves or dwarfs who shot arrows of disease into a person. Consequent cures ranged from application of folk remedies containing various plant, mineral, and animal products to the verbal chant of Old Norse poetry. These latter were considered magical by the Christian theologian, but for the pre-Christianized Icelander, they hearkened to his own polytheism, including Odin the All-father, who had one eye, and Völundr, the Norse god of smiths, who was lame. The Old Scandinavian *Vǫlundarkviða* and *Þiðrikssaga* retell the story of the elf Vǫlundr, who was hamstrung by his enemy, King Niðuðr, and forced to become the royal smith. Similarly functional in literature were

dwarfs who played critical roles in plots from the *Niebelungelied* to *Tristan and Iseult*. Disability in religion and magic was all in the eye of the beholder.

Certainly, people with disabilities themselves could be identified as etiologic agents of disease, enhancing their nature as "others." Thus, with the advent of the Black Death in 1347–1348, some lay people targeted "cripples" or "the mutilated poor" as the source of the epidemic, along with Jews and the wealthy. The cause of such fear was clearly a sense of otherness. Disability was as ostracizing a feature of the life of a medieval commoner as non-Christian religion or elite status. In this latter translation, we can detect an inherent association between poverty and disability. Disabilities could also be part of curses—"may you go blind," "damn your eyes"—in the Middle Ages and beyond, furthering the negative imagery of disabilities. Similarly, as charity provoked almsgiving some beggars in thirteenth-century Paris disguised themselves as disabled people to generate more alms. When they were discovered, a more general backlash against all beggars ensued.

But the topos of disability, feigned or otherwise, had less sinister meanings and more nuanced as well. The residents of Norwich, for example, feigned madness when King John was to visit their town in order to avoid having to pay to feed his retainers; disability could have its uses. The topos of concealing body-type could be important for recognition of the ideal. In one version of the lay of *Tristan and Iseult*, Tristan feebly disguises himself, and Iseult says he is not her lover, Tristan, because he is not "tall and straight-backed." Disability in medieval literature could be used as comedic counterpoint, as moralistic trope or as social wedge to address liminal issues such as homosexuality, as in the thirteenth-century French play *The Boy and the Blind Man*.

Medieval disabilities, through the lens of concepts such as charity, transformed the medieval landscape, literally and figuratively. Thus, institutions, notably the Catholic Church but also municipal and early state governments, played a significant part in resource allocation for people with disabilities who were unable to achieve social independence. Charity was a critical religious guide for medieval disability. Given the depredations of war, disease, natural disasters and climatic shifts, economic cycles, crime, old age, large but young families, and accidents, many medieval people, more often among the poor but not infrequently among the wealthy, experienced periods of deprivation, which threatened their life and health. It is noteworthy that the relationship between the "haves" and the "have-nots" in the Middle Ages was complex. While the poor lacked terrestrial power, they, as recipients of alms, held the metaphorical power to obviate sins. Poverty was not seen as an alleviable condition, but a state of permanence, betokened in part by the plethora of the poor, especially in the urban setting. The Biblical parable of the rich man feasting while his dog licked the wounds of beggars at his door, the two then reversing benefits in heaven, suggested the dangers of wealth, which could be mitigated by the gratitude and prayers of recipient poor. The tension in the Church between its rhetoric of poverty and its evident wealth, notably among its "princes," sparked internal and external criticism, reform and backlash, especially in the thirteenth century with the Franciscan order's creation. But with the high-wage labor shortages of the later fifteenth century, hostility to the poor rose, even among Church leaders.

Medieval Christian charity took many forms—for example, almshouses, hospitals, clothes, food, money, and goods dispensed at church doors, even temporary employment. Some 20,000 leper hospitals were established by 1300 throughout Europe dotting the spaces circumscribed by town walls and notions of "us/them." Yet in any one locale, that charity was probably insufficient to meet the needs of a populace of poverty, including the disabled. Even in a time of decreased population, after the Black Death, relative plenty could not do away with the permanence of poverty and the need for charity.

Tensions also existed in the characterization of the poor—significantly in anticipation of the early modern differentiation of the deserving and undeserving poor. Disability played some role in these assignations, as at times, lepers were castigated with moral inequity, often of a hypersexual variety. On the other hand, lepers and those unable to work because of physical incapacity (e.g., old age or physical disability) were often the specific target of open charity. To that end, the poor were sometimes impugned with allegations of cutting off one of their children's extremities or blinding them in hopes of attracting

more charity. In the end, the repulsive forces inherent in notions of difference were offset by the attractive needs of living in fairly small communities. For example, medieval laws, which governed cognitive disabilities, changed over time from the comparatively tolerant to the more invasive, yet they frequently allocated full rights of land ownership. The poor disabled could be pitied, reviled, reared, and acknowledged as part of the community. The heavenly world overlapped the terrestrial in a myriad of ways.

The Roman Catholic Church, both materially and doctrinally, had an enormous role in shaping the experience of disabilities in the Middle Ages. From pulpits, parishioners heard of the laudable need for charitable works. But they also heard stories of miraculous cures of the disabled by Jesus. Certain conditions, such as leprosy, increasingly were castigated by the Church as being the result of sin, thus accentuating social stigmatization. And the doctrinal relationship between medieval Christians and their body changed markedly from the early to the late Middle Ages. Notably, the rise of mimicry of Jesus' suffering ennobled pain as a venue toward redemption. Throughout the Middle Ages, the symbolic power of Jesus' body motivated creation and recreation of the import of the physical body. In the early Middle Ages the *body* was most closely associated with the peasant and manual labor. In the later Middle Ages it became an emblem of contest between the individual and the community and an object of redemption. Thus, painful conditions or pain in general, previously perhaps more socially disabling, became badges of Christian virtue to be sought out and embraced. Similarly, the rise of the Franciscan order in the early thirteenth century and new modes of charity altered the potential reaction of the disabled beggar and the almsgiver.

Documentation of a wide range of conditions, which we associate with "disabilities," exists from throughout the Middle Ages. Differentiation into "physical" and "mental" is anachronistic and does not convey the complex intermingling of the medieval mind, body, and soul. Hrabanus (Rabunus) Maurus, a ninth-century monk, for example, observed that "disabilities/infirmities of the flesh mirror disabilities of the mind, and earthly ointments represent the soothing agents of heavenly grace" (Maurus 1864). Examples of paralyses, amputations, scolioses, seizures, madness, blindness, deafness, developmental disabilities, birth defects, chronic infection, and many others abound from this time period. Collectively, it is difficult to identify words that one may clearly translate as the modern, nuanced *disability*, from medieval Latin, French, German, Italian, English, Spanish, Catalan, and the other tongues of the Middle Ages. Thus, modern scholars must be cautious in generalizing and adducing synthetic conclusions from medieval statements.

> Henry Hotspurs hath a halt,
> And he is falling lame.
> Francis Physician for that fault
> Swear[s] he was not to blame.

This medieval children's rhyme reminds us that the signification of disabilities in the Middle Ages was manifold. At once founded in the historically objective and in the culturally inflected, medieval disabilities are redolent for the modern reader and worthy of much more investigation.

—Walton O. Schalick III

See also Teresa de Cartagena; Galen; Hippocrates; Humors, Theory of.

Further Readings

Bragg, Lois. 1997. "From the Mute God to the Lesser God: Disability in Medieval Celtic and Old Norse Literature." *Disability & Society* 12:165–177.

Dyer, Christopher. 1990. *Standards of Living in the Later Middle Ages: Social Change in England, c. 1200–1520*. Cambridge, UK: Cambridge University Press.

Covey, Herbert C. 1998. *Social Perceptions of People with Disabilities in History.* Springfield, IL: Charles C Thomas.

Finucane, Ronald C. 1997. *The Rescue of the Innocents: Endangered Children in Medieval Miracles*. New York: St. Martin's.

Gomez, Ricardo Hernandez. 1965. "Evolucion historica del concepto de discapacitdo ante la sociedad" *Asclepio* 17:261–271.

Karenberg, Axel and Irmgard Hort. 1998. "Medieval Descriptions and Doctrines of Stroke: Preliminary Analysis of Select Sources. Parts I, II, and III." *Journal of the History of Neurosciences* 7:162–200.

Maurus, Rabunus. 1864. "De universo." Pp. 501-502 in *Patrologiae cursus completus . . . latina,* edited by J.-P. Migne. T. 111. Paris: Garnier.

Schalick, Walton O., III. 2003. "To Market, to Market: The Theory and Practice of Opiates in the Middle Ages." Pp. 5–20 in *Opioids and Pain Relief: A Historical Perspective*, edited by M. Meldrum, Vol. 25. Seattle, WA: IASP Press.

Siraisi, Nancy G. 1990. *Medieval & Early Renaissance Medicine: An Introduction to Knowledge and Practice*. Chicago: University of Chicago Press.

Skinner, Patricia. 1997. *Health and Medicine in Early Medieval Southern Italy*. Leiden, the Netherlands, and New York: E. J. Brill.

Stiker, Henri-Jacques. 2000. *A History of Disability*. Translated by William Sayers. Ann Arbor: University of Michigan Press.

Turner, Wendy. 2000. "'Afflicted with Insanity': The Care and Custody of the Feeble Minded in Late Medieval England." Ph.D. dissertation, Department of History, University of California, Los Angeles.

HISTORY OF DISABILITY: PLEISTOCENE PERIOD

THE ANTIQUITY OF HUMAN DISABILITY

Assessments of the presence, severity, and incidence of forms of disability among early human societies can provide us with indications of the degrees to which afflicted individuals were able to survive under conditions vastly less conducive to recovery and persistence than is normally found in modern, technologically aided human societies. In particular, it is helpful to evaluate the presence of significant disabilities among Pleistocene human populations since it is during this time period that the underlying biological pattern characterizing all of living humanity appeared. This period, from approximately 1.8 million years ago to about 10,000 years ago, began with the emergence of the genus *Homo,* saw its spread throughout the Old World and eventually into the Pacific and Americas, and concluded with the emergence of humans of modern form about 100,000 years ago and the beginnings of sedentary life by 10,000 years ago.

Any evaluation of human disabilities in the Pleistocene era must acknowledge the nature of the evidence and the series of steps necessary for the identification and interpretation of possible impairments of normal function. The evidence consists entirely of the incomplete skeletal and dental remains of extinct human groups. Until people began burying their dead about 100,000 years ago, it consists principally of cephalic portions of the calcified tissue. In addition, sample sizes remain small, geographically scattered, and spread out over thousands of years, making calculations of incidence levels largely meaningless.

The interpretive issues involve a series of logical steps. First, the observed skeletal/dental anatomy has to be identified as abnormal and not confused with expected normal ranges of variation, bearing in mind that there have been significant changes in human anatomy during the past 1.8 million years. Second, accurate diagnoses must be made of the observable lesions or abnormalities in overall skeletal morphology. Third, the lesions have to be integrated into a more general diagnosis of the individual's abnormalities. In so doing, the scholar must consider that the observed alterations may be linked or independent and may have occurred synchronously or sequentially. Often, given the limitations of fossilized remains, it may only be possible to narrow the diagnosis to a set of possible etiologies, rather than specifying a specific cause for the lesions. Fourth, depending on the diagnosis, the presence of significant soft tissue abnormalities must be assessed, ones that can only be inferred from the skeletal biology. Fifth, a determination has to be made whether the diagnosis would imply any loss of function. Sixth, if some reduction of function is implied, the individual's disability must be evaluated in terms of whether it would have affected the survivability of the individual in its social, technological, and environmental context. However, since survival of the condition is required for the formation of skeletal lesions or abnormalities, all known cases are by definition cases of some degree of survival. A methodological consequence is that we have little or no data on socio-biomedically lethal disabilities, only the chronic ones.

In addition to the compounding levels of inference from lesion identification to survivability, one must realize that all of these Pleistocene human populations were hunters and gatherers, living exclusively from foraged resources naturally occurring on the landscape. For most of the Pleistocene, until less than 30,000 years ago, population density was extremely low, and the associated social integration behaviors

were strictly local. Fundamental aspects of technology, such as effective weaponry and fire, were established only about 400,000 years ago, and mobility on the landscape was essential. In fact, before 10,000 years ago, there are no known cases of lesions of the lower limbs that would have impaired walking, and there are several cases of individuals persisting in walking despite severe osteoarthritis and less disabling injuries to the legs and feet.

Despite these limitations of the human fossil record and the inferential process, there are numerous identified cases of lesions among Pleistocene humans. Most are relatively minor traumatic and degenerative lesions, and only a few would be classified as disabilities. The extent to which each one would have affected survivability without significant social assistance remains debated.

The oldest known case is from Salé, Morocco, from 400,000 years ago. It consists of a partial cranium of a young adult with reduced and altered development of the nuchal plane, which has been interpreted as the result of congenital torticollis. It is followed about 200,000 years ago by an isolated adult mandible from Aubesier, France, with pervasive periodontal inflammation, apical abscesses, and almost complete tooth loss, requiring complete processing of any ingested food outside of the mouth. Slightly younger, at 150,000 years ago, is the isolated mature cranium from Singa, Sudan, with unilateral labyrinthine ossification, which would have seriously impaired the individual's equilibrium.

One Neanderthal specimen, from Shanidar Cave, Iraq, dated to about 50,000 years ago, survived multiple, possibly related, lesions. The more serious of them include a lateral facial fracture disrupting the functioning of the left eye and multiple fractures, atrophy, infection, and possible amputation at the elbow of the right arm, leaving little more than a withered stump. The same individual had sufficient leg and foot injuries to induce an abnormal gait that resulted in bowing of the left leg. He also represents the oldest known case of DISH (diffuse idiopathic skeletal hyperostosis). To this individual could be added two other Neanderthals, one from Shanidar that survived a unilateral pneumothorax for at least several weeks and another from the original Neanderthal site in Germany that had a fractured elbow with sufficient deformity to reduce elbow flexion and produce atrophy of the arm bones.

Among early modern humans, there is a child from Qafzeh, Israel, who lived to about three years of age with pronounced hydrocephaly, resulting in both characteristic cranial changes and limb alterations. A more recent individual from Dolní Vestonice, Czech Republic, survived to young adulthood with an undetermined congenital dysplasia, which produced asymmetrical shortening of the legs, abnormal bowing of the right thigh and upper arm, and secondary changes of the left arm and facial skeleton. Yet, this latter individual exhibits a level of limb strength similar to those of other humans from the same time period, implying that he kept up with and assisted his highly mobile social group.

These few examples are those for which there is sufficient confidence in the identification and diagnosis of the individual lesions and deformities and are likely to have caused more than short-term reduction of some vital function (bearing in mind that what was "vital" in the Pleistocene need not be essential for survival in current sedentary and technologically aided societies). What remains uncertain is the degree to which any one of these sets of abnormalities would have directly affected the survivability of the individuals in their prehistoric social contexts, requiring the prolonged direct assistance of other members of the social group. However, it is probably not coincidental that these conditions first appear in the human fossil record about the time (400,000 years ago) that there are significant improvements in weaponry, fire control, and other aspects of human behavior, all of which would have facilitated survival in harsh environments.

—Erik Trinkaus

See also Archaeology.

Further Readings

Lebel, S. and E. Trinkaus. 2002. "Middle Pleistocene Human Remains from the Bau de l'Aubesier." *Journal of Human Evolution* 43:659–85.

Spoor, F., C. B. Stringer, and F. Zonneveld. 1998. "Rare Temporal Bone Pathology of the *Singa calvaria* from Sudan." *American Journal of Physical Anthropology* 107:41–50.

Tillier, A. M., B. Arensburg, H. Duday, and B. Vandermeersch. 2001. "An Early Case of Hydrocephalus: The Middle

Paleolithic Qafzeh 12 Child (Israel)." *American Journal of Physical Anthropology* 114:166–70.

Trinkaus, E. 1983. *The Shanidar Neanderthals.* New York: Academic Press.

Trinkaus, E., V. Formicola, J. Svoboda, S. W. Hillson, and T. W. Holliday. 2001. "Dolní Vestonice 15: Pathology and Persistence in the Pavlovian." *Journal of Archaeological Science* 28:1291–1308.

HIV/AIDS

As we enter the third decade of the AIDS pandemic, its global impact is highly evident. Since the first reported cases of AIDS in the United States in June 1981, the disease has crossed all geographic boundaries; numerous countries in Africa and Asia already confront serious decimation of their populations while other global regions and countries are on the edge of emergent crises. The statistics are staggering. The World Health Organization (WHO) 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 claimed an estimated 3 million lives, and almost 5 million people acquired HIV, 700,000 of them children. Over the next decade, the only prognosis for those without effective treatment will be to endure its complications and die.

THE VIROLOGY OF HIV/AIDS

The human immunodeficiency virus (HIV) mediates its effect in the human body by interfering with cell-mediated immunity that eventually destroys the entire immune system and compromises all major organ systems. Without successful medical treatment, most people infected with HIV go on to develop the most advanced stage of the disease known as acquired immunodeficiency syndrome (AIDS). In addition to provoking immunodeficiency in the body, HIV also activates autoimmunity and nervous system dysfunction. AIDS manifests itself clinically as a spectrum of diseases that cause both physical and mental disability in those affected. People living with the virus can experience a wide variety of symptoms due to opportunistic infections, malignancies, and wasting.

Early HIV symptoms, which typically occur between 1 and 4 weeks following exposure, often mimic flu or mononucleosis-like symptoms. These symptoms include headache, loss of appetite, night sweating, a sore throat, and swelling of the lymph nodes. A skin rash may develop on the chest, abdomen, and/or back. HIV seroconversion, which refers to the development of detectable HIV antibodies in the blood, is most likely to take place at 3 to 6 weeks following exposure, although it can occur at any point in the following six months.

The incubation period for AIDS refers to the interval that begins with HIV infection and ends when the person exhibits the first signs of developing AIDS, as specified by a set of clinical criteria. In young to middle-age adults, the median incubation period is about 10 years, although the interval appears to be lengthening or even forestalled as new and more effective treatment options become available. While this incubation period tends to be shorter in children and individuals over age 50, it does not appear to vary significantly by gender or race. A host of cofactors are believed to play a role in disease progression, including genetic factors, age, gender, route of HIV infection, drug use, smoking, nutrition, and the co-occurrence of other infectious diseases. Without treatment, the period from AIDS diagnosis to death, known as AIDS survival time, ranges from 1 to 20 years with a median interval of 10 years.

DISEASE CLASSIFICATION AND STAGING

A variety of classification and staging systems have been proposed for understanding and mapping the full progression of the disease from HIV infection to the advanced stages of AIDS and possible death. Most use some combination of the CD4 lymphocyte count and symptoms. In 1993, the Centers for Disease Control and Prevention (CDC) made the CD4 lymphocyte count central to its classification system for HIV disease. Since then, CDC expanded its AIDS surveillance case definition to include all HIV-infected persons who have < 200 CD4+ T-lymphocytes/microL, or a CD4+ T-lymphocyte percentage of total lymphocytes of < 14, as well as the addition of pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer to

the 23 clinical conditions in the AIDS surveillance case definition published in 1987.

The progression of HIV immunosuppression generally correlates with CD4 lymphocyte count or percentage; thus, CD4 lymphocyte count is currently the principal laboratory test used in clinical management of HIV infection, including antiviral therapy as well as prophylaxis of opportunistic infections. The combination of CD4 lymphocyte count, viral load (quantity of HIV detected in the peripheral blood), and clinical symptoms is likely to provide the basis for future attempts at staging HIV disease.

Counting subsets of lymphocytes is often impossible in developing countries because the needed technology is not available or is too expensive for routine use. As an alternative, the World Health Organization (WHO) Global Programme on AIDS proposes the following simplified staging system that does not rely on lymphocytes testing, and its diagnostic criteria are clinically based and sufficiently flexible for use in different parts of the world:

Early HIV disease (Stages 1 to 3). In these stages, individuals may develop opportunistic infections such as tuberculosis, malaria, pneumococcal pneumonia, shingles (herpes zoster), staphylococcal skin infections, and septicemia. These diseases can also occur in individuals with normal immune systems. With HIV, these diseases occur at much higher rates.

Advanced HIV disease (Stage 4, equivalent to AIDS). This stage is characterized by the development of opportunistic infections such as pneumocystis and toxoplasmosis. In addition, the diseases listed under Stages 1–3 are present in atypical ways, for example, tuberculosis disseminated from the lung or recurrence of nontyphi salmonella septicemia. Malignancies such as Kaposi's sarcoma and other cancers may also arise.

MODES OF TRANSMISSION AND RISK FACTORS

The principal modes of transmission for HIV are through sexual contact, introduction of the virus into the blood stream by blood or blood products, and through vertical transmission from mother to infant either before and during childbirth or via breastfeeding. Body fluids, which have been scientifically proven to transmit HIV, include blood, semen, vaginal fluid, and breast milk. Other suspected but unproven possibilities include cerebrospinal fluid, synovial fluid, and amniotic fluid. Extensive research documents that HIV is not transmitted through casual contact such as handshaking or insect bites. Globally, the leading cause of HIV infection is through sexual contact.

The first AIDS cases reported in June 1981 in the United States were among younger men who had sex with men. Later, it became known that people of both sexes and all age groups are susceptible to HIV and AIDS. Groups in the United States who are particularly vulnerable to infection are men who have sex with men, injection drug users and their sexual partners, members of racial/ethnic minorities, and an increasing number of women. The following are the most common modes of transmission in the United States:

unprotected sexual contact, particularly with multiple partners;

use of HIV-contaminated equipment among injection drug users, including needles, cotton, cookers, and water used in drug administration; and

needle stick injuries among health care professionals.

Although once a serious problem, the risk of transmission though blood transfusion from infected blood and blood products has decreased significantly since the mid-1980s after legal enactment of national blood-screening requirements. The United States also has seen dramatic reductions, since the mid-1990s, in mother-to-child transmission due to widespread promotion of routine HIV counseling and voluntarily testing of pregnant women for HIV, and as the result of offering antiretroviral therapy to infected women during pregnancy and delivery and for infants after birth.

HIV PREVENTION STRATEGIES

Without a vaccine available to protect against HIV, the major focus of preventive efforts at the individual, dyadic, and social network levels are designed to minimize the transmission of HIV through unsafe sexual practices and the sharing of contaminated injection

drug equipment. A number of methods have been developed and scientifically shown effective in reducing risky behavior when applied under specific conditions. These methods include indigenous leader and peer outreach strategies, prevention case management, needle hygiene and syringe distribution programs, social support groups organized around risk reduction, and Internet interventions. At the health services level, prevention efforts focus primarily on promoting HIV counseling and testing, offering therapy for HIV-positive pregnant women and their infants, continued stringent screening of all products used medically for blood transfusions, and appropriate protection of health care workers.

The process of "partner notification" is gaining increasing attention for preventing the spread of infection from patients with diagnosed HIV (index patients) to healthy persons. Through this process, sex and needle partners of index patients are informed of their possible exposure to infection and the need for medical evaluation. There are two basic mechanisms of partner notification: provider referral and patient referral. *Provider referral* is a confidential process in which public health personnel or other appropriate counselors request names and identifying information about sex partners from the index patient to notify those partners of their exposure. *Patient referral* is a process by which partners are notified by index patients on their own without assistance. The goal of partner notification is to help ensure that individuals who are HIV seronegative remain so and to identify and bring those individuals who have unknowingly contracted the virus into the health care system for early treatment and care.

HIV/AIDS DIAGNOSIS

Early detection of HIV infection is critical to instituting timely and effective therapeutic regimens. Since the first HIV antibody tests became commercially available in 1985, HIV diagnostic technology has progressed remarkably. The most common types of screening and confirmatory assays are the following:

Enzyme-linked immunosorbent assays (ELISAs). These are the most widely used type of assays; they have high sensitivity and specificity and are able to detect HIV-1/HIV-2 and HIV variants. ELISAs are especially useful for screening large numbers of specimens needed for surveillance and centralized blood transfusion services. The most recent "combination assays" combine p24 antigen ELISAs with traditional antibody ELISAs, allowing for the simultaneous detection of HIV antigen and antibodies using a single test.

Simple/rapid assays. These are the high-quality, easy-to-use HIV tests, which require little or no additional equipment. The tests are designed for use with individual or a limited number of samples. These tests are increasingly being used in voluntary counseling and testing centers and antenatal clinics where making same-day results available can result in timely treatment interventions.

Confirmatory assays. These assays are used to confirm whether specimens found reactive with a particular screening test contain antibodies specific to HIV. The most commonly used confirmatory test is the Western Blot (WB). However, it is a very expensive test and produces large numbers of indeterminate results. Similar confirmatory assays, generically called Line immuno-assays (LIAs), have been developed, which in general produce fewer indeterminate results as compared to WB, although they are equally expensive. There is evidence that combinations of ELISAs or simple/rapid assays can provide results as reliable as the WB at a much lower cost.

p24 antigen and nucleic acid technologies. A number of other assays have been introduced in recent years that in addition to establishing the diagnosis of HIV infection may also be used to monitor the progress of the infection and the response to therapy. These procedures are particularly valuable for early diagnosis of mother-to-child transmission and for monitoring the viral load of patients who are taking antiretroviral therapy. From a practical standpoint, this technique can have limited specificity; needs sophisticated equipment, rigorous laboratory conditions, and highly trained staff; and is very expensive.

Alternative specimens. HIV diagnostic technology has also evolved to the development of assays that can use alternative body fluids to serum/plasma such

as saliva, whole blood, and urine. Potential advantages include safety, convenience, noninvasiveness, and cost-effectiveness. The quality of these assays as compared to conventional serological tests, however, is still undetermined.

HIV/AIDS TREATMENT

In the first 15 years of the AIDS epidemic, individuals with HIV infection had few treatment options. Since then, research has shown that certain antiretroviral drugs can inhibit HIV replication, delay immune deterioration, and improve survival and quality of life. Prior to the initiation of antiretroviral therapy, patients require a clinical assessment, which includes a thorough clinical history, physical examination, and ancillary tests. Other critical elements of the assessment include a past medical history, current and past HIV-related illnesses, coexisting medical conditions (such as tuberculosis, hepatitis B or C, or pregnancy), and concomitant medications in use that may influence choice of therapy. Minimum laboratory tests include an HIV antibody test and hemoglobin or hematocrit level. Where resources permit, it is preferable to get a complete blood count, CD4 count, serum alanine and aspartate aminotransferase levels, serum creatinine, blood urea nitrogen, serum glucose, bilirubin, and lipids levels, and pregnancy tests for women.

Treatment modalities for HIV are rapidly changing as the result of scientific research. No single medical regimen is universally accepted, although some are now preferred for initial therapy. At the time of this writing, the Food and Drug Administration (FDA) has approved the use of 20 different drugs to combat HIV infection—often in some form of combination. These drugs fall into four main types:

1. *Nucleoside and nucleotide analog reverse transcriptase inhibitors* inhibit HIV's ability to copy a healthy cell's DNA. HIV needs the cell's DNA, or genetic instructions, to replicate itself. Without complete DNA, HIV cannot make new virus copies. Drugs include zidovudine, lamivudine, stavudine, abacavir, didanosine, zalcitabine, emtricitabine, and tenofovir. Brand combination drugs include Combivir (lamivudine and zidovudine) and Trizivir (abacavir, lamivudine, and zidovudine).
2. *Nonnucleoside reverse transcriptase inhibitors* also prevent HIV from using a healthy cell's DNA to make copies of itself, but they have a different mechanism of action. Drugs include nevirapine, delavirdine, and efavirenz.
3. *Protease inhibitors* prevent infected cells from releasing HIV into the body. Drugs include saquinavir, indinavir, ritonavir, nelfinavir, amprenavir, lopinavir (combined with ritonavir as Kaletra), fos-amprenavir, and atazanavir.
4. *Fusion inhibitors* prevent the entry of the HIV virus into healthy cells. Presently, the only FDA-approved drug in this class is enfuvirtide.

Highly active antiretroviral therapy (HAART) refers to combination antiretroviral regimens of three or more drugs from one or more different classes of anti-HIV drugs to suppress HIV replication and prevent progression to AIDS and death. Two key classes of drugs include those that prevent the virus from copying itself (reverse transcriptase inhibitors) and those that prevent the virus from becoming infectious (protease inhibitors). The main goal of using combination therapy is to address the issue of constant mutations of the HIV virus, which leads to the ongoing emergence of new and drug resistant strains. Resistance to any single drug is thought to occur almost universally at the baseline even prior to initiation of drug therapy. It is not uncommon, however, for the effectiveness of different drug combinations to diminish over time. Hence, new combinations may need to be implemented over the course of a person's treatment. The actual drugs and their regimens are constantly under investigation and are revised as new information and medications become available.

A recent study from the National Institute of Allergy and Infectious Diseases, at the National Institutes of Health, indicates that the combinations and particular order of antiretroviral drugs must be considered when designing treatment strategies for patients new to antiretroviral therapy. When HIV-infected individuals begin treatment with a combination of the drugs zidovudine (better known as AZT), lamivudine, and efavirenz, the treatment retains its effectiveness for a longer period of time than when individuals begin treatment with one of several other three-drug regimens.

Meanwhile, administering a single dose of nevirapine to an HIV-infected woman at the onset of labor and to her child within 72 hours of birth have been found to markedly reduce the rate of HIV transmission in newborns. The WHO endorses this method as routine procedure for preventing mother-to-child transmission in HIV high-prevalence developing countries. However, this strategy is not without controversy; some recent evidence suggests that administering nevirapine treatment at infancy may result in greater vulnerability to infection following HIV exposure in later life.

GLOBAL DISPARITIES

The AIDS epidemic takes on different prevalence patterns and epidemiological profiles in different parts of the world. The continent of Africa, particularly the southern region, continues to have the highest HIV/AIDS incidence and prevalence rates globally. Many of the highly industrialized countries of the Western Hemisphere, including the United States, report declining epidemiological trends in AIDS overall, but their incidence rates in certain subpopulations are rising. In the Eastern Hemisphere, countries that once formed the Soviet Union face a young and rapidly growing epidemic. Latin America and the Caribbean exhibit evidence of a growing threat, while East and Southeast Asia, which include countries such as China and India that contain some of the world's largest populations, may someday outstrip Africa in terms of their absolute number of cases if their current escalating rates of HIV/AIDS go unchecked. Not all countries, however, are experiencing such acceleration. Brazil, Thailand, and Uganda serve as role models for others in successfully reducing previously rising transmission rates.

Throughout the world, the high cost of antiretroviral drugs places treatment beyond the range of many individuals living with the virus, particularly residents of the developing world. The exact cost of antiretroviral therapy in a particular geographic location varies and is determined by a complex set of factors including global politics, the existence of donor funds, public and private insurance and/or entitlement programs, and the policies and drug-testing activities of large pharmaceutical firms. At present, the cost of antiretroviral therapy in the least developed countries ranges from US$300 to US$1,200 per annum, a sum that places it out of reach for many. Currently, 6 million people infected with HIV in the developing world are estimated to need access to antiretroviral therapy to survive. Only 400,000 have this access. A number of global programs are either poised for or actively engaged in facilitating or providing treatment, but the demand throughout the world far exceeds the numbers to be served.

WHO policy, in recognizing that the multiple challenges involved worldwide in stopping the HIV/AIDS epidemic, calls for the adoption of a comprehensive public health approach to reach this goal. Not the least of these challenges lies in improving access to and reducing the cost of antiretroviral drugs. Other recommendations include establishing sustainable financing for AIDS treatment and drug procurement, regulatory mechanisms to ensure blood safety and appropriate delivery of HIV/AIDS services, improvement in health infrastructure, training of health care workers, education and involvement of communities, and the mobilization of diverse stakeholders. In addition to the development of a vaccine to end the AIDS epidemic, WHO recommendations also point to the need for developing and implementing scientifically proved strategies to encourage technology transfer and the successful adoption of evidence-based behavioral interventions and appropriate clinical treatment and care.

GLOBAL COST OF THE AIDS PANDEMIC

Besides taking an enormous toll in human life, the AIDS epidemic also erodes both personal and national capabilities including those of human sustenance and economic development. Private costs of living with HIV/AIDS can be categorized into direct and indirect costs. The direct costs of living with HIV/AIDS include service-related expenses for medication, general therapy and ongoing care in health care facilities or at home, and increasing dependence on transport for traveling to and from health providers and care facilities due to reduced mobility. Among the disease's many indirect costs are the possibilities of increased absenteeism from work, loss or reduction of income, lowered productivity both at home and in

society's public/private sectors, and the incurring of personal stigma associated with the disease. Family members of those with HIV/AIDS and others in their social networks also may incur some level of costs directly and indirectly, as do the functionary agencies and institutions that serve human economic, social, and health services needs. In some parts of the world, the AIDS epidemic, in combination with its emergent fiscal and health care crises, is driving countries toward insolvency. In Zimbabwe, for example, one-third of the population between the ages of 15 to 49 is infected with HIV/AIDS.

Such grim statistics remind us that AIDS is more than a life-threatening illness; its occurrence is also a societal problem inherently linked to and fed by existing social disparities and invidious socioeconomic conditions. Lack of access to antiretroviral therapy and the social stigma attached to the disease mitigate against many HIV-infected individuals' chances of living a long and symptom-free life. Almost universally, a diagnosis of HIV infection engenders significant stigma that can result in the shunning of infected individuals by their communities and even family members. Many HIV-positive persons also face difficulties in finding or retaining employment or housing once their HIV status is known. Meanwhile, growing gender imbalances in HIV rates among women globally, and the tendency for the virus to be found disproportionately among marginalized and disadvantaged populations throughout the world, mirror deeply entrenched systems of societal inequality that help to fuel further spread of the epidemic.

Even in the face of such societal and personal disaster, it should be acknowledged that most people worldwide have not acquired the virus. An important public health challenge is to enable individuals at risk to protect themselves against HIV while providing appropriate treatment to those living with the virus. Although a number of drugs currently are available that halt or modify AIDS disease progression, no vaccine currently exists to prevent infection, and once acquired, there is no cure for HIV infection. Until these become available, societal and behavioral prevention remain the world's main defense in halting the epidemic and its consequences.

HIV/AIDS AND DISABILITY

The creation and reinforcement of physical, mental, and social disabilities constitute some of the epidemic's most serious and far-reaching consequences in the world's fight against AIDS. Physical disability related to HIV/AIDS is mainly due to the manifestations of the disease process and/or the adverse effects of therapy that result in some form of physiological impairment. HIV-infected persons also may experience disabling mental health conditions including memory loss, depression, and psychosis. These conditions require clinical or other forms of effective treatment such as HIV counseling and testing and follow-up referral services to ensure needed psychosocial support. Social disabilities occur when people with HIV/AIDS, due to their illness, lose or encounter reduced opportunities to take part in society on an equal level with others. These three categories of disability are not mutually exclusive, and some individuals experience all three forms.

Because AIDS affects almost all the organs of the body as well as all systems, only patients who have a positive response from therapy are likely to lead a life that does not require some form of adaptation to physical disability or somatic compromise. Among those receiving HIV/AIDS treatment, the difficulties associated with ongoing multiple-drug intake and their adverse effects are substantial. Adverse effects include gastrointestinal symptoms, such as bloating, nausea, and diarrhea, which occur commonly and may be transient or persist throughout therapy. Generalized fatigue, malaise, headache, anemia, peripheral neuropathy, and hypersensitivity reactions are other adverse effects associated with various individual and combination drugs. More serious but less common adverse effects include lactic acidosis, hepatic steatosis, hyperlactatemia (elevation of venous lactic acid), hepatotoxicity, hyperglycemia (leading to diabetes mellitus), fat maldistribution (lipodystrophy), hyperlipidemia, bleeding disorders, bone loss, and skin rashes. Fatigue is common among patients with HIV/AIDS and may contribute to limitations in physical functions and disability. Fatigue may occur in conjunction with multiple AIDS-related opportunistic infections, wasting, myopathy, adrenal insufficiency, and hypogonadism.

The physical conditions of HIV/AIDS and its treatment can negatively influence the mental well-being of people living with the virus and also engender considerable social stigma and other disadvantages. Consider the example of the physical, mental, and social effects of developing *lipodystrophy.* This medical term denotes the changes in body shape that were first reported in 1998 among people taking anti-HIV therapy. Originally thought to result from treatment using protease inhibitors, the condition later was found among people who had never been treated for HIV or whose therapy did not include such drugs. The literal meaning of lipodystrophy is accumulation of fat. The pathogenesis of lipodystrophy is complex and likely due to combined endocrine and metabolic abnormalities including dyslipidemias (low levels of high-density lipoprotein and high levels of low-density lipoprotein and triglyceride in the blood), high blood sugar, insulin resistance and raised liver enzymes, and accelerated bone loss. Associated conditions include heart disease, stroke, and pancreatitis. Risk for lipodystophy is greater for people with other co-occurring disorders such as high blood pressure, diabetes, obesity, smoking, or a family history of heart disease. It also occurs in 15 to 50 percent of those taking antiretroviral therapy.

The body fat changes often seen in people with HIV include both fat gain and fat loss. Fat deposition mainly occurs around abdomen, breasts, jaw, and dorsocervical spine (upper back and neck)—causing the "buffalo hump." The abdominal fat gain is due to visceral fat accumulation around internal organs, causing the belly to feel taut and pushed out. This symptom (absence of squeezable fat) is distinguishable from the fat deposition due to overeating or lack of exercise. Fat loss is usually evidenced by facial wasting, especially of the cheeks, wasting of the buttocks, and prominent veins in the arms and legs. Such visible evidence of HIV and its alteration of the body may call attention to the person's illness and become the basis for or exacerbate negative reactions from others. The resulting stigma and the challenges of coping with an altered body image are potential sources of stress and worry among people who experience the condition.

As is true for many AIDS-related illnesses, the best course of treatment for lipodystrophy is unknown. Treatments under study to stem the disorder span a gamut of drug and behavioral options including the use of human growth hormone, anabolic steroids, appetite stimulants, weight training, regular exercise, smoking cessation, switching from the contraceptive pill to another form of birth control, dietary changes, and/or changing anti-HIV therapy.

Lipodystrophy is just one of numerous conditions that people living with HIV may need to physically, mentally, and socially manage. For those individuals who receive life-prolonging treatment or otherwise achieve effective symptom management, HIV/AIDS constitutes a chronic condition that must be managed similarly to other serious long-term or permanent debilitating illnesses. This includes coping with the treatment itself. Therapy with antiretroviral drugs is not free from adverse effects, and most drugs have potential interactions with other drugs. Up to 25 percent of patients discontinue their initial HAART therapy due to treatment failure, toxic effects, or noncompliance. Drug toxicity needs to be monitored clinically based on patient reports and physical examination, supplemented by laboratory tests. After initiating therapy, viral RNA tests need to be performed every 4 to 6 weeks until reaching the therapeutic goal of undetectable viral RNA. Subsequently viral RNA tests are needed every 3 to 4 months. In case of treatment failure, a second-line regimen is recommended. In sum, living with HIV and AIDS is an ongoing physical, mental, and social challenge for those afflicted.

CO-OCCURRING DISABILITIES

While a substantial body of literature addresses the array of disabilities associated with HIV and AIDS in previously healthy individuals, there is a paucity of research concerning individuals who were living with a disability prior to contracting HIV/AIDS. Globally, *approximately 600 million people are estimated to be living with a physical, sensory, intellectual, and/or mental health disability. Some unknown proportion of these individuals either has, or is, at some risk for HIV/AIDS.*

In this regard, from the standpoint of normal human behavior, it is highly probable that the major risk factors associated with HIV infection also are present

among people who experience disability through other conditions. Unfortunately, in terms of HIV/AIDS vulnerability, individuals living with a disability also are more likely than their unimpaired peers to live in poverty, to be less educated, and to be unemployed. In addition, due to experiencing more than one disabling condition, they may encounter multiple stigmatizations that decrease their likelihood of participating fully in the social, legal, religious, and political decision making and affairs of their communities that would give them a voice in managing their own health care. From the standpoint of prevention programming, all too often, people living with a disability are assumed to be sexually inactive, nonusers of illicit drugs, and unlikely to be victims of violence including rape. In reality, they can be at risk for HIV/AIDS for all of the same reasons as people without disabilities.

Misconceptions about the risk for HIV infection in persons with disability translate into insufficient preventive and therapeutic efforts targeting this population, and few research studies are conducted that would help inform this effort. One notable exception is a global survey on HIV/AIDS and disability, sponsored by the World Bank, currently under way by researchers at the Yale University School of Public Health in the United States. The study includes a survey that was distributed to more than 3,000 organizations, advocates, and activities in July 2003, and thus far has yielded responses from 57 countries. Although collection and analysis of the survey are still under way, some preliminary results indicate the following:

> HIV/AIDS is a significant and almost completely unrecognized problem among populations of people with disabilities worldwide;
>
> while all individuals with a disability are at risk for HIV infection, certain population subgroups are a higher risk—most notably women, members of ethnic and minority communities, adolescents, and institutionalized individuals; and
>
> HIV/AIDS educational, testing, and clinical programs are largely inaccessible to individuals with disabilities.

Further results from the study are expected to provide additional information regarding risk factors and interventions to mitigate risk to persons with disabilities.

PROTECTION OF HUMAN RIGHTS

Even with the challenges that living with HIV/AIDS presents, people who receive appropriate treatment are typically capable of successfully carrying out their daily lives. Also, with more effective drug therapies becoming available, HIV-positive individuals are living longer and remaining in or returning to the workforce as productive workers in increasing numbers. In many, but not all, countries, those who experience disabling conditions due to the disease have the right to the same legal protection, care, and consideration given to people confronting other physical and/or mental disabilities.

The American with Disabilities Act (ADA) enacted in 1990 in the United States aims to provide broad protection against disability discrimination, including discrimination against people infected with HIV. The act is based on a U.S. Supreme Court ruling that declares that HIV infection must be regarded as a physiological disorder with an immediate, constant, and detrimental effect and, therefore, the properties of the illness satisfy the definition of a disability during every stage of the disease. The ADA, which covers employers of 15 or more people, applies to employment decisions at all stages. Despite enactment of this legislation, however, individuals infected with HIV face discrimination in finding employment, and lawsuits filed by HIV-infected workers continue under the ADA. Similar problems of job discrimination and social stigma are reported worldwide, although efforts are under way on a number of fronts to reduce this condition.

The increasing involvement of people living with HIV/AIDS in community-based organizations and at national and international forums for the development of policies and the delivery of services on their behalf is an encouraging trend toward meeting their needs. Of note is the "Montreal Manifesto," released at the V International AIDS Conference in 1989, in Montreal, Canada. It advocates for an international code of rights to promote the active involvement of effected communities of people with HIV disease in decision making that may affect them. This document, while more than a decade old, is a continued call to action by everyone to ensure that all people affected by HIV/AIDS have proper food, housing, education, employment, and health care and that they are able to

exercise their rights in this regard without any hindrance whatsoever.

—Memoona Hasnain and Judith A. Levy

See also Americans with Disabilities Act of 1990 (United States); Child Care; Disability in Contemporary Africa; Emerging Disabilities; Immunologic Diseases.

Further Readings

Carpenter, C. C., M. A. Fischl, S. M. Hammer, M. S. Hirsch, D. M. Jacobsen, D. A. Katzenstein, J. S. Montaner, D. D. Richman, M. S. Saag, R. T. Schooley, M. A. Thompson, S. Vella, P. G. Yeni, and P. A. Volberding. 1996. "Antiretroviral Therapy for HIV Infection in 1996. Recommendations of an International Panel. International AIDS Society-USA." *Journal of the American Medical Association* 10; 276(2): 146–154.

Centers for Disease Control and Prevention. 1986. "Classification System for Human T-lymphotropic Virus Type III/ lymphadenopathy-Associated Virus Infections." *MMWR Morbidity and Mortality Weekly Report* 35(20): 334–339.

———. 1987. "Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome." Council of State and Territorial Epidemiologists; AIDS Program, Center for Infectious Diseases. *MMWR Morbidity and Mortality Weekly Report* 36(Suppl. 1): 1S–15S.

———. 1992. "1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS among Adolescents and Adults." *MMWR Recommendations and Reports* 41(RR-17): 1–19.

Chiao, E. Y., K. M. Ries, and M. A. Sande. 1999. "AIDS and the Elderly." *Clinical Infectious Diseases* 28:740–745.

Cohen, P. T., M. A. Sande, and P. A. Volberding, eds.; D. H. Osmond, M. B. Feinberg, S. Deeks, S. Safrin, L. D. Kaplan, and J. L. Gerberding, assoc. eds. 1999. *The AIDS Knowledge Base: A Textbook on HIV Disease from the University of California, San Francisco School of Medicine, and San Francisco General Hospital.* Philadelphia: Lippincott Williams & Wilkins.

Department of Health and Human Services and Henry J. Kaiser Family Foundation. 1998. "Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents." *MMWR Recommendations and Reports* 24; 47(RR-5): 43–82. Erratum in 1998. *MMWR Morbidity and Mortality Weekly Report* 31; 47(29): 619.

Esparza, J. and S. Osmanov. 2003. "HIV Vaccines: A Global Perspective." *Current Molecular Medicine* 3(3): 183–193.

Greensides, D. R., R. Berkelman, A. Lansky, and P. S. Sullivan. 2003. "Alternative HIV Testing Methods among Populations at High Risk for HIV Infection." *Public Health Reports* 118(6): 531–539.

Groce, N. E. 2003. "HIV/AIDS and People with Disability." *Lancet* 26; 361(9367, April): 1401–1402.

Hoover, D. R., N. M. Graham, B. Chen, J. M. Taylor, J. Phair, S. Y. Zhou, and A. Munoz. 1992. "Effect of CD4+ Cell Count Measurement Variability on Staging HIV-1 Infection." *Journal of Acquired Immune Deficiency Syndromes* 5(8): 794–802.

Levy, J. A. and S. E. Fox. 1998. "The Outreach-Assisted Model of Partner Notification with IDUs." *Public Health Reports* 113(Suppl. 1): 160–169.

Mathews, C., N. Coetzee, M. Zwarenstein, C. Lombard, S. Guttmacher, A. Oxman, and G. Schmid. 2002. "A Systematic Review of Strategies for Partner Notification for Sexually Transmitted Diseases, Including HIV/AIDS." *International Journal of STD and AIDS* 13:285–300.

Montessori, V., N. Press, M. Harris, L. Akagi, and J. S. Montaner. 2004. "Adverse Effects of Antiretroviral Therapy for HIV Infection." *Canadian Medical Association Journal* 20; 170(2): 229–238.

Newell, M. L. 2003. "Antenatal and Perinatal Strategies to Prevent Mother-to-Child Transmission of HIV Infection." *Transactions of the Royal Society of Tropical Medicine and Hygiene* 97(1): 22–24.

Persaud, D., Y. Zhou, J. M. Siliciano, and R. F. Siliciano. 2003. "Latency in Human Immunodeficiency Virus Type 1 Infection: No Easy Answers." *Journal of Virology* 77(3): 1659–1665.

Pomerantz, R. J. and D. L. Horn. 2003. "Twenty Years of Therapy for HIV-1 Infection." *Nature Medicine* 9(7): 867–873.

Saag, M. S. 2003. "Antiretroviral Therapy: Select Lessons from Recent Studies." *Tropical HIV Medicine* 11(5): 164–168.

UNAIDS/WHO Joint United Nations Programme on HIV/AIDS. December 2004. "AIDS Epidemic Update, United Nations and World Health Organization." Geneva: UNAIDS/WHO Joint United Nations Programme on HIV/AIDS (http://www.unaids.org/wad2004/report.html).

WHO International Collaborating Group for the Study of the WHO Staging System. 1993. "Proposed World Health Organization Staging System for HIV Infection and Disease: Preliminary Testing by an International Collaborative Cross-Sectional Study." *AIDS* 7(5): 711–718.

Zhang, M. and J. Versalovic. 2002. "HIV Update: Diagnostic Tests and Markers of Disease Progression and Response to Therapy." *American Journal of Clinical Pathology* 118(Suppl.): S26–S32.

Websites

Americans with Disabilities Act of 1990, http://www.brta-lrta.org/law/americans-disabilities-act.htm

New Brunswick Human Rights Commission, "HIV/AIDS Guideline for Discrimination against HIV Disabled Persons," http://www.gnb.ca/hrc-cdp/e/gaids.htm

HOFFMAN, C. COLDEN (1819–1865)

American missionary

Reverend Cadwallader Colden Hoffman, an American Episcopalian minister, was a missionary in Liberia from 1849 until his death (Fox 1868). He included some deaf boys in his schools (Brittan 1860) and started teaching blind people to read using Moon's embossed script. While itinerating up-country, Hoffman came in contact with many disabled people leading what he considered pitiful existences. He opened a small center on the coast, where blind and other disabled people could live while learning handicrafts and reading: "I have received into it a native man, armless and with a crooked spine, who is only 3 ft. 5 3/4 ins. in height, but of good mind. He begins to read, and can thread a needle, turn a hem, and sew, with his toes" (Moon 1877). Hoffman also planned a center for deaf people, but died before this could be achieved. In sub-Saharan Africa, Hoffman's efforts are among the earliest recorded formal educational and vocational work with blind and deaf people.

—Kumur B. Selim

See also Blind, History of the; Deaf, History of the.

Further Readings

Brittan, H. G. 1860. *Scenes and Incidents of Every-Day Life in Africa.* Pudney & Russell. Reprinted (1969), New York: Negro Universities Press.

Fox, G. T. 1868. *A Memoir of the Rev. C. Colden Hoffman.* London: Seeley, Jackson and Halliday.

Moon, W. 1877. *Light for the Blind.* London: Longmans.

HOME MODIFICATION

Home modification represents the area of assistive technology in which accessibility and universal design concepts are incorporated into private residences. Through this application, an individual with a disability is able to maximize his or her independence in areas that include entry to and exit from the home, personal care, transfers, meal preparation, cooking, and housekeeping.

In the United States, the Americans with Disabilities Accessibility Guidelines (ADAAG) provide information on the required architectural elements for accessibility in public spaces. Regarding private residences, a municipality may refer to ADAAG, state guidelines, or local codes that address accessibility. Where guidelines differ from one another, the stricter code takes precedence.

Where sufficient space exists, entry to and exit from the home is addressed through the use of ramp systems. The maximum slope allowed for ramp systems is 1:12 (one inch/unit of rise for every 12 inches/units of run). Level platforms are required at the top landing, so that individuals with disabilities can maneuver through the doorway without being on a ramped surface, and at any turns or rest areas. Where space is limited, an electrically powered vertical platform lift may be appropriate.

Accessible bathroom designs include elements to maximize access and safety. This may include the use of a cantilevered sink, lever-profile water faucet handles, and insulated water supply and drain lines. A taller toilet profile makes use easier for those who have difficulty in sitting or standing, or for those who transfer from a wheelchair. Grab bars provide surfaces for stability as an individual transfers or uses the toilet. For bathing, roll-in or walk-in showers with limited-threshold profiles enable individuals to enter and exit the space. Single-lever water controls not requiring fine motor control can make setting of a comfortable temperature possible. Pressure-balancing valves within the wall help keep the water at the set temperature, compensating for water pressure fluctuations due to water use elsewhere in the home. Grab bars assist in this area as well.

Transfers between bed and mobility bases can be assisted through the use of powered transfer lifts. Supported from the ceiling, these electrically powered devices provide vertical travel of a sling or frame support, enabling the user to be lifted safely. For individuals transferring independently, the device can be powered in the lateral direction as well, traveling along a ceiling track to a position above the second surface. For others, the device travels along this track via a ball bearing system, making it easy for the person providing assistance to move the user laterally.

Modifications made in the kitchen to promote independence include lowered countertops, cabinets with D-shaped door handles and carousels or pull-out

shelves, countertop or table space with knee clearance beneath, stoves with controls along the front edge, side-by-side refrigerators, and sinks with knee clearance beneath.

In general, wide doorways and pathways within the home, lever-profile doorknobs, and accessible-height light switches and outlets can make efficient use of the space feasible. Retrofitting of these elements into existing homes is usually possible. Home modification elements can easily be incorporated into new home design.

—Glenn Hedman

See also Accessibility Codes and Standards; Aids for Activities of Daily Living; Fair Housing Act Amendments of 1988 (United States); Independent Living.

Further Readings

U.S. Access Board. 2002. "ADA Accessibility Guidelines for Buildings and Facilities (ADAAG)." Washington, DC: U.S. Access Board. (http://www.access-board.gov/adaag/html/adaag.htm).

HOME SUPPORT

Home support—otherwise known as home care, personal supports, or attendant care—is the provision of human assistance to a person with a disability that enables his or her greater participation in society. Dumont-Lemasson, Donovan, and Wylie (1999) defined home care as "an array of services which enables clients, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives." The service can assist people with disabilities to perform activities of daily living such as eating, bathing, meal preparation, and errands when it is difficult or impossible for them to do these things on their own. Importantly, in some regions of the world this service facilitates the achievement of life goals in areas associated, for example, with employment, education, health, recreation, and spirituality.

Home support is a concept that is most frequently found in the developed world and in particular countries where social and health care programs exist. People with disabilities consider this a critically important service because it can enable an individual who lives with physical, emotional, or cognitive impairment to engage in society as a participating citizen, particularly when the home support activities are directed and controlled by the disabled user of the service. The development of the notions of user flexibility, choice, and control of personal assistant service is closely tied to the independent living movement. It is also a service that has become increasingly necessary in a context of people leaving institutions to live in the community and as people are discharged earlier from hospital care.

ISSUES

Direct Funding

When people who receive the home support service play a direct role in determining how to implement it, this is often referred to as direct funding or self-directed care. This approach to the provision of home support exists for people who live in countries such as the United States, the United Kingdom, and Canada and is guided by the independent living principles of flexibility, choice, and control. Users are provided with resources to pay for the service, and they are responsible for administrative duties, including interviewing, hiring, training, and firing their attendants. Consumers of the service are not paid for doing administrative work, which reduces overall costs. However, it is important for such programs to involve a local disability organization, which can provide support to individual consumers.

This approach is distinct from other systems of support provision affiliated with government departments or private health care agencies that are guided by principles of efficiency rather than consumer control. High staff turnover results in workers not becoming aware of the preferences, personality, and life goals of the individual they are expected to support.

Unionization of Workforce

This is an important issue, currently being debated in Canada. People who provide assistance are primarily women who are paid a relatively low wage. While those who receive home support services recognize that workers deserve protections and a decent wage, they

may be concerned that unionization will further transform their homes into institution-like workplaces and reduce their choice in directing their own care and lives.

Pressures on Informal Care Providers

As populations age, governments are projecting an increase in the need for home support, and as private agencies become increasingly involved in the provision of this service, there is a greater concern for economic returns. Over the past decade, efforts have been made to make it increasingly difficult to be eligible for services and, when services are provided, to narrow the range of services. These factors put greater pressure on families, friends, and neighbors to provide needed care, which in turn has had a negative impact on the health, both of those receiving assistance and the informal unpaid caregivers. Children are expected to care for a disabled parent, a spouse is expected to provide care while also working to meet the family's financial needs, and older women with impairments themselves are having to care for their spouses as their health deteriorates.

DEVELOPMENT: THE EXAMPLE OF CANADA

In countries such as Canada, home support has undergone significant changes during the past decade. In some regions of Canada, the eligibility requirements have become more restrictive, resulting in fewer people accessing the service. The range of services in some regions has now been reduced to basic personal care—bathing and toileting—and no longer includes meal preparation, household cleaning, or any other activity relating to the person's social, economic, political, or spiritual participation in society. In fact, many users can only receive this support inside their own homes. People who have received supports for years are being reassessed using the newer, more restrictive, criteria. There are few arms-length appeal mechanisms for people with impairments to use when they have their services reduced or denied. Disability organizations have found that it can be particularly problematic for people, more often women, who have impairments that are invisible and fluctuating.

Although the Canada Health Act is in place to protect universal access to health-related services in Canada, home support has never been included under this act. At the time the act was developed, deinstitutionalization, community-based models of health care, and the independent living movement had not yet increased awareness of the need for home support service. Because the service is not protected under the act, it is particularly vulnerable to social and economic pressures. The same is true in the United States and other countries with partial health coverage such as Medicare and Medicaid.

Policy making in this area has been influenced by medical models of disability and economic reductionism. Policies reflect and emphasize the notion of disability as a biological limitation rather than one that recognizes the role of society in creating barriers for people who accomplish their goals differently. Services in some regions aim to keep people merely alive and are unconcerned with providing supports that would allow them to leave their homes or bedrooms. This has led some disability activists to see this move as another form of institutionalization.

Policies also tend to be guided by notions of economic restraint, further fueled by rhetoric about the rising cost of health care and the growing number of older Canadians requiring care. Some regions of the country have developed policies that emphasize the goal of spending less on home support service, viewed in isolation. The policy ignores the holistic analysis in which the objective of home support not only is self-direction of one's life but also maintaining its role in health prevention and promotion (e.g., by addressing the social determinants of health and increasing basic nutrition). When people with physical impairments, for example, no longer receive basic care to maintain their lifestyle and health in the community, they can experience a worsening of their health, which in time will require more costly acute care treatment. Home support is clearly less expensive than institution- or hospital-based care, but more important, the disability community views this economic emphasis as a step backward in terms of their human rights.

THE NEED FOR NATIONAL STANDARDS

In Canada and other countries, the administration of home support programs tends to be decentralized to

provinces, regions, or smaller administrative units. Studies have indicated that without a national standard there will be significant differences in eligibility criteria, user fees, and range of services across the country. Variation in approaches to service delivery will also exist. In some areas, services are directly provided by public employees, in others competitive tendering results in private agencies delivering services, and in yet others a partnership is created between government and nonprofit providers.

Differences in eligibility criteria are a particular problem, as they appear to be designed to create ineligibility simply in order to reduce costs, rather than to facilitate the exercising of rights. Competition between provinces or municipalities to "reduce costs" threatens the eligibility for services of people who live with long-term impairments. Reassessment can be introduced across the board in regions or it can be initiated by factors such as an individual's move to a region. People with disabilities are not free to move from one location to another because there is no assurance that their services would continue under new local eligibility criteria. A set of national standards for home support established by the central government could help to solve this problem, especially if, as in Canada, the standard-setting, federal government makes adherence to the standards a condition for qualifying for federal funding or cost-sharing.

INTERNATIONAL CONTEXT

Home support should also be seen in light of internationally developed conventions and treaties developed to protect or ensure rights of children and adults who live with disability. Article 23 of the Convention on the Rights of the Child states that "parties recognize that a mentally or physically disabled child should enjoy a full and decent life in conditions that ensure dignity, promote self-reliance, and facilitate the child's active participation in the community." The UN Standard Rules of Equalization of Opportunity was developed in collaboration with member states and disability representatives with the intent of developing a guiding framework for developing policy and services while supporting community participation for people with disabilities. Rule 4 of the UN Standard Rules stipulates that "states should support the development and supply of services including assistive devices, personal assistance and interpretation programs to people with disabilities."

What the future holds for home support depends to a degree on pressure from the international community to live up to the standards set by the UN Standard Rules and possibly in the near future, to the UN Disability Convention. Much will also depend on the willingness of the United Nations and national and local governments to directly involve those who are affected by these home support policies—people with disabilities, parents of children with disabilities, family members—to contribute and be listened to.

At the same time, the growth and ever-increasing power of multinational health care corporations, guided entirely by economic concerns, will redirect attention away from consumer control and citizen-based outcome criteria for services. Government may increasingly feel the pressure to transfer health care services to the multinationals. An increasingly aware, and active, disability movement, joining forces with the rest of the population whose life and health will be affected by these developments, will be required to ensure that home support can involve, and be under the control of, those who are directly affected by these services.

—Kari Krogh

See also Disability Law: Canada; Independent Living; Personal Care Attendants; United Nations Standard Rules.

Further Readings

Bookwala, J., J. L. Yee, and R. Schultz. 2000. Caregiving and Detrimental Mental and Physical Health Outcomes. Pp. 93–131 in *Physical Illness and Depression in Older Adults: A Handbook of Theory, Research and Practice,* edited by D. M. Williamson, P. A. Parmelee, and D. R. Shaffer. New York: Plenum.

Burke, M. 2000. Efficiency and the Erosion of Health Care in Canada. Pp. 178–193 in *Restructuring and Resistance: Canadian Public Policy in an Age of Global Capitalism,* edited by M. Burke, C. Mooers, and J. Shields. Halifax, NS: Fernwood.

Council of Canadians with Disabilities. 2002. *Consumers with Disabilities Speak Out on Health Issues.* Submission to the Romanow Commission on the Future of Health Care in Canada. Winnipeg, MB: Council of Canadians with Disabilities.

Dumont-Lemasson, M., C. Donovan, and M. Wylie. 1999. *Provincial and Territorial Home Care Programs: A Synthesis for Canada.* Ottawa, ON: Health Canada.

Krogh, K. 2001. *Beyond Four Walls: Impact of Home Support on Work, Health and Citizenship of People with Disabilities* [Multimedia research report distributed at the World Health Organization's Rethinking Care from the Perspectives of People with Disabilities: A Global Congress] Retrieved May 6, 2003 (http://www.ryerson.ca/~kkrogh).

———. 2004. "Redefining Home Care for Women with Disabilities: A Call for Citizenship." In *Caring For/Caring About: Women, Home Care and Unpaid Caregiving,* edited by Karen Grant, Carol Amaratunga, Pat Armstrong, Madeline Boscoe, Ann Pederson, and Kay Willson. Aurora, ON: Garamond.

Krogh, K., M. Ennis, J. Johnson , and T. Bowman. 2005, February. *A National Snapshot of Home Support from the Consumer Perspective: Enabling People with Disabilities to Participate in Policy Analysis and Community Development*. Final research report. Published by and available from the Council of Canadians with Disabilities (www.ccdonline.ca/publications/index.htm).

Krogh, K. and J. Johnson. Forthcoming. "A Life without Living: Challenging Medical and Economic Reductionism in Home Support Policy for People with Disabilities." In *Critical Disability Theory,* edited by D. Portier and R. Devlin. Vancouver: University of British Columbia Press.

Masuda, S. 1998. *The Impact of Block Funding on Women with Disabilities.* Ottawa, ON: DisAbled Women's Network Canada.

Priestley, M. 1999. *Disability Politics and Community Care.* Philadelphia: Jessica Kingsley.

Wendell, S. (2001). "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities." *Hypatia* 16(4): 17–33.

Websites

Independent living principles, Canadian Association of Independent Living Centres, www.cailc.ca

HOMER (EIGHTH CENTURY BC)

Greek epic poet

The earliest surviving Greek epic poems, the *Iliad* and the *Odyssey* (dated around the eighth century BC) have traditionally been attributed to Homer, even though his existence has been questioned by many since antiquity. He was believed to have been born blind or to have lost his sight from an eye disease early in life, before completing the *Iliad* or beginning the *Odyssey.* His blindness was accepted by such ancient authors as Herodotus, Theopompus, Plutarch, Cicero, Pausanias, Silius Italicus, Hesychius, and Suidas. It is also represented in several ancient portraits of the poet, whereas others depict him with a piercing gaze. His account, in the eighth book of the *Odyssey*, of Demodocus the blind bard of the Phaeacians (with its implicit notion of the gift of song as a compensation for loss of sight) has been taken as a self-portrait of the poet. The Greek historian Thucydides (fifth century BC) regarded as a genuine work of Homer the "Hymn to the Delian Apollo" in which the author describes himself as a "blind man living in harsh Chios."

Several ancient biographers of Homer mention his blindness, but all of them are late. In the *Phaedrus* (Section 243a), Plato draws a strange parallel between Homer and the poet Stesichorus, who was said to have been punished with blindness for his attack on Helen.

Many modern scholars contend that Homer's blindness is apocryphal, being the result of a misattribution projected from one of the characters of the *Odyssey*. Rejection of Homer's blindness is implied by authors who stress the importance of visual memory for description, such as Velleius Paterculus (AD first century) among the ancients and Minchin (2001) in modern times. Similarly, although Homeric references to eyes and vision are formulaic, Homeric facial gestures may reflect aspects of character and reveal psychological situations, thus standing in for acts and, especially, words (Soteroula 1994). The idea, suggested by Schumann in 1955, that the peculiar structure of Homeric dreams is a proof of their author's blindness has been rejected by scholars such as Mirko Grmek in 1989.

The picture of the blind Homer has left its profound impact on the notion of the blind singer, although the notion itself is not confined to classical Greece. Some recent scholars have endeavored to understand the role of the blind characters in the Homeric poems (such as Tiresias, Demodocus, and Polyphemus) in connection with the legendary blindness of the poet himself.

—D. P. M. Weerakkody

See also Blind, History of the; Marcus Tullius Cicero.

Further Readings

Anonymous. 1909. "La Cécité d'Homère." *Chronicle of Medicine* 12:680.

Dyer, R. 1975. "The Blind Bard of Chios (Hymn Hom. Ap. 171–176)." *Classical Philology* 70:119–121.

Grmek, Mirko D. 1989. *Diseases in the Ancient Greek World.* Translated by Mireille Muellner and Leonard Muellner. Baltimore: Johns Hopkins University Press.

Hunter, Robert Austin. 1997. "A Literary Profile of Depictions of the Physically Blind with an Emphasis on Selected Work by Some Outstanding Spanish and Spanish-American Writers." Ph.D. dissertation, Texas Tech University.

Kononeno-Moyle, Natalie. 1979–1980. "Homer, Milton, and Asik Veysel: The Legend of the Blind Bard." *Harvard Ukranian Studies* 3(4): 520–529.

Minchin, Elizabeth. 2001. *Homer and the Resources of Memory: Applications of Cognitive Theory in the Iliad and the Odyssey.* Oxford, UK: Oxford University Press.

Richter, Gisela M. A. 1965. *Portraits of the Greeks.* London: Phaidon.

Ross, Ishbel. 1951. *Journey into Light: The Story of the Education of the Blind.* New York: Appleton-Century-Crofts.

Schumann, H. J. von. 1955. "Phaenomenologische und psychoanalytische Untersuchung der Homerischen Traume: Ein Beitrag zur Klarung der umstriten Blindheit des Dichters." *Acta Psychotherapica* 3:205–219.

Soteroula, Constantinidou. 1994. "Vision of Homer: The Eyes of Heroes and Gods." *Antichthon* 28:1–15.

Wilson, James. 1821. "An Account of the Life and Writing of Homer." In *Biography of the Blind.* 1995. Belfast (republished by the Library of Congress).

HOUSING: LAW AND POLICY

Throughout North America and in most European countries, organized housing for people with disabilities was historically derived from charity-based models relying on institutionalization in one form or another. For example, much of the Western approaches to housing law and policy have roots in the Elizabethan poor laws of 1601. These laws were an attempt in early industrial England to dichotomize the poor as either deserving or nondeserving. Those orphaned, blind, or otherwise disabled were viewed as deserving by their conditions and thus were more entitled to charity than the nondeserving poor. Housing for the deserving poor took the form of almshouses and other charity-based facilities. Individuals who were blind, deaf, or had cognitive or other types of disabilities would move into a facility for shelter and education and live out their entire lives within walls.

Contemporary Western approaches to housing policy have seen a shift from charity and welfare models to a focus on community-based models of housing. This has given rise to the adoption of a number of antidiscrimination housing laws and policies in the United States and internationally. Nevertheless, institutions housing individuals with disabilities still exist today, although their numbers are decreasing.

U.S. HOUSING LAW AND POLICY

Fair Housing Act of 1937

Federal housing policy in the United States emerged from the Great Depression of the 1930s and the economic conditions that produced widespread unemployment. In the housing sector, both the finance and construction markets were severely challenged by the Depression. In response, policy makers created the Federal Housing Administration (FHA). The FHA insured private mortgages in order to increase housing construction and stabilize the housing economy.

To assist the poor, a group that included people with disabilities, policy makers also created a public housing program. Under the Fair Housing Act of 1937, the federal government created a program to fund almost the entire cost of public housing. The housing itself was built and managed by local housing authorities, who were required to manage the public housing following federal guidelines.

By the 1960s, new solutions to housing problems emerged including housing for senior citizens, rent supplements, and housing allowances, followed by the Section 8 program in 1974. The Section 8 housing allowance program provided funding through local housing authorities to subsidize housing rehabilitation, implement new construction, and subsidize rents in private housing.

The Section 8 program exists today. In the program, housing vouchers are issued to low-income families and families with members who have disabilities. These vouchers allow the individual or family to do a housing search and find private housing that fits their needs. Under the Section 8 program, the family pays 30 percent of its total income for rent and the housing authority pays the remainder. The local housing authority maintains a listing of public housing and

allocates the housing to individuals who meet its eligibility requirements. Housing authorities may choose to give preference to certain groups including individuals living in unsatisfactory conditions, terminally ill people, and people with disabilities. Individuals who fit within these criteria are allowed to move into housing sooner than others on the registry.

Government subsidization is not a program unique to the United States. A number of countries, including the United Kingdom, Austria, and Australia, have created housing programs for people with disabilities subsidized with government funds.

Housing Law

Until the early 1970s, housing laws generally did not include individuals with disabilities as a protected class. Rather, laws such as the Fair Housing Act (Title VIII of the Civil Rights Act of 1968) addressed discrimination on the basis of race. It was not until the passage of the Rehabilitation Act of 1973 in the United Sates that housing law specifically dealt with discrimination faced by individuals with disabilities in housing.

Section 504 of the Rehabilitation Act

Under Section 504 of the Rehabilitation Act of 1973, qualified individuals with disabilities are protected from discrimination in housing programs that receive federal funding. Qualified individuals with disabilities are defined as persons who have a physical or mental impairment that substantially limits them in one or more major life activities. Impairments may include, but are not limited to, visual or hearing impairments, mobility impairments, psychiatric impairments, HIV infection, cognitive impairments, and drug addiction (not current illegal use).

Major life activities include caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. Substantial limitation in these activities is determined by whether or not the average person can perform them with little or no difficulty.

Newly constructed federally funded housing is required to be physically accessible to tenants with disabilities under Section 504. At least 5 percent of units (or a minimum of at least one unit) must be accessible to tenants in wheelchairs and other mobility devices. Two percent (or at least one unit) must have the accessibility features needed by individuals with hearing or vision impairments. Accessible units are to be distributed throughout housing sites to ensure that tenants with disabilities have a variety of options in location and amenities. There are also requirements for physical accessibility when federally funded housing is altered as well.

Reasonable accommodation for tenants with disabilities is another major feature of Section 504. Accommodations may include changes to a policy, program, service, or dwelling unit that allow tenants with disabilities to fully participate in the housing experience. For example, the federally funded housing program may install a ramp for a tenant in a wheelchair or allow a service animal despite a "no pets" policy. These modifications are to be carried out at the expense of the federal funding recipient, unless it would result in an undue financial or administrative burden. Undue burden is defined as substantial administrative difficulty or expense. When deciding whether or not an action would be an undue burden, the housing entity must consider all resources available to them.

Fair Housing Act Amendments of 1988

The Fair Housing Act of 1968 prohibits discrimination in housing practices on the basis of race in almost all forms of housing sold or rented in the United States. It was amended in 1988 to include protections for people with disabilities. This amendment extended protection for people with disabilities beyond those in Section 504 to include private housing. Disability is defined under the Fair Housing Act using the same criteria as under Section 504 and the Americans with Disabilities Act.

Actions prohibited under the act include the refusal to sell or rent to an individual with a disability or to a family that includes a member with a disability. The Fair Housing Act also prohibits the refusal to negotiate; making housing unavailable; denying a dwelling; setting different terms, conditions, or privileges for sale or rental; providing different housing services; falsely denying that housing is available for sale or rental; persuading owners to sell or rent; or denying anyone access to or membership in a facility or service to people with disabilities.

Mortgage lenders are not allowed to refuse to make a loan, refuse to provide information regarding loans, impose different terms or conditions on a loan, discriminate in appraising property, refuse to purchase a loan, or set different terms or conditions for purchasing a loan when working with individuals with disabilities protected under the Fair Housing Act.

Similar to Section 504, housing entities must make reasonable modifications to policy and procedure to allow individuals with disabilities to use their housing. For instance, an apartment complex that provides unassigned parking to its tenants would have to allow a tenant with a mobility impairment a reserved accessible parking space near his or her unit.

Tenants with disabilities are also allowed to make reasonable modifications to their dwellings as well as to the common areas of the complex if this will allow them the use of their unit or the public areas. For instance, if a tenant with a disability needed to widen the doorways in an apartment, under the act, the landlord would have to allow the tenant to make the needed changes. The tenant would be responsible for restoring the unit to its original state when he or she moves. The costs of the reasonable accommodations provided by federally funded housing programs under Section 504 of the Rehabilitation Act are the responsibility of the housing provider, but reasonable modifications under the Fair Housing Act are at the expense of the individual with a disability.

Housing complexes that first had occupancy after March 13, 1991, and have an elevator or four our more units are required to be physically accessible to tenants with disabilities. In addition to the accessibility of the public and common areas, ground-floor dwelling units must also be accessible. Accessible features include doors and hallways that are wide enough for wheelchairs, accessible light switches and other environmental controls, reinforced bathroom walls for the possible installation of grab bars, and kitchens and bathrooms that are usable by tenants with mobility impairments.

Americans with Disabilities Act of 1990

The Americans with Disabilities Act of 1990 (ADA) prohibits discrimination in employment, state and local government programs, the provision of goods and service in business, transportation, and in certain circumstances, housing. Individuals with disabilities are protected under the ADA in housing in several situations. If housing is part of a public accommodation or business that is open to the public such as a hotel, it is covered under the ADA. Specifically, hotel rooms need to be physically accessible under the ADA. Hotels are also required to provide auxiliary aids and services such as visible alarms and text telephones (TTY) for guests who are deaf. Places of lodging might also have to modify policies and procedures if those policies discriminate against guests with disabilities such as eliminating a no-pets policy for guests with disabilities who have service animals.

Hotels that include residential areas would be covered both under the ADA and the Fair Housing Act. The area occupied by individuals living in the hotel would be subject to the requirements outlined in the Fair Housing Act, while the transient lodging section of the facility would be held to the regulations in the ADA. Public areas in housing complexes such as rental offices and community rooms may also be covered under the ADA. For instance, if the community room of a housing complex is rented to community members for events, it would then fall under the ADA and need to be accessible to individuals with disabilities.

INTERNATIONAL CIVIL ANTIDISCRIMINATION LAWS

Many countries across the world have enacted civil antidiscrimination laws protecting people with disabilities from discrimination. Some of the most extensive antidiscrimination laws including protection for individuals in housing have been enacted in Australia, Canada, the United Kingdom, and the United States. These laws in general protect people with disabilities from discrimination in employment through the provision of accommodations and public accommodations or business in regard to the provision of physical access and policy modification.

Internationally, Hong Kong, the Philippines, Costa Rica, Hungary, India, Israel, Japan, Nepal, New Zealand, Peru, and Thailand all have antidiscrimination laws that include protection for people with disabilities in employment, services, and public accommodations but not housing.

Disability Discrimination Act of 1992 (Australia)

The Australian Disability Discrimination Act of 1992 (DDA) prohibits discrimination against people with disabilities in employment, education, land possession, the provision of goods and services, and access to premises, clubs, sports, other facilities, and housing.

Under the act, it is illegal for housing agents to discriminate against an individual with a disability or anyone associated with an individual with a disability by refusing the person's application for housing, discriminating in the way the housing is offered, deferring the application of a person with a disability, limiting or denying access to any service or privilege related to housing, evicting due to disability, and refusing to allow the individual with a disability to make alterations to housing related to disability at the individual with disabilities' expense.

Human Rights Act of 1985 (Canada)

The Canadian Human Rights Act of 1985 prohibits discrimination against individuals with disabilities in the provision of goods and services and facilities that are open to the general public, employment, commercial premises, and housing. Under the act, discriminatory practices in the provision of housing or residential accommodation include denying occupancy to an individual with a disability or giving preferential treatment to a person without a disability over an individual with a disability in any housing negotiation.

Disability Discrimination Act of 1995 (United Kingdom)

The Disability Discrimination Act of 1995 (DDA) provides protection for individuals with disabilities in employment, access to goods and services, and housing. In the area of housing, the DDA makes it illegal to sell or rent property in ways that would discriminate against people with disabilities.

FUTURE OF HOUSING LAW AND POLICY

The future of housing law and policy as it relates to people with disabilities is predominantly a positive one. Throughout the world, many laws have been enacted and policies created that give greater and greater protection to people with disabilities in almost every aspect of housing rental, sale, and purchase. Housing law and policy has moved from a welfare and charity focus to one of empowerment and independence. If the past is any indication, this trend should continue to grow in the future.

—Charles Davis

See also Americans with Disabilities Act of 1990 (United States); Charity; Disability Discrimination Act of 1995 (United Kingdom); Fair Housing Act Amendments of 1988 (United States); Rehabilitation Act of 1973 (United States).

Further Readings

Allen, Michael. 2003, March. "Rights and Responsibilities of Tenants with Disabilities: Cases Construing the Fair Housing Act and Section 504 of the Rehabilitation Act of 1973." Washington, DC: Bazelton Center for Mental Health Law.

Cooper, Jeremy, ed. 2000. *Law, Rights & Disability.* Philadelphia: Jessica Kingsley.

Disability Rights Education and Defense Fund. 2000. "A Survey of International, Comparative and Regional Disability Law Reform." Washington, DC: Disability Rights Education and Defense Fund. Retrieved November 12, 2003 (http://www.dredf.org/symposium/degener1.html).

Graham, Hugh Davis. 2000. "The Surprising Career of Federal Housing Law." *Journal of Policy History* 12(2): 215–232.

Martinez, Mel. 2002. *Fair Housing: Equal Opportunity for All.* Washington, DC: U.S. Department of Housing and Urban Development.

Quadel Consulting. 2003. "About Subsidized Housing in the United States." Washington, DC: Quadel Consulting. Retrieved November 11, 2003 (http://www.quadel.com/resources/history.asp).

Ross, Jamie A., ed. 2001, Spring. "*The Olmstead Factor: Integrating Housing for People with Disabilities.*" The NIMBY Report. Washington, DC: National Low Income Housing Coalition.

Shapiro, Joseph P. 1993. *No Pity.* New York: Random House.

U.S. Commission on Civil Rights. 2000. "Sharing the Dream: Is the ADA Accommodating All?" Washington, DC: U.S. Commission on Civil Rights. Retrieved November 12, 2003 (http://www.usccr.gov/pubs/ada/main.htm).

U.S. Department of Housing and Urban Development. 2001. "Compliance with Section 504 of the Rehabilitation Act of 1973 and the Disability/Accessibility Provisions of the Fair Housing Act of 1988." Federal Notice. Washington, DC: U.S. Department of Housing and Urban Development.

White, Frederic. 2001. "Outing the Madman: Fair Housing for the Mentally Handicapped and Their Right to Privacy versus the Landlord's Duty to Warn and Protect." *Fordam Urban Law Journal* 28(Spring): 783.

HUMAN RIGHTS ACT OF 1998 (UNITED KINGDOM)

"Disability was, until very recently, the forgotten dimension of human rights and unacknowledged as a subject for a right to equality" (Daw 2000:8). It is fair to say, however, that the implementation in October 2000 of the UK Human Rights Act 1998 has led to an increase in the (successful) use of human rights arguments in the context of disability specifically in the United Kingdom.

Prior to the implementation of the act, anyone who wished to complain of a violation of the EU European Convention on Human Rights (referred to below as the convention) had to exhaust domestic remedies for complaint and then take their case before the European Court of Human Rights—there was no means by which a claim of breach of the convention could be brought in the UK courts.

The act—as well as making virtually all of the convention rights directly enforceable in the UK courts—brought fundamental change to the way in which courts and tribunals interpret legislation. Section 6 of the act provides that it is unlawful for a public authority to act in a way that is incompatible with a convention right (i.e., it cannot act in a way that would breach any of the rights in the convention—this is a positive duty placed on public authorities to uphold the convention rights); Section 3 of the act obliges courts to "read and give effect" to legislation in a way that is compatible with the convention rights (this means that when considering any piece of legislation, the court must interpret it in line with the convention rights; e.g., any family law provisions will have to be considered in light of Article 8, the right to respect for private and family life). And courts can make a "declaration of incompatibility" where a legal provision cannot be read and given effect in a way that complies with the convention (i.e., state that it is not possible to interpret the provision in such a way as to be compatible with the convention). Although the government would not be obliged to act following such a declaration, it is likely that it would do so, as otherwise a successful claim against the government could be brought in the European Court of Human Rights.

The convention rights, listed in Schedule 1 to the act, are as follows:

Right to life

Right to freedom from torture and inhuman and degrading treatment

Right to freedom from slavery or servitude

Right to liberty and security

Right to a fair trial

Right to no punishment without law

Right to respect for private and family life

Right to freedom of thought conscience and religion

Right to freedom of expression

Right to freedom of assembly and association

Right to marry

Right to enjoyment of the rights and freedoms without discrimination on any ground

Some of the rights—such as the right to life—are absolute, while others are qualified.

In purely numerical terms, mental health has been one of the areas in which the Human Rights Act has been frequently raised—there have been 10 declarations of incompatibility, three of which have related to the Mental Health Act 1983 and one of which has led to remedial legislation being introduced. Many of these challenges have related to Articles 5 and 6, the right to liberty and the right to a fair trial, respectively.

The key articles that have otherwise been invoked in relation to disability have been Article 2, the right to life (particularly in relation to the withdrawal/refusal of treatment of disabled people); and Article 8, the right to respect for private and family life (and dignity—successfully invoked in a case involving the provision by the local authority of care in the home, and the provision of local authority housing). While it is too early to fully judge the impact of the act in relation to disability, it can nevertheless be said that it is being increasingly invoked by disabled people and there have been some significant successes in cases brought under it.

—Catherine Casserley

See also Disability Discrimination Act of 1995 (United Kingdom).

Further Readings

Bernard v. London Borough of Enfield, EWHC 2282 (2002).

Botta v. Italy, 26 EHRR 241 (1998).

Bowen, Paul. "Is This a Revolution? The Impact of the Human Rights Act on Mental Health Law." Doughty Street Chambers.

Clements, Luke and Janet Read. 2003. *Disabled People and European Human Rights: A Review of the Implications of the 1998 Human Rights Act for Disabled Children and Adults in the UK.* Bristol, UK: Policy Press.

Daw, R. 2000. *The Impact of the Human Rights Act on Disabled People.* London: Disability Rights Commission.

Price v. United Kingdom, 34 EHRR 1285 (2001).

The Queen (On the application of (1) A (2) B v. East Sussex County Council, CO/4843/2001.

The Queen (On the application of Oliver Leslie Burke) and General Medical Council, EWCH 1879 (2004).

HUMANITIES

Disability studies in the humanities has arrived somewhat belatedly, the field having been dominated by medical professionals, rehabilitation specialists, or social scientists who tended to focus on institutional or pathological contexts. Certain studies within the social sciences such as Erving Goffman's *Stigma* (1968), Georges Canguilhem's *Le normal et le pathologique* (1966), and Michel Foucault's *The Birth of the Clinic* (1963) provided humanist scholars with significant tools for complicating the medical model that had dominated the field until the mid-1980s. The emergence of cultural studies in the 1990s helped link disability with identity categories based around gender, race, and sexuality and provided a set of methodological tools for doing cross-cultural analysis. Publications such as David Mitchell and Sharon Snyder's collection, *The Body and Physical Difference,* Rosemarie Garland Thomson's *Extraordinary Bodies,* and Lennard Davis's *Enforcing Normalcy* explored the cultural meanings of disability and linked the disabled body to other identity categories. Special issues of journals devoted to disability issues, the formation of the Modern Language Association's Committee on Disability Issues, the emergence of the Disability in the Humanities chatlist (DS-HUM), and the evolution of interdisciplinary disability studies programs at various universities created a context for studying disability within the humanities.

Disability studies has proceeded through several stages, analogous to those undergone within feminism, queer, or minority activism. Unlike these other identity movements, these stages within disability studies are relatively coterminous, each modifying and adumbrating the other rather than succeeding each other in a linear sequence. The first stage has involved identifying stereotypes of the disabled figure in cultural texts and exploring ways that a physical impairment has been used figuratively as a sign of lack, instability, or moral phobia. First-wave disability studies has created an archive of texts—novels, films, poems, autobiographies, paintings—in which disability is featured and assesses the possibilities for resistance to and rearticulation of those stereotypes.

The second stage—the cultural nationalist moment—coincides with the rise of an activist disability movement and involves establishing a disability community. On the one hand, this implies wresting the category "disability" from definitions established within the medical and psychoanalytic professions. On the other hand, it means establishing consensus among constituencies who may be isolated within medical and therapeutic regimes. Vital to this stage of disability studies is the proliferation of first-person accounts by disabled artists and intellectuals such as those by Nancy Mairs, Audre Lorde, Paul Monette, Robert Murphy, John Hockenberry, and Susan Sontag. Such life-stories are essential for a population that often lacks access to official publishing and media venues and whose narratives are often told by doctors and health care professionals. At the same time, a renewed interest in disabled artists creates a new consciousness of the role that disability has played in the arts (Toulouse Lautrec, Chuck Close, Goya), literature (John Keats, Samuel Johnson), and music (Beethoven). Thus, a main component of second-wave disability work involves giving voice to the disability rights slogan "Nothing about us without us."

A third stage of disability studies emerges in the 1990s, influenced by work in cultural studies and post-structuralism, that attempts to understand processes by which a physical or cognitive impairment becomes stigmatized. Key works by Rosemarie Garland Thomson, Simi Linton, Michael Bérubé, and Lennard Davis focused on the ways that bodily normalcy is reinforced within able-bodied (or what Thomson calls

"normate") society. These works remove the emphasis on the impairment and shift the focus to the ways that society enforces certain cognitive, physical, and sensory ideals.

The stress on a social rather than medical model has led to significant research on the cultural meaning of disability in literature, art, film, and history. Historical work on late nineteenth-century medicine, for example, has revealed the extent to which the concept of disability was invented through projects of national consolidation and racialization. Rosemarie Garland Thomson and Robert Bogdan showed how the phenomenon of freak shows, in which nontraditional bodies were displayed as "human curiosities," becomes an extension of a larger impulse toward standardization of the body. Such scholarship suggests that disability, like homosexuality or race, is largely a product of a specific historical period for which technologies (photography, film), methodologies (statistics, comparative anatomy, psychoanalysis), and social theories (eugenics) contribute to an ideal of normalcy in the Victorian period.

Third-stage disability studies by Lennard Davis, David Mitchell, Sharon Snyder, and Tobin Siebers, while drawing on key formulations by Judith Butler and Michel Foucault, have nevertheless questioned the limitations of social constructionist definitions when faced with actual, historical bodies. Many social constructionists, Siebers (2001:742) argued, "assume that it is extremely difficult to see through the repressive apparatus of modern society to any given body, but when they do manage to spot one, it is rarely disabled. It is usually a body that feels good and looks good." Davis similarly observed that identity is perhaps not the "sharpest instrument" around which to base an intellectual project if the end of all rights-based claims is the ideal of achieving the status of white, middle-class males. It is possible that beneath the liberatory rhetoric of identity politics lurks an idealized norm, for which the disabled body provides an antidote. In *Bending over Backwards* (2002), Davis has created a portmanteau term, "dismodernism," to describe how disability undermines identity positions that emerged with early modernism and that were based around medical and eugenics models.

Third-stage disability studies builds on a cross-cultural analysis, finding parallels between disability and queer or colonial or racialized identities. Many disability theorists have seen their critical projects as analogous to queer theory, "cripping" (on the analogy of "queering") normative discourse to reveal implications of able-bodiedness. Instead of seeing the person with a disability as a metaphor for some other condition (castration, moral phobias), scholars and disability activists have studied the constitutive function of such figures in various cultural objects and documents. David Mitchell and Sharon Snyder, for example, noted that the disabled figure in novels and films perform a "prosthetic" function for narrative. Not only do novels rely on a disabled character to create pathos (Tiny Tim, the Elephant Man) or pathology (Ahab, Lear); such figures are foundational for narrative form itself. What, for example, would be the meaning of Oedipus's tragic loss if he were not blind? Like the prosthetic limb, the disabled person provides an illusion of presence and wholeness that must be eliminated by the end of the novel or film so that the able body can be restored.

These developments in scholarship have important implications for humanities pedagogy. If the humanities is underwritten by an idealized body, what happens when that body does not match Michelangelo's heroic David or Leonardo's Vitruvian Man? More specifically, what happens when the humanities classroom includes a disabled student or instructor? At one level, both have greater access to the physical classroom itself, due to legislation such as the Americans with Disabilities Act and the growth of new technologies (computers, voice translators, distance learning) that make learning more accessible. On another level, the introduction of disability as a subject challenges the student to ask new questions about the self-evident categories of aesthetic and epistemological endeavor. What might the study of poetry be like for a Deaf student for whom "heard melodies" may not be so sweet as those produced by sign language? What is this student to make of terms such as "oral tradition," "limping meters," "eye rhymes," "accentual verse," and other basic terms of prosody that presume a hearing readership and print representation of a spoken text? In like manner, what might humanities study be like if we were to treat *Paradise Lost* as the product of a blind person, the dissonant harmonies of Beethoven's late quartets as the product of a deaf person? Disability asks such questions in order to rethink the "human" in "humanities" and imagine that it

includes a woman with a cane, a child using sign language, a man with a compromised immune system.

—Michael Davidson

See also Anthropology; Disability Studies.

Further Readings

Couser, G. Thomas. 1997. *Recovering Bodies: Illness, Disability, and Life Writing.* Madison: University of Wisconsin Press.

Davis, Lennard J. 1995. *Enforcing Normalcy.* London: Verso.

———. 2002. *Bending over Backwards: Disability, Dismodernism and Other Difficult Positions.* New York: New York University Press.

Mitchell, David T. and Sharon L. Snyder. 2000. *Narrative Prosthesis: Disability and the Dependencies of Discourse.* Ann Arbor: University of Michigan Press.

Siebers, Tobin. 2001. "Disability in Theory: From Social Constructionism to the New Realism of the Body." *American Literary History* 13(Winter): 736–754.

Snyder, Sharon L., Brenda Jo Brueggemann, and Rosemarie Garland Thomson, eds. 2002. *Disability Studies: Enabling the Humanities.* New York: Modern Language Association.

HUMORS, THEORY OF

Humors are bodily fluids that according to some ancient physicians presided over illness and health. The excess of any one of the humors would lead to specific diseases, as a good balance was the condition of health. The theory of humors, which was central in medical theory for centuries, is now completely banished from the field of medicine, even if it is still part of the heritage of some alternative medicines.

The first medical references to humors are found in the Hippocratic corpus:

> The body of man has in itself blood, phlegm, yellow bile and black bile; these make up the nature of his body, and through these he feels pain or enjoys health. Now he enjoys the most perfect health when these elements are duly proportioned to one another in respect of compounding, power and bulk, and when they are perfectly mingled. ([Hippocrates], *Nature of Man* 4, translation by W. H. S. Jones)

These were to become the canonical four humors, but even the Hippocratic corpus contains variations. For instance, the treatise *Diseases* IV lists phlegm, blood, bile, and water ([Hippocrates], *Diseases* IV, 32).

The text *Nature of Man* not only names the humors but also links them with the four seasons and with the mixtures of the qualities warm, cold, dry, and humid. Although the humors are always present in the body and are necessary to life, they are found in greater quantities according to the times of the year: phlegm in the winter, blood in the spring, yellow bile in the summer, and black bile in the autumn. The predominance of one humor is connected with a similarity between the humor and the season. For instance, the increase of phlegm in the winter is related to the fact that phlegm is the coldest humor. Daily occupations, the way you live, and food influence the quantity of the humors in the body: Dark wines, lentils, snails, and the meat of bulls and goats are all prone to produce black bile. Humors are natural and necessary to life, but their mixture needs to be in a state of balance toward one another. An increase in the amount of one humor or in the concentration of one humor in one place can cause diseases, such as hemorrhoids, anthrax, and cancer in the case of black bile. The cures to such imbalances are found in purgation and bloodletting.

The names of the four humors and the theory of humors were to become prevalent because they were attached to the name of Hippocrates and because they were adopted and developed by Galen, the second-century AD physician, who was to become central both in occidental and Arabic medicine. Yet there were competing theories. Praxagoras of Cos, for instance, was able to distinguish 11 humors. On the other hand, Erasistratus of Iulis did not reject the theory of humors, but showed caution, and was bitterly reproached by Galen for this reason. Asclepiades of Bithynia and the Methodists, a medical school that became popular in Rome, rejected the explanation of humors as a cause of diseases.

Galen adopted a system relating the humors to the four elements—earth, air, fire, water —and to a mixture of qualities—warm, cold, dry, humid—and to a certain extent to seasons and ages. Some of the developments of the theory were specifically medieval: the complete theory of the four ages of life; the four temperaments, namely, phlegmatic, sanguine, choleric and melancholic; and the perfect integration of the

microcosm into the macrocosm. Critiques of the humoral theory appeared as early as the Renaissance, but the system was influential until the nineteenth century.

—Anne-France Morand

See also Galen; History of Disability: Early Modern West; Hippocrates; Melancholy.

Further Readings

Galen, 1997. *Selected Works.* Translated by P. N. Singer. Oxford, UK, and New York: Oxford University Press.

———. 2000. "On Black Bile." In *Galen on Food and Diet,* translated by M. Grant. London and New York: Routledge.

[Hippocrates]. 1931. *Nature of Man.* Translated by W. H. S. Jones, Vol. IV. Cambridge, MA: Loeb Classical Library.

Klibansky, Raymond, Erwin Panofsky, and Fritz Saxl. 1964. *Saturn and Melancholy: Studies in the History of Natural Philosophy, Medicine, Religion and Art.* London: Thomas Nelson.

Pigeaud, Jackie. 1985. "L'humeur des anciens." *Nouvelle Revue de Psychanalyse* 32:51–69.

HUNT, PAUL (1937–1979)

British activist

Paul Hunt is regarded by many disability activists as the founder of the modern disabled people's movement. He has been influential not only in the United Kingdom but internationally. It was at Le Court Leonard Cheshire residential home that he and other disabled people first developed the ideas and philosophy that were to inform the Union of the Physically Impaired against Segregation (UPIAS). UPIAS was established in 1972 and can be seen as a key starting point for the development of the British disabled people's movement. Its Fundamental Principles of 1976 gave birth to the social or social oppression model of disability.

Paul Hunt's edited collection (1966) of disabled people's accounts is now identified as one of the key texts in the development of the British disabled people's movement and disabled people's thinking more generally. He was influential both through his writings and as a key participant in UPIAS. Hunt also played a pioneering role in the development of disabled people's (emancipatory) research. He and other disabled people invited academic researchers into Le Court to hear their views and felt betrayed when these researchers conceived of them instead as "parasites." Paul Hunt in turn described such researchers as "parasites, questioned the balance and neutrality of traditional disability research, and raised the question of "whose side are you on?" which continues to concern disability research.

—Peter Beresford and Fran Branfield

See also Disabled Peoples' International; Union of the Physically Impaired against Segregation (UPIAS).

Further Readings

Campbell, Jane and Mike Oliver. 1996. *Disability Politics: Understanding Our Past, Changing Our Future.* Basingstoke, UK: Macmillan.

Hunt, Paul, ed. 1966. *Stigma: The Experience of Disability.* London: G. Chapman.

Websites

Centre for Disability Studies, University of Leeds, http://www.leeds.ac.uk/disability-studies/

HUSSEIN, TAHA (1889–1973)

Egyptian intellectual and modernizer

Taha Hussein (also spelled Husayn) was born in an obscure village of Upper Egypt and lost his sight in early childhood. He learned locally to memorize and recite the Qur'an and continued in 1902 to Al-Azhar University where for centuries there has been a school for blind students of Islam (Dodge 1974). He studied further at the new secular university at Cairo, writing a dissertation on the freethinking blind poet Abu 'l-`Ala al-Ma`arri, with whom he identified. Taha Hussein's abilities and persistence earned him a ticket to study in France from 1915 to 1919. He acquired a doctorate and some Braille, but he relied also on a French reader, Suzanne, who became his wife. Returning to Egypt, Hussein taught literature at the University of Cairo. His first book, using source criticism on pre-Islamic poetry, seemed to impugn parts of the Qur'an, which led to a great uproar. The first volume of his autobiography *Al-Ayyam* (*The Days*) had a better reception, and it is this

cumulative work for which he became internationally celebrated (Husayn 1926–1927, 1940, 1955; Malti-Douglas 1988). A prolific writer, critic, and energetic campaigner for modernization, he was briefly Egypt's Minister of Education (1950–1952), and in the longer term a cultural ambassador between the Arab and Western worlds (Goldschmidt 2000).

—Kumur B. Selim

See also Abu 'l`Ala al-Ma`arri; Blind, History of the.

Further Readings

Dodge, Bayard. 1974. *Al-Azhar: A Millennium of Muslim Learning.* Memorial ed. Washington, DC: Middle East Institute.

Goldschmidt, A., Jr. 2000. "Husayn, Dr. Taha." Pp. 81–83 in *Biographical Dictionary of Modern Egypt.* Boulder, CO: Lynne Rienner.

Husayn, Taha. 1926–1927; 1940; 1955. *Al-Ayyam* (*The Days*), 3 vols. Cairo: Dar al-Ma'arif. Vol. 1, transl. E. H. Paxton (1932), *An Egyptian Childhood*, Washington, DC: Three Continents Press; Vol. 2, transl. H. Wayment (1948), *The Stream of Days,* London: Longmans; Vol. 3, transl. K. Cragg (1976), *A Passage to France,* Leiden: Brill.

Malti-Douglas, Fedwa. 1988. *Blindness and Autobiography: Al-Ayyam of Taha Husayn.* Princeton, NJ: Princeton University Press.

HYDROTHERAPY

Common usage of the term *hydrotherapy* refers to use of relatively large quantities of water on the external surface of the body, including wounds, for water's properties of buoyancy, cleansing, and high thermal capacity, that is, its ability to heat or cool. Related terms include *aquatic physical therapy*, *hot tub therapy*, and *whirlpool bath*. As with other forms of therapeutic heat and cold, hydrotherapy is a treatment, or adjunct to treatment, and not a cure in itself.

The property of buoyancy comes from the pressure exerted on the body by the surrounding water, in proportion to the volume of water displaced by the body. Buoyancy, depending on the depth of the water, allows walking with reduced weight bearing on the joints of the lower limbs. It also reduces the load on the back. This affords the patient with rheumatoid arthritis and other forms of arthritis the chance of near pain-free ambulation. This, in turn, results in improved range of joint motion and even increased fitness, if the patient is very deconditioned to begin with, and the exercise is done with progressively increasing vigor.

The cleansing action of water is greatly helped by agitation and the use of a detergent. This is similar to the action of a clothes washing machine, except that far less detergent is used or needed in hydrotherapy, and the detergent may have antibacterial and emollient (skin softening) properties in addition to breaking up the surface tension of the water, allowing it to "wet" better. Hydrotherapy of this type may be applied with the large Hubbard Tank, which is shaped like the "angels" children make when they lie on their backs in the snow and spread their arms and legs. This shape permits the nurse or therapist to come close to the buoyant patient and remove adherent dressings as they begin to float away from the burns or other wounds. Jets around the sides of the Hubbard Tank agitate the water.

Various sizes and shapes of whirlpool baths enable the patient to sit in a tub or place an arm and hand or leg and foot in the water. Jets can provide more concentrated agitation than is possible with the Hubbard Tank. The most focused form of hydrotherapy for cleansing is applied with pulsatile lavage. With this, no part of the body is submerged, but a device similar to the one used in many homes for teeth and gum hygiene applies sterile saline (salt water in a concentration similar to that of human blood) directly to the wound, to improve the local environment for healing. With pulsed lavage, care must be taken to be sure that there is no *Acinetobacter* in the wound or this can result in pneumonia of the patient treated or other patients in the hospital.

Finally, hydrotherapy allows application of therapeutic heat or cold. The larger the amount of the body submerged, the more care must be taken not to greatly disturb the core (center) temperature of the body. This high thermal capacity of water can be used to the advantage of multiple sclerosis patients, whose symptoms are greatly worsened by heat. They can swim in cool (about 72 degrees F) and obtain aerobic exercise benefit without the adverse effects of increased body temperature.

Water can also be used to "couple" ultrasound to the body part being treated, but no agitation should be

used, since the bubbles will reflect ultrasound and make it ineffective.

—Barbara deLateur

See also Arthritis and Cartilage Diseases and Injuries; Burns.

Further Readings

Basford, Jeffrey R. 2005. "Therapeutic Physical Agents." Pp. 251–270 in *Physical Medicine and Rehabilitation: Principles and Practice,* 4th ed., edited by Joel A. DeLisa, Bruce M. Gans, Nicholas E. Walsh, William L. Boeckenek, Walter R. Frontera, Steve R. Geiringer, Lynn H. Gerber, and William S. Pease. Philadelphia: Lippincott Williams & Wilkins.

Bell, M. J., S. C. Lineker, A. L. Wilkins, C. H. Goldsmith, and E. M. Badley. 1998. "A Randomized Controlled Trial to Evaluate the Efficacy of Community Based Physical Therapy in the Treatment of People with Rheumatoid Arthritis." *Journal of Rheumatology* 25:231–237.

University of Bath and the Royal National Hospital for Rheumatic Diseases Pain Management Unit. 2005, March (last modified). "Annual Report, April 2002-April 2003," p. 7. (http://www.rnhrd.nhs.uk/documents/annual_report/Annual%20Report%202002-003.doc).

HYPERTENSION

Hypertension is one of the most frequently diagnosed disorders in the developed world. In the United States, the cost of antihypertensive drugs accounts for about 10 percent of the country's total spending on medications. Increasingly, hypertension is viewed as a problem also in the developing world. In 2001, the African Union placed it second only to AIDS in the health challenges facing African countries.

Hypertension today is predominantly treated as a risk factor for stroke and heart disease, and treatment is preventive. This has not always been the case. Well into the 1950s, hypertension itself, in its malignant phase, was feared as a disabling and often deadly disease. Most noticeably disabling were effects on patients' eyesight, breathing difficulties, and headaches. Before effective treatments became widely available, people with hypertension were expected to die within one year of diagnosis. Malignant hypertension has become rare in the developed world since the 1940s and 1950s, when more and more patients were treated first by surgery and later with the new antihypertensive drugs. However, poorer sections of the population and members of ethnic minorities still face a higher risk of complications from undiagnosed and untreated hypertension than the more affluent.

The modern, noninvasive method of measuring blood pressure was devised in 1905 by a Russian army surgeon, Nicolai Korotkoff. Physicians examining applicants for industrial life insurance policies in the United States were the first to systematically apply this method. Compilations of actuarial data gathered by the insurance companies, as well as several long-term epidemiological studies undertaken in different countries since World War II, produced evidence of a statistical association between blood pressure and life expectancy, indicating that the higher a person's blood pressure, the higher was the probability that this person might die prematurely. However, the causes of the high blood pressure itself have remained unclear for the majority of patients.

As moderately high blood pressure is statistically associated with a higher probability of early death but does not produce any immediate symptoms, questions of treatment and the determination of a clear boundary between normal and pathological blood pressures have been the subject of intense debates among medical experts. The early drug therapies caused serious side effects, often worse than the symptoms of the disease. These drugs demonstrated that long-term treatment increased the life expectancy of patients with malignant hypertension, but only the development of drugs with less severe side effects, such as thiazide diuretics or beta-blockers, allowed the preventive treatment of patients with mild and moderate hypertension.

Most physicians today follow a pragmatic approach to therapy. They prescribe antihypertensive drugs if the benefits of long-term treatment are likely to be greater than the risks associated with the medication. However, some have continued to argue that in many cases both the neurosis caused by being labeled "hypertensive" and the side effects of the antihypertensive drugs might have worse consequences than the high blood pressure itself.

—Carsten Timmermann

See also Cardiac Conditions; Stroke.

Further Readings

Page, Irvine H. 1988. *Hypertension Research: A Memoir 1920–1960.* New York: Pergamon.

Pickering, George W. 1968. *High Blood Pressure,* 2d ed. London: Churchill.

Postel-Vinay, Nicolas, ed. 1996. *A Century of Arterial Hypertension, 1896–1996.* Chichester, UK: Wiley.

HYPOCHONDRIA

Hypochondria, a word of Greek origin, meaning literally "below the cartilage" (referring to ailments in the abdominal region), gradually acquired the designation of a psychological malady: the morbid preoccupation with serious illness without demonstrable organic disease. This preoccupation is based on a misinterpretation of bodily sensations, functions, or symptoms and persists despite appropriate medical evaluation and reassurance. Affected patients are significantly distressed, and there is impairment in personal, social, and occupational functioning. The beliefs about illness are not delusional in that the individual can acknowledge the possibility of exaggerating symptoms and admit that a dreaded disease state may not exist. Nevertheless, there tends to be a high use of medical care, repeated doctor visits, and costly laboratory and diagnostic testing. The persistence of this pattern for at least six months is necessary to classify it as a psychiatric disorder.

Prevalence estimates for hypochondria in the medical setting, both in the United States and internationally, range from 3 to 5 percent of this population, and it is equally common in males and in females. There does not appear to be any correlation with socioeconomic status, educational level, race, or marital status. Onset can occur at any age but tends to be most common in young adults. There tends to be a high comorbidity with other psychiatric conditions, such as depression, anxiety disorders, and personality disorders. Hypochondria is distinguished from other psychosomatic illnesses by its core feature of fear of having or contracting a disease, as opposed to concern about symptoms (as in somatization disorder), concern about physical appearance (as in body dysmorphic disorder), or disturbances in motor or sensory functions (as in conversion disorder). In addition, hypochondria should be distinguished from malingering or manipulation in that the hypochondriacal patient actually experiences symptoms and is quite anguished about them.

There are various theoretical explanations regarding the psychological origins of hypochondria. These include the transformation of unacceptable hostile or aggressive feelings into physical complaints, that is, to reproach one's caregivers with unremitting suffering; the physical expression of wishes for care and nurturance; a defense against low self-esteem; a defense against guilt, with physical suffering serving as atonement; an attempt to gain sympathy or to control and manipulate, that is, what can be thought of as the secondary gain of the sick role; and as a form of selective attention and cognitive distortion regarding physical sensations.

Although hypochondria tends to be chronic and episodic, some patients do recover, and many respond to a sensitive, individualized treatment approach. Cognitive-behavioral therapy, group therapy, and psychodynamic therapy have all demonstrated some effectiveness. In addition, pharmacotherapy, such as the use of antidepressants, can be used as an adjunct to psychotherapy and educational treatments, especially if there are comorbid symptoms such as depression. In general, a guiding principle of treatment is care rather than cure. The goal of treatment should be aimed at helping the individual cope with and tolerate symptoms rather than trying to eliminate them. An attempt should be made to disconnect the experience of bodily symptoms from receiving care and to encourage the direct, verbal expression of feelings. In the words of the nineteenth-century British anatomist Henry Maudsley: "The sorrow that has no vent in tears makes other organs weep" (quoted in Cantor 1996:60).

—John L. Perri

See also Depression; Psychiatric Disorders; Psychiatry.

Further Readings

American Psychiatric Association. 2000. *Diagnostic and Statistical Manual of Mental Disorders,* 4th ed (text revision). Washington, DC: American Psychiatric Association.

Cantor, Carla with Brian Fallon. 1996. *Phantom Illness: Shattering the Myth of Hypochondria*. Boston and New York: Houghton Mifflin.

Fallon, Brian A. and Suzanne Feinstein. 2001. "Hypochondriasis." Pp. 27–65 in *Somatoform and Factitious Disorders* (Review

of Psychiatry Series, Vol. 20, No. 3, J. M. Oldham and M. B. Riba, series eds.), edited by Katharine A. Phillips. Washington, DC: American Psychiatric Publishing.

Hilty, Donald M., Mona Gill, and Kelly A. Biegler. 2002. "Hypochondriasis." Retrieved May 8, 2002 (http://www.emedicine.com/med/topic3122.htm).

Starcevic, Vladan and Don R. Lipsitt, eds. 2001. *Hypochondriasis: Modern Perspectives on an Ancient Malady.* New York: Oxford University Press.

HYSTERIA

No longer part of psychiatry's official diagnostic nomenclature, *hysteria* is a term that continues to capture the public imagination, despite the fact that its significance is largely historical. The term, whose origins and definition have been the subject of centuries of scholarly debate, is generally used to describe a wide range of behaviors and symptoms—from paralysis to blindness to cough—that do not appear to result from physical illness. From the ancient Egyptians to Hippocrates to Freud and Charcot to contemporary psychiatry, hysteria has played an important role in our efforts to understand the duality of mind and body.

ANCIENT ORIGINS

Taking its name from the Greek *hystera,* meaning uterus, hysteria originated as a disorder of women. Although the standard historical account dates its inception to Hippocrates, called the father of medicine, references to the disorder can be found as early as 1900 BC in the *Kahun Papyrus,* an Egyptian medical manuscript. The ancient Egyptians believed that the uterus was an independent organism whose movement within the body led to behavioral disturbances. This idea was further elaborated by classical healers and philosophers (including Plato), who believed that as the womb wandered throughout the body, it created symptoms particular to its location. For example, cough and loss of voice, as well as a choking sensation known as *globus hystericus,* were believed to be the result of the uterus migrating to the throat.

Hippocratic texts linked uterine migration to abnormal sexual activity, including abstinence, and consequently recommended marriage and pregnancy as primary treatments. Additional measures—derived from the ancient Egyptians—focused on returning the womb to its proper location, either by cleansing the woman's vagina with fragrant substances to attract the uterus or by ingesting foul-tasting potions to drive the womb away from the upper body. Galen of Pergamon (AD 129–ca. 199/216), who believed that hysteria was due not to movement of the uterus but to uterine retention of a fluid analogous to male semen, proposed a cure that involved release of the congested sperm through increased sexual activity or digital manipulation by the physician—essentially, cure by orgasm.

Beginning in the seventeenth century, the uterine theory of hysteria gave way to a neural etiology, as physicians such as Thomas Sydenham (1624–1689) began to describe hysteria as an affliction of the mind that found expression in the body. It was now theoretically possible for men, in whom similar symptoms had previously been diagnosed as hypochondriasis, to suffer from hysteria. In practice, however, most of the patients remained women.

JEAN MARTIN CHARCOT (1825–1893)

Jean Martin Charcot, a French physician who was the director of the Paris women's hospital, the Salpêtrière, in the 1880s, is widely considered to be the father of modern hysteria. A neurologist who had made a name for himself using the "anatomical-clinical method" to study multiple sclerosis, poliomyelitis, neurosyphilis, and amyotrophic lateral sclerosis, Charcot turned his considerable nosologic skills to hysteria. He described a four-stage epileptiform attack, three categories of hysterical stigmata (sensory disturbances, such as anesthesias; disturbances of the senses, such as deafness or blindness; and motor disturbances, such as paralysis), and 20 hysterogenic zones on the female body. Charcot demonstrated the attacks at two weekly public performances at the Salpêtrière, in which hysterical patients would be hypnotized and display their symptoms to audiences of as many as 500. Toward the end of his life, Charcot's ideas were challenged by his rivals, including both some of his own students and Hippolyte Bernheim of the University of Nancy (known as the Nancy school), who suggested that

Charcot's patients had been coached and were not acting under natural hypnosis.

After his death, Charcot's study of hysteria was continued by his protégé, Pierre Janet, a French physician who delivered a famous series of 15 lectures titled "The Major Symptoms of Hysteria" at the inauguration of the new buildings at Harvard Medical School in 1906. Janet described hysteria as characterized by *idée fixé* (fixed ideas) that lingered below the surface of consciousness, and he may have predated Freud in his belief that treatment of hysteria involved making these unconscious ideas manifest.

SIGMUND FREUD (1856–1939)

Sigmund Freud, the father of psychoanalysis, studied with Charcot at the Salpêtrière in 1885 and 1886 and developed his own account of hysteria's neurotic origins. Based on 10 years of work with hysterical patients, he and Joseph Breuer wrote *Studies on Hysteria* (1895), a volume of case studies in which they argued that hysterical symptoms were the expression of psychic trauma and that the cure involved retrieving memories of the originating event, often through hypnosis. Breuer's first case was of Anna O. (a pseudonym for Bertha Pappenheim, who later became an active feminist), a young woman who developed multiple physical symptoms—cough, headaches, contractures of her right arm and leg, sleepwalking, and loss of voice—in the context of nursing her ill father. During the course of her treatment with Breuer—a method she called "the talking cure"—she translated her symptoms into a narrative, bringing to light her internal conflict between her guilt over her father's death and her desire to escape a repressive, patriarchal family. "Hysterics suffers mainly from reminiscences," Breuer and Freud wrote, theorizing that hysterical symptoms are due to selective blockage of memory. Out of hysteria, psychoanalysis was born.

By 1896, Freud had developed the "seduction theory," a model of hysteria based on the notion that the condition originated from repressed memories of childhood (and sometimes infantile) sexual abuse, often perpetrated by the father. By the following year, however, he had abandoned this theory, hypothesizing instead that hysterical patients were expressing fantasies based on their own unconscious Oedipal desires. In 1905, he published "Fragment of an Analysis of a Case of Hysteria," in which he described the case of Dora (a pseudonym for Ida Bauer), a young woman with relatively mild hysteric symptoms—chronic cough, headaches, and depressions—who had been brought to see Freud by her father after threatening suicide. Dora accused her father of having an affair with a family friend, Frau K., and felt that because of his desire to protect the secret of his own adultery, her father had turned a blind eye to the fact that Frau K.'s husband, Herr K., was making sexual advances toward Dora. Freud interpreted the situation in light of his own Oedipal theories, concluding that Dora was unconsciously attracted to Herr K. as a stand-in for her father. After 11 weeks, Dora broke off the treatment; but despite its short duration, this case remains one the most important in the history of hysteria, providing the first example of Freud's theory that hysteria represented a conversion of forbidden (and unconscious) libidinous impulses into physical symbolization.

Women treated for hysteria in the nineteenth century were often significantly disabled. Unable to engage in the work of relationships and daily life, they frequently required 24-hour care at home, or—if their families could not afford in-home care—were institutionalized for life.

IN THE TWENTIETH– AND TWENTY-FIRST CENTURIES

In the years after Freud, hysteria splintered into multiple psychiatric diagnoses, including hysterical conversion (or conversion hysteria), hysterical personality, and multiple personality disorder. The change reflected the conflict between a symptom-based approach (hysteria as something that one *has*) and a character-based approach (hysteria as something that one *is*). *Conversion hysteria* described the disorder in which psychological phenomena are expressed through physical symptoms, while *hysterical personality* described a character structure distinguished by emotional instability, dependency, self-dramatization, vanity, attention seeking, seductiveness, self-centeredness, and immaturity (traits listed in the second edition of the *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association). In 1952, hysteria was removed from

psychiatry's lexicon, partially in response to criticisms that the term was too nebulous and that it perpetuated misogyny. Around the same period, in an attempt to clarify and destigmatize the disorder, hysteria was renamed *Briquet's syndrome*, after the French physician Pierre Briquet, who treated hysterics in the mid-nineteenth century.

With the publication of *DSM-III* (*Diagnostic and Statistical Manual of Mental Disorders*, third edition), hysteria was subsumed by three major categories: somatoform disorders, dissociative disorders, and personality disorders. In *DSM-IV* (American Psychiatric Association, 2000) conversion hysteria is now known either as *conversion disorder*, a disorder in which pseudo-neurological symptoms (including blindness, numbness, paralysis, and pseudo-seizures) appear without organic etiology and context of stressful life events, or *somatization disorder*, in which unexplained physical symptoms occur in three domains (sexual, pseudo-neurological, and gastrointestinal). Hysterical personality is now known as *histrionic personality disorder*, a disorder diagnosed mostly in women and characterized by excessive emotionality and attention seeking.

The notion of dissociated traumatic memories, once so important to understanding hysteria, has been relegated to the category of dissociative disorders, including a range of phenomena, from *dissociative fugue*, characterized by a brief period of amnesia, to *dissociative identity disorder*, in which a person's consciousness has been splintered into multiple distinct identities (often as a result of childhood sexual abuse).

—Sonya Rasminsky

See also Depression; Dissociative Disorders; Sigmund Freud; Hippocrates; Psychiatric Disorders; Psychiatry.

Further Readings

American Psychiatric Association. 2000. *Diagnostic and Statistical Manual of Mental Disorders,* 4th ed (text revision). Washington, DC: American Psychiatric Association.

Gilman, Sander L., et al. 1993. *Hysteria Beyond Freud.* Berkeley: University of California Press.

Micale, Mark S. 1989. "Hysteria and Its Historiography: A Review of Past and Present Writings I and II." *History of Science* 17:223–261, 319–351.

Showalter, Elaine. 1997. *Hystories: Hysterical Epidemics and Modern Culture.* New York: Columbia University Press.

Slavney, Phillip. 1990. *Perspectives on "Hysteria."* Baltimore: Johns Hopkins University Press.

Veith, Ilza. 1965. *Hysteria: The History of a Disease.* Chicago: University of Chicago Press.

I

IBN AL-ATHIR (1149–1210)

Arab scholar

Majd Ad-Din ibn Al-Athir was a learned man of Mosul who wrote works on hadiths and philology and held high office in the administration. Eventually the opportunity of associating with powerful men lost its charm. While working as secretary of state to the lord of Mosul, Ibn Al-Athir suffered paralysis of his arms and legs, which obliged him to retire from public service. A healer from the Maghreb came to treat him, and Ibn Al-Athir began to regain the use of his limbs. He then asked his brother to pay the healer a suitable fee and send him away. He explained that, in his present condition, he was under no obligation to visit the great and court their favor with the usual tedious ceremonies. He was enjoying rest and solitude. If anything serious occurred that needed his attention, people would come and ask his advice. To remove this liberty by continuing in therapy would be pointless. He preferred to spend his remaining days in peace. Ibn Al-Athir's family admitted the strength of his argument and discontinued the treatment.

—Kumur B. Selim

Further Readings

Ibn Khallikan's Biographical Dictionary. 1842–1871. Translated by Mac Guckin de Slane, Vol. 2, pp. 551–554. Paris.

Rosenthal, F. 1971. "Ibn al-Athar." Pp. 723–725 in *Encyclopaedia of Islam,* new edition, Vol. 3. Leiden, Netherlands: Brill.

IBN SIRIN (654–728)

Arab law lecturer

Muhammad ibn Sirin of Basra was an esteemed law lecturer, also valued as an accurate transmitter of sayings of the prophet Muhammad, though these skills seem hardly to have been lucrative. His father had been a coppersmith, a trade hazardous to the hearing of anyone near the noise. Ibn Sirin worked as a draper but was imprisoned for debt and is said to have died in debt. He was well known to have impaired hearing. To students of law, "As-Shabi used to say 'Stick to that deaf man!' meaning thereby Ibn Sirin; because he was dull of hearing" (*Ibn Khallikan's Biographical Dictionary* 1842–1871), but evidently he was worth hearing on law and on the sayings of Muhammad. He also became famous for interpreting dreams and was a man of great piety and notable eccentricity.

—Kumur B. Selim

Further Readings

Fahd, T. 1971. "Ibn Sirin." Pp. 947–948 in *Encyclopaedia of Islam,* new edition, Vol. 3. Leiden, Netherlands: Brill.

Ibn Khallikan's Biographical Dictionary. 1842–1871. Translated by Mac Guckin de Slane, Vol. 2, pp. 586–589. Paris.

IBN UMM MAKTUM (SIXTH CENTURY)

Companion of the prophet Muhammad

Abdullah ibn Umm Maktum, a companion of the prophet Muhammad and relative of Muhammad's

wife Khadijah, was born blind. He was among the earliest believers in Islam and was reportedly keen to learn the Qur'an from the mouth of Muhammad. Once when Muhammad was debating with leaders of the Quraysh tribe, Ibn Umm Maktum interrupted the prophet, who frowned and turned away. Afterward, Muhammad announced a revelation from Allah, which appears in the Qur'an, Sura 80. This seems to censure Muhammad for turning away from Ibn Umm Maktum (other interpretations also exist). Several incidents are recorded in which Ibn Umm Maktum's blindness figured. For example, once he failed to give the dawn call to prayer until a sighted person told him it was morning; another blind man was allowed to pray at home because he lacked anyone to guide him to the mosque, but Ibn Umm Maktum was not granted this dispensation, possibly because he was a potential prayer leader. Sometimes when Muhammad needed to be away from Madinah, he is said to have made Ibn Umm Maktum governor of the city during his absence, indicating high confidence in his character and ability.

—Kumur B. Selim

Further Readings

Al-Baghawi (revised by at-Tibrizi). 1994. *Mishkat al-masabih,* repr. Translated by J. Robson, Pp. 138, 217, 221, 231, 708. Lahore, Pakistan: Sh. Muhammad Ashraf.

ICF/ICIDH

See International Classification of Functioning, Disability, and Health (ICF/ICIDH)

IDENTITY

Identity can be defined as the way people view themselves and how others understand them and their roles and relationships in society. Identity is important because it allows individuals to answer the questions Who am I? and Who are you? Identities have personal and social dimensions—they have both commonalities (what people share with each other) as well as unique elements (which characterize an individual alone). The development of identity is therefore a continual, reflexive process.

Like other forms of identity, disability identity is an incredibly complex phenomenon. The experience of disability is only one element of a person's identity—among the many other factors that may also influence identity are age, gender, race, religion, class, sexuality, and nationality. Some people with disabilities argue that disability is one of the least important elements of their identities, whereas others suggest that it is central to their lives and personalities. Negative stereotypes about disability mean that some people are reluctant to identify as disabled for fear that they might face discrimination and prejudice. On the other hand, others have been encouraged to identify publicly as disabled by the growth of disability culture and the disability pride movement.

Identity formation is often influenced by wider cultural processes of representation and stereotyping, which can give individuals a sense of their expected roles in society. These social processes can allocate some groups to the social margins and give others a sense of entitlement and power. A number of common stereotypes regarding disability have influenced the identity formation processes of many disabled people. The work of Wolf Wolfensberger has helped to identify many of the stereotypes that have historically been associated with disabled people, including representations of disabled people as animals or as subhumans, as a burden, as eternal children, as a menace to society, as sick or diseased, as objects of ridicule, and as holy innocents. Each of these stereotypes, in its own way, contributes to the social devaluation and exclusion of disabled people. Such stereotypes not only lead some disabled individuals to feel less valuable than other persons, they can also contribute to wider social processes of rejection, segregation, abuse, loss of opportunities, and poverty. Two quite different responses have developed in regard to these processes of devaluation: a conservative response, known as *normalization,* and a more radical response, known as *disability pride.*

Normalization involves attempts to organize the lives of disabled people and to structure service delivery in ways that will ensure that disabled people occupy "socially valued" roles. Wolfensberger and

Thomas (1983) argue that human services should support disabled people in participating "in valued activities, in valued settings with valued citizens" (p. 1). This means that service-providing agencies should blend in with their community settings. They should also be located away from devalued groups and should engage in activities that enhance the social image of their clients. Within the disability rights movement, normalization is often regarded as a conservative philosophy and practice, because it is an approach that tries to change disabled people rather than the practices of a disabling society. Also, it assumes that the norms of the dominant group in society are unproblematic—that disabled people need to adopt "socially valued" identities rather than build their own positive social identity as disabled people. In this regard, normalization seems quite hostile to diversity and difference.

A more radical approach to difference can be found in the cultural politics known as disability pride, which is based on the idea that developing a positive sense of disability identity involves challenging narrow conceptions of normality. It therefore involves finding merit in the atypical, beauty in the uncommon, and value in the unusual. Disability activists who support this philosophy have often argued that *normality* and *abnormality* are value-laden terms that have enormous power to harm. For instance, Linton (1998) suggests that these concepts affect individuals' most private thoughts about their worth, social position, and acceptability. The association of disability with abnormality denies legitimacy to the experiences of disabled people. Likewise, Davis (1995) understands disability not as an object of the body but as part of a hegemonic way of thinking about the body and its role in the body politic. Davis believes that the goal of disability activists has often been "to help 'normal' people to see the quotation marks around their assumed state."

Carol Gill (2001) argues that the identities of disabled people are often devalued by messages of partial acceptance. She highlights the contradictory nature of many responses to disability, such as admiration and nurturance combined with charity and paternalism. Many disabled people are socialized into believing that parts of them are unacceptable, and they feel compelled to hide some parts of themselves in order to project a more acceptable image. Gill stresses that such processes can reduce a person's self-esteem and self-determination. In an article first published in 1995, Gill identifies four distinct elements of the development of disability identity and disability culture: fortification, unification, communication, and recruitment. She argues that collective gatherings of disabled people and expressions of disability culture fortify the identities of disabled people; unite disparate sections of the disability movement around common issues; promote a shared appreciation of certain art, language, symbols, and rituals; and form the basis for recruiting new members into a vibrant community. It nevertheless needs to be recognized that membership in the disability community is different from belonging to many other cultures. In particular, unlike people who are members of ethnic minority groups, many disabled people grow up in families where they are the only members with that identity. This can make it difficult for a disabled person to develop a positive sense of identity, as family members are sometimes ashamed of the disabled person or feel guilty about his or her disability. Like many people with nonheterosexual identities, many disabled people experience familial estrangement and look elsewhere for peer support.

A SENSE OF "US" AND "THEM"

When people organize in groups, they mark their identities by distinguishing themselves from others. In times of crisis, people tend to desire a sense of certainty and may gain security from the feelings of belonging that their identities bestow on them. Group identities are therefore based on a sense of difference, and there is often a temptation within groups to develop a binary approach to identity—that is, a strong sense of "us" as very distinct from "them." In practice, members of groups often strengthen their own sense of identity by exaggerating group members' differences from nonmembers and ignoring the diversity that may exist within their own group. For instance, within a group of disabled people there may be individuals from different socioeconomic groups, ethnicities, and locations, but the group members may

develop a sense of collective identity by highlighting what they have in common rather than focusing on their differences.

The boundaries of identities are always open to dispute. Groups always exclude some people who challenge that exclusion by contesting the boundaries of the groups' identities. Likewise, some people assert their right to their own unique identities and object to assumptions that they are represented by any group. A good example of this issue within a disability context is the case of Deaf people. Some people who are Deaf assert that they belong to a unique cultural and linguistic group, and they believe that they are not "disabled." Others emphasize the experiences of discrimination based on physical difference that they have in common with disabled people in general and strongly identify as disabled. This example reflects one of the biggest problems with identity politics—the fact that boundaries are not as secure as some political rhetoric might suggest.

Identities are often represented symbolically. For instance, in many Western countries, a common symbol used to represent disability identity is that of a wheelchair. Depictions of wheelchairs are used on signs in malls, parking garages, and other public spaces in order to indicate that a space can accommodate the needs of disabled people. However, there is often an element of exclusion embedded in such symbols (for instance, a wheelchair symbol may not seem appropriate for people who do not use wheelchairs and whose impairments are located in other parts of their bodies). Identities require a personal emotional investment, and when people feel alienated by symbols that they feel do not include them, they may resist identifying with the groups represented by those symbols.

Mental health system survivors constitute another group of people who have voiced significant problems with the disability identity. Barnes and Shardlow (1996) point out that there are particular exclusions from citizenship rights (such as involuntary commitment, forced medical treatment, and supervision following discharge from hospital) that mental health system survivors alone experience, and the disability movement in general has avoided discussion of these issues. Also, people who have experienced severe mental distress may be very reluctant to identify as disabled when they are well (i.e., when they are not experiencing any symptoms of their illness).

The long-term process of living with a disability identity is very different from the "sick role" that Talcott Parsons envisioned in 1951. Parsons suggested that "being sick" was a temporary, socially sanctioned interruption to good health. His arguments were innovative because he realized that illness is as much a social role (excusing people from work for a short period of time) as it is a medical condition. Although this concept was useful in the 1950s because it challenged the biological reductionism of that era, it relied on a health/illness binary that did not exist in practice, and it did not recognize that many disabled people are not ill (although some are). The process of developing and maintaining a positive disability identity involves a far more complex dynamic than simply managing one's health.

For people with developmental disabilities, the advocacy group People First has provided an important impetus for a positive disability identity. Based on principles of self-advocacy, this organization's work is based on the principle that developmentally disabled people need to engage in self-advocacy, emphasizing, "We are people first; our disabilities come second." This emphasis on a language of "people first" is different in some respects from the approach of those British disability activists who have chosen to identify as "disabled people." The rationale for this language is that disability is a form of oppression similar to racism and sexism, and in the same way as one would not use the language "person with racism" or "person with sexism," one would not refer to a "person with a disability." This argument is very popular in Britain, but it is a minority position in other countries.

The concept of stigma, as developed in the work of Erving Goffman (1961, 1963), has been very important in terms of an understanding of disability identity. According to Goffman, stigma is a deeply discrediting experience that separates certain groups of individuals (such as disabled people) from what he calls "normals." Goffman highlights many of the social processes that can undermine a disabled person's self-esteem, such as public staring, unwanted help, and invasions of privacy. He also addresses the differences in experiences

between people whose stigma is visible and those whose stigma is invisible. For the latter group, Goffman notes, negotiating identities involves making decisions about "passing" and disclosure. Michael Oliver (1990) has criticized Goffman's concept of stigma because it suggests that disability is an individual trait rather than a social dynamic rooted in structural oppression. Watson (2003) argues that Oliver's reading of Goffman is unfair and incomplete, however, and asserts that the connections between stigma and broader social structures are present in Goffman's work.

NARRATIVES AND IDENTITY

Tom Shakespeare (1996) stresses the importance of narratives in terms of disability identity, stating, "Disability identity is about stories, having the space to tell them, and an audience that will listen" (p. 111). He suggests that the stories we tell about the lives of disabled people are very important in terms of their individual and collective effects. Positive narratives of disability help disabled individuals to develop a sense of pride and overcome internalized oppression, but such narratives also are a condition for collective organization. Likewise, Shakespeare argues that involvement in the collective disability movement can assist individuals in the development of a positive disability identity.

Major cultural stereotypes have significant effects on the types of narratives told about disabled people, with attendant effects on disability identities. One of the major cultural constructions around disability that has had a significant impact on the identities of many disabled people is the image of the poster child. In his history of the American disability rights movement, Joseph Shapiro (1993) comments that "no other symbol of disability is more beloved by Americans than the cute and courageous poster child—or more loathed by people with disabilities themselves" (p. 12). The concept of the poster child is controversial because it assumes the presentation of the disabled child as a symbol of pity, and pity is associated with identities that are inferior, tragic, helpless, and dependent. The images of disability associated with the poster child are also controversial because of their connections to another important disability stereotype: the "supercrip"—that is, a disabled person who has successfully "overcome" his or her disability, triumphing over presumed tragedy. This image also has important effects on disability identities. Shapiro argues that fear underlies both pity for the poster child and the celebration of the supercrip. Neither the supercrip nor the poster child is accepted as equal to the nondisabled—both, in different ways, are positioned as "Other." Another historically important barrier to positive disability identities was the freak show. In the freak show, disabled people were often positioned as "monstrous," "deformed," and "bizarre." Hierarchies of embodiment were cultivated by the freak show, leading many disabled people to loathe themselves and their bodies. Cultural spectacles such as the freak show helped to establish a disability identity as a mark of otherness.

The development of a disability culture and the rise of disability pride have been major influences on the identities of many disabled people in recent years. Eli Clare (1999) has highlighted the importance of disability pride in providing an impetus for collective action, such as the campaigns of disability rights activists around the inappropriate placement of disabled people in nursing homes. Clare believes that the significance of disability pride lies in its capacity to overturn shame, isolation, and silence around human rights abuses. Whereas pride involves strength, joy, and anger, internalized oppression involves shame, denial, fear, and self-loathing. It is therefore an act of resistance, Clare argues, to turn internalized oppression into pride.

Clare promotes a transgressive disability identity that involves *flaunting,* which includes the reclaiming of words of hatred to turn them into words of pride. In recent years, some disability activists have reclaimed words such as *crip* and *gimp* as a form of cultural defiance. However, Clare notes that flaunting may be a double-edged sword, because words of hate still retain their original meanings at some level. Those who argue for transgression and flaunting often also explicitly reject another political position—assimilation. The argument for assimilation rests on the common humanity of disabled and nondisabled; it emphasizes that disabled people are "just like you" and therefore deserve exactly the same rights as nondisabled people. The proponents of transgression suggest that this is a minimalist agenda that leaves unchanged some of the

major elements of disability oppression, such as restrictive notions of body shape, beauty, normality, and intellect.

Ian Parsons makes an argument similar to Clare's in his book *Cripples, Coons, Fags and Fems: A Look at How Four Human Rights Movements Have Fought Prejudice* (1999). Parsons argues that social movements encourage their participants to move beyond a simple pride in their humanity into a celebration of their difference. In this context, Parsons encourages disabled people to develop transgressive identities that accentuate, rather than minimize, their sense of difference. According to Parsons, in order to challenge and change traditional structures, people must sometimes adopt confrontational and controversial tactics, such as organizing along separatist lines (as do organizations that accept only disabled people as members).

VARIABLES AFFECTING DISABILITY IDENTITY

Disability is only one of many identities that disabled individuals have. Diversity is the hallmark of the disability movement, and no one person or group can speak on behalf of all disabled people. Disability scholars from ethnic minority backgrounds, such as Ayesha Vernon (1998), have argued that there is a temptation to separate discussions of disability from other dimensions of social life, such as experiences of racism and sexism. Vernon asserts that such an approach is based on a problematic additive model of identity that fails to examine the ways in which social forces often operate together. Vernon stresses that sexism, racism, and disableism can operate in isolation or in combination, and that when these forces operate simultaneously, they are often more powerful than the sum of the parts. In this context, Vernon argues that disabled people who are also members of ethnic minority groups can often be positioned as "multiple Others." Likewise, Ahmad, Darr, and Jones (2000) suggest that cultural diversity within the Deaf community is often ignored, and experiences of racist marginalization among Deaf people are rarely acknowledged. These authors note that self-organization by ethnic minority Deaf people involves negotiating an identity that includes Deafness as well as ethnicity and religion. What this means in practice is that professionals have a responsibility to assist Deaf children in becoming aware of their ethnic and religious backgrounds as well as their Deafness.

Historically, disability has been central to debates about social inequality, immigration, and citizenship. People with other stigmatized identities have often made significant efforts to distance themselves from disability, which has often been assumed to be a marker of real, biological inferiority. Douglas Baynton's (2001) excellent historical research on immigration policy in the United States—an area not usually associated with disability—suggests that the central discourse used by various immigrant groups in order to define their worthiness as U.S. citizens was that *they were not disabled.* The absence or presence of disability was a key factor in debates over who deserved to be included and excluded as citizens. Likewise, Rosemarie Garland Thomson (1997) observes that discursive links have often been drawn between women and disabled people in attempts to denigrate and sometimes to defend women. In making this connection, however, Thomson notes an important difference between feminization and disability when she argues that people stare at disabled people, whereas they gaze at women.

Over the past 30 years, disabled women and feminist scholars have consistently emphasized the fundamental importance of gender in the experience of disability and in the development of disability identities. However, Morris (1991) argues that the political agenda of the disability movement has tended to ignore the specific concerns of disabled women with regard to gendered family and domestic roles. Meekosha and Dowse (1997) assert that disabled women are often placed in an ambiguous position relative to the public and private spheres—somewhere between the public and the private, and yet framed as a "burden" in both. These authors stress that disabled women's identities are structured by the intersection of gender, disability, and the denial of citizenship rights in many areas, including sexuality, reproductive rights, and marriage rights.

Rolland (1988) argues that the type of identity developed by a disabled person is strongly dependent on the type of impairment the individual has and whether the impairment is new, chronic, or terminal. For instance,

for people with progressive impairments such as Lou Gehrig's disease or diabetes, the increasing severity of their impairment over time has a huge impact on their individual identities. Rolland suggests that although it may be possible for a person in the early stages of such impairment to deny a disability identity, as the impairment becomes more severe, the individual needs to incorporate this experience into his or her identity. In contrast, people with sudden and traumatic impairments often experience crises of identity as they struggle to come to terms with their new life experiences. Rolland asserts that such a sudden identity crisis is less likely in an individual whose impairment has existed since birth. Rolland suggests that people who have relapsing or episodic impairments face a different set of identity issues, particularly relating to disclosure, denial, and anxiety over relapses.

Priestley's (1999) examination of the experiences of disabled children in mainstream schools suggests that the identities of disabled children are structured by the discourses that circulate throughout the education system, such as those of "charity," "treatment," and "provision." Middleton (1999) notes that disabled children are often assumed to be genderless, raceless, asexual, and classless, and so they need to be supported in developing positive self-images in all these areas. In their study of children and disability, Baker and Donelly (2001) found that four important social dynamics have significant effects on the identities of disabled children: Disabled children (a) generally have few disabled friends, (b) socialize with peers who are not disabled, (c) are less popular and more often abused than nondisabled children, and (d) have more unstable, conflictual, and uncooperative relationships than do nondisabled children. Baker and Donelly therefore argue that increased attention needs to be placed on the environments in which disabled children grow up; family and school responses to disability need to be changed in order to cultivate safer environments and more positive identities among disabled children.

Marks (1999) identifies four major psychological processes that discourage acceptance of a disability identity: splitting, projection, reaction formation, and rationalization. These defenses against disability can, respectively, lead people to attribute negative characteristics to all disabled people, to project negative attributes onto disabled people, to hide or obscure their real feelings around disabled people, and to rationalize discriminatory treatment.

Robert Scott's classic study *The Making of Blind Men* (1969) emphasizes another important factor in the development of a disability identity: contact with the disability service system. Scott argues that blindness is a learned social role, rather than a biological fact: "Blind men are not born, they are made" (p. 121). He stresses the social nature of this role by pointing out that the vast majority of people who are classified as blind can actually see at some level. Rather than being completely sightless, Scott presents these people as "sighted people who experience difficulty seeing" (p. 43). The importance of socialization is evident because of the key role that "blindness workers" play in the development of the attitudes, behaviors, and emotions associated with being blind. In effect, Scott argues, these workers teach their clients how to behave like "blind people."

ERIKSON'S THEORY OF IDENTITY DEVELOPMENT

One of the most influential psychoanalytic theories dealing with identity development is that presented by Erik Erikson (1963). This theory suggests that human beings pass through eight stages of identity development over the life cycle. In the first stage, from birth to 18 months of age, babies develop their sense of trust, or mistrust. From 18 months to 3 years, toddlers develop some sense of autonomy—or a sense of shame and doubt. In the preschool age, from 3 to 6 years, children develop a sense of initiative, or they develop a fear of failure as a result of guilt or punishment. From 6 to 11 years, children develop a sense of industry (confidence and skills for work as they learn to enjoy their achievements), or they develop a sense of inferiority. In adolescence, from 12 to 18 years, young people develop a sense of identity (or role confusion) in terms of sex roles, occupation, religion, and politics. Erikson invented the term *identity crisis* to explain the troubled sense of self that some people experience. In young adulthood, from 19 to 40 years, people develop a sense of intimacy or isolation in terms of personal relationships. From ages 40 to 65,

adults face a basic conflict regarding generativity or stagnation—finding a meaningful way to support the next generation. After 65, individuals reflect on their lives and experience either ego integrity or despair. Erikson believed that each of these developmental crises occurs at a certain stage in a person's life but is never resolved permanently. For instance, people return to the struggle over trust and mistrust at various stages of their lives. There is a danger that people's achievements in one of these areas may be undermined by later developments—but, conversely, failure to negotiate one of the stages of identity development successfully can be rectified by later growth.

A number of disability scholars have taken issue with Erikson's theory. By mechanistically applying the stages described by Erikson, psychologists have positioned many disabled people as having automatically missed key stages of human development. In their critique of Erikson's theory, Mackelprang and Salsgiver (1999) argue that nondisabled people are the template for the theory, which ignores the healthy development of disabled people—or assumes that such development is impossible.

ESSENTIALIST AND SOCIAL CONSTRUCTIONIST APPROACHES TO IDENTITY

Political rhetoric often draws on notions of a well-defined community with a shared past and tradition in order to bind people to a common identity. This rhetoric, which relies on a sense of clear-cut boundaries around an unchanging, fixed identity, has been called a tendency toward essentialism within identity politics. An essentialist approach to disability identity would suggest there are certain characteristics that all disabled people share. An essentialist approach to identity can be contrasted with a social constructionist approach, which emphasizes the socially constructed, contingent, and fluid nature of identity. A social constructionist approach to disability identity would suggest that there are significant differences as well as similarities among disabled people and would recognize that the meaning of disability changes over time and across cultures. It would therefore problematize any claim that one set of experiences is the only "true" disability identity.

Some sociologists, such as Anthony Giddens (1991), argue that the modern world could be characterized as a "risk society"—that is, a society in which social change is progressing at such a rapid rate that people experience a heightened sense of uncertainty that profoundly affects their identities. Giddens asserts that traditional patterns and habits are less influential in a risk society, where people are pressured to express their identities through their lifestyles. As a sociologist, Giddens is interested in the social and economic pressures that operate in modern consumer societies. He highlights the social and economic changes that have resulted in a veritable explosion of ways in which to express individual lifestyles, preferences, and identities. These social and economic pressures make essentialist notions of identity even less credible.

In his book *Bending over Backwards: Disability, Dismodernism and Other Difficult Positions* (2002), Lennard Davis argues that disability identity is inherently unstable, but that this malleability can be part of a new way of thinking about identity. Davis asserts that essentialist notions of identity are discredited and outdated, but that the instability inherent in self-definitions of disability allows disability identity to transcend the problems of identity politics. Davis therefore believes that disability may be "the postmodern subject position." His argument is very similar to that of Corker and Shakespeare (2002), who also acknowledge that postmodern ideas present significant challenges to the ways in which disability has traditionally been conceptualized. Postmodernism problematizes issues of identity, embodiment, discourse, power, and agency far more than do traditional notions of disability. Corker and Shakespeare suggest that the rich tapestry that makes up the disability movement, involving people of all ages, with different impairments, challenging dominant notions of embodiment, exerting their own agency while they experience disabling barriers and simultaneously face a range of other inequalities, means that disability is "the ultimate postmodern concept."

CONCLUSION

Identity is of fundamental importance to the modern world, allowing people to connect with others as well as to experience feelings of uniqueness. Many disabled

people lack disabled role models in their families, do not necessarily feel connected to the wider disability movement, and struggle to develop a positive disability identity. For others, developing a positive self-image often involves challenging internalized oppression and refusing to be defined by rigid definitions of normality. Disability identity is also influenced by such factors as the nature of the impairment and the ethnicity and gender of the person. Identity presents different challenges at various stages of the life course. Therefore, disability identity is a complex topic. For some people, becoming involved in the disability movement, connecting with disability culture, and developing disability pride are very helpful actions in terms of building self-esteem and a sense of belonging. Others see their experience of disability as shameful and seek to avoid the stigma of disability by hiding their identity. Many people try to find individual solutions for themselves, for instance, by being critical of rigid notions of normality and by finding beauty in difference.

—Mark Sherry

Further Readings

Ahmad, W. I. U., A. Darr, and L. Jones. 2000. "'I Send My Child to School and He Comes Back an Englishman': Minority Ethnic Deaf People, Identity Politics and Services." Pp. 67–84 in *Ethnicity, Disability and Chronic Illness,* edited by W. I. U. Ahmad. Buckingham, UK: Open University Press.

Baker, K. and M. Donelly. 2001. "The Social Experiences of Children with Disability and the Influence of Environment: A Framework for Intervention." *Disability & Society* 16:71–85.

Barnes, M. and P. Shardlow. 1996. "Identity Crisis: Mental Health User Groups and the 'Problem of Identity.'" Pp. 114–134 in *Exploring the Divide: Illness and Disability,* edited by C. Barnes and G. Mercer. Leeds, UK: Disability Press.

Baynton, D. C. 2001. "Disability and the Justification of Inequality in American History." Pp. 33–57 in *The New Disability History: American Perspectives,* edited by P. K. Longmore and L. Umansky. New York: New York University Press.

Clare, E. 1999. *Exile and Pride: Disability, Queerness and Liberation.* Boston: South End.

Corker, M. and T. W. Shakespeare. 2002. "Mapping the Terrain." Pp. 1–17 in *Disability/Postmodernity: Embodying Disability Theory,* edited by M. Corker and T. W. Shakespeare. London: Continuum.

Davis, L. J. 1995. *Enforcing Normalcy: Disability, Deafness and the Body.* London: Verso.

———. 2002. *Bending over Backwards: Disability, Dismodernism and Other Difficult Positions.* New York: New York University Press.

Erikson, E. 1963. *Childhood and Society,* 2d ed. New York: W. W. Norton.

Giddens, A. 1991. *Modernity and Self-Identity: Self and Society in the Late Modern Age.* Oxford, UK: Polity.

Gill, C. J. 1995. "A Psychological View of Disability Culture." Retrieved April 28, 2005, from Independent Living Institute website (http://www.independentliving.org/docs3/ gill1995 .html).

Gill, C. 2001. "The Social Experience of Disability." Pp. 351–372 in *Handbook of Disability Studies,* edited by G. L. Albrecht, K. D. Seelman, and M. Bury. Thousand Oaks, CA: Sage.

Goffman, E. 1961. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates.* Harmondsworth, UK: Penguin.

———. 1963. *Stigma: Notes on the Management of Spoiled Identity.* Harmondsworth, UK: Penguin.

HalfthePlanet Foundation. 2002. "Disability Identity." In *Disability Policy in the 21st Century: Moving on Up.* Washington, DC: HalfthePlanet Foundation. Retrieved April 28, 2005 (http://www.halftheplanet.org/ departments/ think_ tank/disability_identity.html).

Kaplan, D. n.d. "The Definition of Disability." Retrieved April 28, 2005, from Center for an Accessible Society website (http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm).

Linton, S. 1998. *Claiming Disability.* New York: New York University Press.

Mackelprang, R. and R. Salsgiver. 1999. *Disability: A Diversity Model Approach in Human Service Practice.* Pacific Grove, CA: Brooks/Cole.

Marks, D. 1999. *Disability: Controversial Debates and Psychosocial Perspectives.* London: Routledge.

Meekosha, H. and L. Dowse. 1997. "Enabling Citizenship: Gender, Disability and Citizenship in Australia." *Feminist Review* 57:49–72.

Middleton, L. 1999. *Disabled Children: Challenging Social Exclusion.* Oxford, UK: Blackwell Science.

Morris, J. 1991. *Pride against Prejudice.* London: Women's Press.

Oliver, M. 1990. *The Politics of Disablement.* London: Macmillan.

Parsons, I. 1999. *Cripples, Coons, Fags and Fems: A Look at How Four Human Rights Movements Have Fought Prejudice.* Geelong, Victoria, Australia: Villamanta.

Parsons, T. 1951. *The Social System.* Glencoe, IL: Free Press.

Priestley, M. 1999. "Discourse and Identity: Disabled Children in Mainstream High Schools." Pp. 92–102 in *Disability Discourse,* edited by M. Corker and S. French. Buckingham, UK: Open University Press.

Rolland, J. S. 1988. "A Conceptual Model of Chronic and Life-Threatening Illness and Its Impact on Families." In *Chronic Illness and Disability,* edited by C. S. Chilman, E. W. Nunnaly, and F. M. Cox. Newbury Park, CA: Sage.

Scott, R. A. 1969. *The Making of Blind Men.* New York: Russell Sage Foundation.

Shakespeare, T. W. 1996. "Disability, Identity, Difference." Pp. 94–113 in *Exploring the Divide: Illness and Disability,* edited by C. Barnes and G. Mercer. Leeds, UK: Disability Press.

Shapiro, J. 1993. *No Pity: People with Disabilities Forging a New Civil Rights Movement.* New York: Times Books.

Stroman, D. F. 2003. *The Disability Rights Movement: From Deinstitutionalization to Self-Determination.* Lanham, MD: University Press of America.

Thomson, R. G. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature.* New York: Columbia University Press.

Vernon, A. 1998. "Multiple Oppression and the Disabled People's Movement." Pp. 201–210 in *The Disability Reader: Social Science Perspectives,* edited by T. W. Shakespeare. London: Cassell.

Watson, N. 2003. "Daily Denials: The Routinisation of Oppression and Resistance." Pp. 34–52 in *Disability, Culture and Identity,* edited by S. Riddell and N. Watson. Harlow, UK: Pearson Education.

Wolfensberger, W. and Thomas, S. 1983. *PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals): Normalization Criteria and Ratings Manual,* 2d ed. Toronto: National Institute on Mental Retardation.

Websites

Center for an Accessible Society, http://www.accessiblesociety.org
HalfthePlanet Foundation, http://www.halftheplanet.org
Independent Living Institute, http://independentliving.org

IEP

See Individualized Education Program

IMMIGRATION: LAW AND POLICY

One of the driving forces behind early U.S. federal immigration law, beginning with the first major legislation, the Immigration Act of 1882, was the exclusion of "defective" people (as well as those considered criminal or immoral, problems seen at the time as resulting from "mental defect"). Federal legislation throughout this period repeatedly, and with ever-increasing urgency, identified defective immigrants as a threat to the nation. In 1907, the *Annual Report of the Commissioner of Immigration* declared that "the exclusion from this country of the morally, mentally, and physically deficient is the principal object to be accomplished by the immigration laws" (U.S. Bureau of Immigration 1907:62). When immigration quotas based on nationality were enacted in 1924, a rhetoric of "inferior races," based on claims that people of certain nationalities are prone to be physically and mentally defective, was instrumental in creating the image of the "undesirable immigrant."

The desire to keep disabled immigrants out of the United States was not an isolated development; rather, it was one aspect of an era that saw the segregation of disabled people into institutions, the sterilization of the "unfit" under state eugenics laws, intensified stigmatization of disability, and increasing willingness to exclude disabled people from social and cultural life. The Immigration Act of 1882 prohibited entry to any "lunatic, idiot, or any person unable to take care of himself or herself without becoming a public charge." Those placed in the categories of "lunatic" and "idiot" were supposed to be automatically excluded. The "public charge" provision was intended to encompass people with disabilities more generally, and decisions were left to the examining officer's discretion (*United States Statutes at Large* 1883:214). The criteria for excluding disabled people were steadily tightened as the eugenics movement and popular fears about the decline of the "national stock" gathered strength. The Immigration Act of 1891 replaced "*unable* to take care of himself or herself without becoming a public charge" with "*likely* to become a public charge" (*United States Statutes* 1891:1084; emphases added). In 1907, the law was modified to deny entry to anyone judged "mentally or physically defective, such mental or physical defect being of a nature which *may affect* the ability of such alien to earn a living" (*United States Statutes* 1907:899; emphasis added). Although nondisabled immigrants were still admitted unless found to be "likely to become a public charge," disabled people were subject to this more rigorous standard.

Exclusions for mental defect were steadily expanded. In 1903, people with epilepsy were added, as well as "persons who have been insane within five years previous [or] who have had two or more attacks of insanity at

any time previously" (*United States Statutes* 1903:1213). In 1907, "imbeciles" and "feeble-minded persons" were barred, in addition to "idiots" (*United States Statutes* 1907:898). In 1917, the classification of "constitutional psychopathic inferiority" was added, which inspection regulations described as including "various unstable individuals on the border line between sanity and insanity, such as persons with abnormal sex instincts." Officials were instructed to exclude persons with "any mental abnormality whatever . . . which justifies the statement that the alien is mentally defective." This provision, the regulations explained, was intended "as a means of excluding aliens of a mentally inferior type, not comprehended in the other provisions of the law, without being under the necessity, as formerly, of showing that they have a defect which may affect their ability to earn a living" (U.S. Public Health Service 1917:25–26, 28–29, 30–31).

The rules governing exclusion for physical disabilities were equally vague and expansive. Regulations specified that "each individual should be seen first at rest and then in motion" so that officials could detect "irregularities in movement" and "abnormalities of any description." Among the many defects listed as causes for exclusion were arthritis, asthma, bunions, deafness, deformities, flat feet, heart disease, hernia, hysteria, poor eyesight, poor physical development, spinal curvature, vascular disease of the heart, and varicose veins (U.S. Public Health Service 1917:16–19). An Ellis Island medical inspector later wrote that his task was "to detect poorly built, defective or broken down human beings" (Safford 1925:244).

These laws were usually presented as an economic issue. Many immigrants who were excluded, however, had been self-supporting before they left their home countries. Others had been offered jobs while awaiting their immigration hearings but still were deported as likely to become public charges. More important, the laws located the problem in individual bodies rather than in social structures, despite the fact that immigration restriction was just one aspect of a pervasive system of discrimination that made it difficult for disabled people to live and move about independently. For example, the diagnosis of "poor physique" was often used to exclude immigrants as "likely to become a public charge." The immigration service defined it as covering those "who have a frail frame, flat chest, and are generally deficient in muscular development" or who are "undersized—markedly of short stature—dwarf" (Stoner 1912). As one official explained, the "immigrant of poor physique is not able to perform rough labor, and *even if he were able,* employers of labor would not hire him" (McLaughlin 1905:532; emphasis added). That is, the belief that an immigrant was unfit to work justified exclusion, and so did the belief that an immigrant was *likely to encounter discrimination* because of a disability. The diagnosis was also in part a eugenic judgment, as this 1905 memo from the commissioner general of the Bureau of Immigration illustrates:

> A certificate of this nature implies that the alien is undersized, poorly developed and physically degenerate, and not only unlikely to become a desirable citizen, but also very likely to transmit his undesirable qualities to his offspring, should he unfortunately for the country in which he is domiciled, have any. (Sargent 1905)

On January 30, 1906, immigrant Israel Bosak was certified for "poor physique." He was not destitute, having $65 in his possession, usually more than enough for admittance. Bosak had owned a tailor shop in Russia before it was destroyed by a mob during an anti-Jewish pogrom. He intended to send for his wife and children as soon as he got established, explaining that he had "plenty of countrymen here who are just as good as relatives, to help me." Two members of the board voted for admission, but the third held firm for deportation, which meant that the secretary of the U.S. Department of Labor would decide. In his letter to the secretary, the third board member emphasized the danger to the nation's eugenic health of admitting such people, "whose offspring will reproduce, often in an exaggerated degree, the physical degeneracy of their parents." The secretary concurred, and Israel Bosak was returned to Russia (National Archives, file no. 49,968/4).

Because the screening of immigrants was mostly a matter of detecting visual abnormality, the appearance of an individual played a central role. Inspectors prided themselves on making "snapshot diagnoses" as immigrants streamed past them, single file. For most immigrants, a normal appearance meant a quick passage through the immigration station. An abnormal

appearance, however, meant a chalked letter on the back—"L for lameness, K for suspected hernia, G for goiter, X for suspected mental illness," and so on (Kraut 1994:55). Once an individual was chalked, a closer inspection was required.

Donabet Mousekian had an abnormal appearance. On April 23, 1905, this Armenian Turk stood before the Board of Special Inquiry with an inspection certificate that read "feminism." In other instances, the term used for his condition was "lack of sexual development." In this case, "feminism" meant an absence of male sexual organs; in others, it referred to insufficient development. Mousekian's hearing was extraordinarily brief. No one mentioned the diagnosis. After asking the most basic questions concerning Mousekian's identity and background, and noting that he brought $48 with him, the board quickly voted to exclude him as likely to become a public charge. In his appeal, Mousekian explained that he had fled the violent oppression of Armenians in Turkey and had officially renounced his citizenship. As he would never be permitted to return to Turkey and remain free, rather than be sent back, he wrote, "it would be much better that you kill me." His relatives were all in America, including his two brothers who were citizens and well employed. A photographer by trade, as well as a skilled weaver and dyer of rugs and a cook, Mousekian could have worked at any of these trades. He wrote:

> I am not ill, have no contagious disease; my eyes, feet, hands and ears are sound; only I am deprived of male organs; this is not a fault because it has come from God and my mother: what can I do? It won't do any harm to my working; or what harm can I do to the U.S. by my being deprived of male organs?

His brothers wrote in much the same vein, asking plaintively,

> How is it his fault? Our father and mother are dead; he is our only brother; we guarantee that he will not be a public charge; we are able to give the required guarantee; he can not return to Turkey; we are US citizens, hence we beg US government not to separate our brother from us.

The commissioner at Ellis Island supported the board's decision on the basis of Mousekian's appearance: "Appellant is devoid of every external evidence of desirability. He is weak, repulsive in appearance, the doctor's certificate furnishing sufficient indication of his physical defects." Mousekian was returned to Turkey, where, if he lived that long, he would witness the "Armenian holocaust" 10 years later (National Archives, file no. 48,599/4).

The U.S. surgeon general explained in a memo the reasoning behind this exclusion:

> These persons present bad economic risks. . . . [T]heir chief failure to adjust is due to the fact that their abnormality soon becomes known to their associates who make them the butt of coarse jokes to their own despair, and to the impairment of the work in hand. Since this is recognized among employers, it is difficult for these unfortunates to get or retain jobs, their facial and bodily appearance, at least in adult life, furnishing a patent advertisement of their condition. (Cumming 1922)

The disabilities that justified exclusion in the cases described above were matters of abnormal appearance that might invite discrimination and therefore poverty. Thus, these exclusions were based on economic arguments, but at two steps removed.

The justifications given for exclusion were not always economic, however, whether directly or indirectly. Nicolaos Xilomenos was refused entry in 1912 for "lack of sexual development." The commissioner noted that while "the individual may appear strong and robust" and brought with him sufficient cash, his condition indicates the probability of "perversions or mental instability" (National Archives, file no. 53,452-952). In a similar case in 1908, Helena Bartnikowska was refused entry. The physician explained that "this supposed woman" was a hermaphrodite, and that hermaphrodites are "usually of perverted sexual instincts, and with lack of moral responsibility." He added significantly that Bartnikowska's voice was masculine and that she had facial hair. Although her family was willing and able to guarantee her support, she was deported (National Archives, file no. 51,806-16).

In March 1905, Domenico Rocco Vozzo, a 35-year-old Italian immigrant, was puzzled to find himself barred from entering the United States at the port of Boston. Vozzo was a migrant worker on his second

trip to the United States, and he had encountered no difficulty on his first trip three years earlier. He was certified for "debility" and excluded as likely to become a public charge. Vozzo's attorney argued in his appeal that Vozzo was robust and healthy. He noted that Vozzo "looks perfectly healthy below the head" but has a "curiously shaped head, and his skin looks rather white, almost bleached, and his ears are quite thin." During his previous two-year sojourn in the United States he had fully supported himself while saving money. He brought with him $20 in cash and had friends who filed affidavits on his behalf. The commissioner at the Boston station, however, recommended against admission: "I enclose his picture which I think will convince you that he is not a desirable acquisition." Vozzo was deported (National Archives, file no. 48,462).

The principle that persons of abnormal appearance were not "desirable acquisitions" was neither universally held nor consistently applied. For example, when Abram Hoffmann, a 25-year-old tailor with a prosperous brother in New York, was deemed likely to become a public charge in 1906 because of a curved spine, his attorney labeled "ridiculous and absurd" the assumption "that one who is unfortunate enough to suffer from a certain infirmity, is likely for that reason alone, to become a public charge." Warming to the subject, the attorney asked, "Are we living in this enlightened Twentieth Century where everyone is supposed to be given a fair opportunity, or are we going back to the times of the Salem witch-craft, when, because a woman was old and afflicted with a high back [spinal curvature], she was considered and treated as a witch? . . . The immigrants affliction can in no wise affect his earning capacity as a tailor." The commissioner at Ellis was torn. On the one hand, he noted, visually "the spinal curvature for which [Hoffmann] is certified is quite obvious." On the other, "I may state in appellant's behalf, that he is a man of considerable intelligence, is very well dressed, and came as a second cabin passenger." In the end, the positive aspects of Hoffmann's appearance and class status trumped the negative appearance of his disability, and he was admitted (National Archives, file no. 49951-1).

The precise number of immigrants turned away from the United States for disability each year is difficult to pin down. Until 1908, exclusions based on physical defects were mixed with nondefectives in the category of "likely to become a public charge." After 1908, rejected immigrants were counted in the category of "mental or physical defective" if they were deemed defective but not likely to become public charges, and counted in the "public charge" category if they were determined to be both defective and potential paupers. In any case, taken together, exclusions in both categories grew considerably, if erratically, over the years. In 1895, 1,720 were excluded, or .6 percent of all immigrants. By 1905, the number excluded had increased to just over 8,000, or .7 percent of all immigrants. And in 1910, 16,000, or 1.6 percent, were excluded. Due to wartime disruptions, the numbers during and just after World War I fluctuated widely, making useful comparisons difficult (U.S. Immigration Commission 1911).

These numbers are all likely to be only the tip of the iceberg, however. Those inspected at American ports had already been through several screens. First, many were deterred by the general inaccessibility of transportation. Second, given that American immigration laws were widely advertised, many must have decided not to risk the journey, knowing they might be turned back. Third, ship captains were required to examine passengers and certify that they were not physically or mentally defective (*United States Statutes* 1893:569, 1907:901–902). Fourth, the shipping companies that brought rejected immigrants to the United States were required to return them and pay a fine for each, and immigrants later discovered to have disabilities that initially passed unnoticed could be deported for up to three years at the expense of the companies (*United States Statutes* 1903:1218, 1907:901, 905). Shipping companies therefore had strong incentives to refuse passage to disabled people, and ship captains became an unofficial arm of the immigration service. Finally, ticket agents stationed throughout inland Europe were fined by the shipping companies if they sold tickets to anyone turned away at boarding time. In 1894, the superintendent of immigration noted approvingly that steamship lines instructed their agents to refuse tickets to "the blind, deaf and dumb, and crippled persons" (U.S. Immigration Service 1894:12–13). There is reason, then, to suppose that those rejected at the borders were a small minority of those who were deterred. In 1911, the U.S. Immigration Commission estimated that

about 10 times as many were refused transportation for medical reasons as were barred at U.S. ports (U.S. Immigration Commission 1911:26).

In 1924, a new quota system was instituted, based on national origin, that severely limited immigration from southern and eastern Europe. In the debate leading up to this legislation, disability figured prominently. Quota advocates, as well as superintendents of institutions, philanthropists, immigration reformers, and politicians, warned that certain nationalities were disproportionately prone to be mentally defective (Trent 1994:166–169). Rhetoric about "slow-witted Slavs," the poor physiques of Jews, the "neurotic condition of our Jewish immigrants," and the "degenerate and psychopathic types, which are so conspicuous and numerous among the immigrants," was pervasive (Grayson 1913:103, 107–109). Quota advocates emphasized the inferior appearance of recent immigrants. One wrote that "the physiognomy of certain groups unmistakably proclaims inferiority of type." In "every face there is something wrong, . . . sugar-loaf heads, moon-faces, slit mouths, lantern-jaws, and goose-bill noses." Most were physically inadequate:

> South Europeans run to low stature. A gang of Italian navvies present, by their dwarfishness, a curious contrast to other people. The Portuguese, the Greeks, and the Syrians are, from our point of view, undersized. The Hebrew immigrants are very poor in physique . . . the polar opposite of our pioneer breed. (Ross 1914:285–290)

The issues of race, ethnicity, and disability were inextricably intertwined. The characterization of people as physically and mentally defective, and therefore inherently inferior, was used to stigmatize people and to rationalize their exclusion. Similar rhetoric worked to incarcerate, institutionalize, and sterilize untold numbers of disabled and minority citizens during the same period. The label "defective person" was used to justify the denial of basic human rights. Although it is certain that immigration restriction rested in good part on a fear of "strangers in the land," in John Higham's phrase, it was fueled at least as much by a fear of defectives in the land.

National quotas were removed in 1965, and most of the restrictions that applied specifically to disability were removed from U.S. law in 1990. Today, disabled immigrants can still be denied an entry visa on the basis of the "likely to become a public charge" clause, but because records are not kept of such exclusions, it is not known how often this occurs (Stanton 1996:451).

—Douglas C. Baynton

Further Readings

Abbott, E. 1924. *Immigration: Select Documents and Case Records.* Chicago: University of Chicago Press.

Cumming, H. S., Surgeon General, U.S. Public Health Service. 1922, September 29. [Letter, reply to W. W. Husband, Commissioner General, Bureau of Immigration]. National Archives (U.S.), RG 90, Entry 10, File 219.

Fairchild, Amy L. 2003. *Science at the Borders: Immigration Medical Inspection and the Shaping of the Modern Industrial Labor Force.* Baltimore: Johns Hopkins University Press.

Grayson, Thomas Gray. 1913. "The Effect of the Modern Immigrant on Our Industrial Centers." In *Medical Problems of Immigration.* Easton, PA: American Academy of Medicine.

Kraut, Alan M. 1994. *Silent Travelers.* New York: Basic Books.

Longmore, Paul K. and Lauri Umansky. 2001. *The New Disability History: American Perspectives.* New York: New York University Press.

McLaughlin, Allan. 1905, April. "The Problem of Immigration." *Popular Science Monthly* 66:243–255.

National Archives (U.S.). Various dates. Records of the Immigration and Naturalization Service, Record Group 85, Entry 7, file nos. 48,462, 48,599/4, 49,968/4, 49951-1; and Accession 60A600, file nos. 51,806-16, 53,452–952.

Ross, Edward Alsworth. 1914. *The Old World and the New: The Significance of Past and Present Immigration to the American People.* New York: Century.

Safford, Victor. 1925. *Immigration Problems: Personal Experiences of an Official.* New York: Dodd, Mead.

Sargent, F. P., Commissioner-General of the Bureau of Immigration. 1905, April 17. [Letter to the Commissioner of Immigration on Ellis Island.] National Archives (U.S.), RG90, E10, File 219.

Stanton, John F. 1996. "The Immigration Laws from a Disability Perspective: Where We Were, Where We Are, Where We Should Be." *Georgetown Immigration Law Journal* 10:441–465.

Stoner, George, Chief Medical Officer, Public Health and Marine Hospital Service. 1912, November 29. [Letter to the Surgeon General of the Public Health and Marine Hospital]. National Archives (U.S.), RG 90, Entry 10, File 219.

Trent, James W., Jr. 1994. *Inventing the Feeble Mind: A History of Mental Retardation in the United States.* Berkeley: University of California Press.

U.S. Bureau of Immigration. 1907. *Annual Report of the Commissioner of Immigration.* Washington, DC: Government Printing Office.

U.S. Immigration Commission. 1911. *Abstracts of Reports of the Immigration Commission,* Vol. 1. Washington, DC: Government Printing Office.

U.S. Immigration Service. 1894. *Annual Report of the Superintendent of Immigration.* Washington, DC: Government Printing Office.

U.S. Public Health Service. 1917. *Regulations Governing the Medical Inspection of Aliens.* Washington, DC: Government Printing Office.

United States Statutes, Vol. 26. 1891. Washington, DC: Government Printing Office.

United States Statutes, Vol. 27. 1893. Washington, DC: Government Printing Office.

United States Statutes, Vol. 32. 1903. Washington, DC: Government Printing Office.

United States Statutes, Vol. 34. 1907. Washington, DC: Government Printing Office.

United States Statutes at Large, Vol. 22. 1883. Washington, DC: Government Printing Office.

Weber, Mark C. 2004. "Opening the Golden Door: Disability and the Law of Immigration." *Journal of Gender, Race and Justice* 8:153–175.

IMMUNOLOGIC DISEASES

Immunology is the field of science encompassing the study of the specialized molecules and cells involved in defending an organism against infection. Human immunology has its beginnings in the empirical observations of Edward Jenner on the prevention of smallpox in English milkmaids previously infected with cowpox. These important studies provided our initial understanding of the ability of the immune system to acquire memory of an infecting organism and formed the basis for our current practice of immunization against myriad potential infectious diseases. Immunodeficiency diseases arise from defects in the immune system and are classified as primary, usually inherited genetic causes, or secondary, arising from infection or drugs that impair immune system function. In all cases, immunodeficiency diseases may result in considerable physical disability with long-term requirements for medical and rehabilitative care.

The widespread introduction of antibiotic use into the practice of medicine in the middle of the twentieth century permitted recognition of children with multiple recurrent episodes of bacteremia (bacteria in the bloodstream), pneumonias, or skin abscesses. These primary immunodeficiencies are the results of inherited defects in specific genes required for normal immune responses. The study of children with these rare diseases has revealed a great deal about how the normal immune system functions and has resulted in the development of specific therapies aimed at replacing or restoring normal immune system function. In some cases affected children survive with a lifetime of infusions of immune sera, whereas in other cases bone marrow transplantation is required. In all circumstances, affected children as well as their parents and siblings require considerable support for these lifelong chronic diseases.

Secondary immunodeficiencies may arise from infection of the immune system and destruction of cells critical for the normal immune response. The most serious of such infections is caused by the human immunodeficiency virus (HIV), which infects lymphocytes, a specialized white blood cell required for immune function, resulting in acquired immunodeficiency syndrome (AIDS). There is currently no effective vaccine against HIV, and infection is fatal in the absence of long-term treatment with complex, expensive, and relatively toxic drug regimens. The current worldwide pandemic of HIV infection has resulted in devastating human and economic disability for entire nations in Africa and Southeast Asia. In developed countries such as the United States, the disabling effects of HIV infection have imposed enormous cost restraints on the health care system.

Secondary immunodeficiency also occurs following treatment with drugs that suppress immune system function, such as glucocorticoids. These medications are required in patients with diseases such as rheumatoid arthritis and multiple sclerosis and following organ transplantation. In all circumstances these drugs create the potential for serious life-threatening infections. Given the prevalence of these diseases in the population and the increasing frequency of solid organ transplantation in developed nations, such secondary immunodeficiency is becoming a common cause of disability and chronic care in the population. When combined with HIV infection, these immunodeficiency diseases are among the most prevalent and costly sources of human disability worldwide.

—Jonathan D. Gitlin

Further Readings

Delves, P. J. and I. M. Roitt. 2000. "The Immune System." *New England Journal of Medicine* 343:37–49, 108–117.

Firestein, G. S. 2003. "Evolving Concepts of Rheumatoid Arthritis." *Nature* 423:356–361.

Keegan, B. M. and J. H. Noseworthy. 2002. "Multiple Sclerosis." *Annual Review of Medicine* 53:285–302.

Websites

American Academy of Allergy, Asthma & Immunology, http://www.aaaai.org

IMPAIRMENT

Impairment is one of the most contested and complicated terms in disability studies, second only to *disability* itself in terms of multiple definitions and theoretical arguments made around its meaning and significance in the experience and scholarship of the body. It can be traced both chronologically and ideologically, and it continues to be the subject of considerable debate.

The origins of *impairment* as a term in disability studies may be positioned in the development of documents by such organizations as the Union of the Physically Impaired Against Segregation (UPIAS) in Great Britain and the World Health Organization (WHO). In 1976, UPIAS offered its own definitions, omitting *handicap* as a term of art and drawing a distinction between impairment and disability: *Impairment* refers to "lacking part or all of a limb, or having a defective limb, organ or mechanism of the body"; *disability* refers to the social oppression (whether due to stigma or to restrictions) imposed on people with impairments. The important distinction for UPIAS lies in location: Impairment is located in the body; disability is located in society or culture.

In 1980, the WHO's International Classification of Impairments, Disabilities, and Handicaps (ICIDH, revised in 1993 and again in 2001, when it became the International Classification of Functioning, Disability, and Health, or ICF) distinguished among *impairment, disability,* and *handicap* as terms to describe what might be categorized as "nonnormate" bodies. The ICIDH defined impairment as "any loss or abnormality of psychological, physiological or anatomical structure or function." It defined disability as the lack of ability to perform particular acts or functions in a way that is "normal," and handicap as the disadvantage(s) resulting from impairment and disability. Like most such classification systems, all versions of the WHO's definitions were criticized from various corners of the scholarly and professional world, often because such critics thought the distinctions either too rigid and unrealistic in representing the overlaps among the categories or because they saw the definitions as lacking in social consciousness or analysis.

From these competing sets of definitions arose a body of scholarship—originating primarily in Great Britain with such writers as Michael Oliver and Tom Shakespeare—that distinguished between a "social model of disability" and a "medical model of disability." *Impairment* as a term was assigned to the medical model, which was also seen as positing the location of the body's "problems" within the individual and which looked to such tropes as cure, charity, personal tragedy, and pain and suffering as dominant modes of thought. In some circles, much, if not all, of rehabilitative science and practice came to be understood to be located within the medical model. Thus, *impairment,* which in its earlier usage might have been viewed as a neutral term (if such a thing can be said to exist), became a negative, oppressive term in this binary of social/medical pairing, if only by association.

Some theorists argued that discussions of impairment (by which they meant the physical, psychological, and cognitive experiences of individuals) should either be eliminated from disability studies discourse or, at the very least, shared only within the disability community "behind closed doors." Reasons for this argument varied, but they included concerns that any frank discussion of what might be construed as "limitations" might be used to oppress disabled persons even more (i.e., such discussions might be considered evidence that disabled persons really are, in important ways, "inferior" because of their bodies) and might, for example, be used in arguments supporting such things as discriminatory employment practices and physician-assisted suicide. Others feared that too much emphasis on narratives of impairment might depict disabled people as participants in victimology—that such narratives might represent disabled

persons as passive, or whiny, or irrational. Later, as the 1990s drew to a close, many of the original theorists of the social/medical dichotomy began to rethink its efficacy, and the term *impairment* began to be reintroduced in a more wide-ranging set of discursive formations. One of the criticisms of the dichotomy between social model and medical model was that it created an unreal or inaccurate division between impairment and disability; another was that it in some respects was guilty of setting up two "models" where only one group had actually articulated a model—in other words, it is unlikely that physicians and therapists would ever have agreed that they subscribed to all of the things attributed to the "medical model" per se.

One of the most significant critiques of the impairment/disability binary and its respective medical/social model rhetoric came from feminist disability scholars. Most vocal among these were such figures as Susan Wendell, Sharon Stone, Jenny Morris, and Liz Crow. These theorists were particularly articulate in deconstructing the often masculinist assumptions present in the binary, including a devaluing of the significance of pain and suffering in the lived bodies of people with impairments/disabilities and the ways in which bodies affected by invisible or less-visible impairments were often neglected in such discourse. It is probably no accident that many of these lesser-discussed impairments are conditions that disproportionately affect women: chronic fatigue syndrome, depression, and others. Such theorists called for a return of lived experience to the discourse of disability studies and, along with it, a fuller and more detailed theorizing and representation of impairment. Whereas social model scholarship tended to draw its theoretical underpinnings from Marxism and materialist cultural studies, feminist disability studies often came out of phenomenological and ethnomethodological bases. It is important to remind ourselves that to draw a simple gender binary is to be as guilty of reductionism as was the social/medical model; nonetheless, the contribution of feminist disability scholars, particularly women, cannot be underestimated in the reintroduction of impairment as a legitimate area for discussion, scholarship, and theorizing.

A "third wave" of *impairment* as a terminological basis for disability studies theory and scholarship may be seen as emerging in the past several years. In important respects, this wave is actually a cluster of approaches and perspectives, all of which respond to various previous uses of the term and the theories surrounding it. One area is what is being called "sociology of impairment" by theorists such as Bill Hughes and others. This approach argues that the division between social and medical models is incomplete not simply because it runs the risk of demonizing impairment as a concept, but because it misses or underestimates the degree to which impairment itself may be viewed as a social product. For example, Alex Lubet, a disability scholar and trained professional musician, has argued that the field of classical music training in the West has been both disabling and impairing. As instruments and pedagogy have assumed right-handedness as normate, people who are left-handed dominant are required to learn to play music not only in a way that is not natural to their bodies, but in ways that may produce impairments through strain and stress on parts of the body. One can imagine many more examples of instances where either workplace or public facilities that do not accommodate various kinds of bodies may result in different and additional impairments, which, in turn, lead to any number of kinds of disabling conditions, such as limitations on work opportunities or access to various venues of participation in public and private activities.

In addition to the "sociology of disability," there has also been a growing interest (or revival of interest) in what might be termed the phenomenology of impairment, either with or without explicit sociopolitical implications. Disciplinary approaches to such phenomenological methods range from philosophy (e.g., those who build explicitly from the work of such Continental writers as Merleau-Ponty and Husserl) to occupational therapy (e.g., Gary Kielhofner's work on a "model of human occupation" and his various accounts of the phenomenology of hand impairment) to sociologists (e.g., Rod Michalko, who combines phenomenological accounts of his blindness with consideration of socially oppressive implications of this impairment for himself and others) to humanists and artists who either represent or write critically about representations of impairment in the arts and in culture at large. One might include here writers of personal narratives and other literary accounts of impairment ranging from Lucy Grealy's *Autobiography of a Face* (1994) to Kenny Fries's *Body,*

Remember (1997) as well as fictional accounts of impairment by writers such as Mark Salzman and dramatic texts by John Belluso, Susan Nussbaum, Tony Kushner, and others. Visual artists such as Riva Lehrer and performance artists such as Greg Walloch, Terry Galloway, and Petra Kuppers create a discourse of impairment representation in their work as well. There is a sociopolitical dimension to the work of almost all these artists, bringing the once seemingly disparate concepts of impairment and disability closer together through their embodiment in artistic texts.

Impairment will continue to be a "word in process" in disability studies, mapping out different concerns, emphases, and rhetorical positions in various contexts, times, and sites. It is unlikely that, like *handicap,* it will disappear anytime soon, as there is a genuinely productive value in drawing certain distinctions between impairment and disability as phenomena to be analyzed; what is useful is the continuing opening up and inclusion of it in the growing body of disability studies scholarship.

—Bruce Henderson

See also Language of Disability.

Further Readings

Finkelstein, Vic. 1975. "Union of the Physically Impaired against Segregation: Comments on the Discussion between the Union and the Disability Alliance on 22nd November 1975." In Union of the Physically Impaired against Segregation, *Fundamental Principles of Disability.* Retrieved April 30, 2005 (http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/UPIAS%20Principles%20202.pdf).

Fries, Kenny. 1997. *Body, Remember: A Memoir.* New York: Dutton.

Grealy, Lucy. 1994. *Autobiography of a Face.* Boston: Houghton Mifflin.

Hughes, Bill. 2000. "Medicine and the Aesthetic Invalidation of Disabled People." *Disability & Society* 15: 555–568.

Hughes, Bill and Kevin Patterson. 1997. "The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment." *Disability & Society* 12:325–340.

Morris, Jenny, ed. 1999. *Encounters with Strangers: Feminism and Disability.* London: Women's Press.

Oliver, Michael. 1990. *The Politics of Disablement.* London: Macmillan.

Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability.* London: Routledge.

World Health Organization. 1980. *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease.* Geneva: World Health Organization.

———. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

Websites

University of Leeds, Center for Disability Studies, http://www.leeds.ac.uk/disability-studies

World Health Organization, http://www.who.int/en

INBORN ERRORS OF METABOLISM

The identification and categorization of inborn errors of metabolism are among the most important conceptual advances in medical genetics during the twentieth century. Credit for this intellectual revolution belongs primarily to the English physician and scientist Sir Archibald Garrod, whose curiosity was evoked by alcaptonuria, an arthritic disorder in which the urine turns to a reddish brown color when exposed to air. Garrod, who was familiar with the principles of Mendelian genetics, noted the appearance of this syndrome in siblings and its occasional passage through successive generations. He proposed that the discoloration of alcaptonuric urine reflects the inherited deficiency of a "ferment" (enzyme) that in healthy subjects favors the breakdown of homogentisic acid (alkapton), a metabolite of the amino acid tyrosine. Accumulation of this acid, he theorized, gives rise to the arthropathy and discoloration (onchronosis) of cartilage and urine that characterize the disorder. Furthermore, the disease appears only if both (unaffected) parents transmit a "latent factor" to the child.

The estimated incidence of the inborn errors of metabolism is approximately 1 in 5,000 live births, making these disorders a significant source of human disability. They may involve any aspect of human metabolism, including the handling of amino acids, lipids, carbohydrates, and nucleic acids. In most instances the underlying cause is the inheritance of a mutant enzyme or transport system that mediates either the metabolic transformation of one metabolite to another or the movement of a compound across a cell membrane. Inheritance of these diseases usually conforms to

an autosomal recessive pattern, although dominant and sex-linked mechanisms are well documented.

Detection of inherited metabolic disease has been facilitated by the advent in recent decades of two complementary technological developments. The first of these has been the development of chromatographic, electrophoretic, and enzymatic techniques for the isolation and quantitation of relevant metabolites in blood and urine. As a result, it is possible to define those departures from the biochemical norm that ratify Garrod's (1923) insight that "behind a superficial uniformity there exists a diversity which is no less real than that of structure, although far less obvious" (p. 1).

Diagnosis is enabled by a second technological development: the revolution in molecular biology that permits the characterization of mutations in either nuclear or mitochondrial DNA. This methodology can unambiguously characterize those fundamental alterations of the genetic code that give rise to metabolic aberrations. Genetic analysis has proved invaluable for the diagnosis of affected individuals, the detection of heterozygotes, and the assessment of the fetus at risk.

Inborn errors of metabolism can result in injury to virtually any tissue, but the most dramatic and characteristic consequence is damage to the developing brain. In most instances the encephalopathy reflects the accumulation of an otherwise normal metabolite that becomes toxic when present in excess concentration. An example is the extreme elevation of the amino acid phenylalanine that accompanies a congenital defect of phenylalanine hydroxylase, the mutant enzyme in classical phenylketonuria. The biochemical sequence that leads from phenylalanine accumulation to frank mental retardation remains obscure, although it is likely that the underlying pathophysiology evokes alterations of brain energy metabolism, neurotransmitter synthesis, and myelin formation.

The outlook for the affected child has improved dramatically in recent years. Diet therapy, or the purposeful interdiction of a potentially injurious nutrient, often attenuates or even prevents brain injury and permits normal neurological development, even when the underlying metabolic defect is near complete. For many disorders, transplantation of bone marrow or of liver or kidney has palliated the underlying lesion and afforded near-normal metabolism. A particularly exciting therapeutic prospect is gene therapy, or the administration of a vector that safely and efficiently carries the deficient gene to cells of the affected patient, thereby reconstituting normal or near-normal enzymatic competence.

—Marc Yudkoff

Further Readings

Fernandes, John, Jean-Marie Saudubra, and Georges Van Den Berghe. 2000. *Inborn Metabolic Diseases: Diagnosis and Treatment.* New York: Springer-Verlag.

Garrod, Archibald. 1923. *Inborn Errors of Metabolism.* London: Henry Frowde & Hodder and Stoughton. Retrieved April 30, 2005 (http://www.esp.org/books/garrod/inborn-errors/facsimile).

Scriver, Charles R., Arthur L. Beaudet, David Valle, William S. Sly, Barton Childs, Kenneth W. Kinzler, and Bert Vogelstein. 2000. *The Metabolic and Molecular Bases of Inherited Disease,* 8th ed., 4 vols. New York: McGraw-Hill.

INCLUSION AND EXCLUSION

The question of the inclusion and exclusion of disabled people cannot be separated from the way in which a society constructs social cohesion or produces social dissociation. Each society has its own way of integrating and rejecting certain categories or certain subjects, that is, of creating social links or not. The two terms *inclusion* and *exclusion* go in tandem and can be understood only in relationship to each other; for any definition of inclusion there is a corresponding definition of exclusion.

MECHANICAL INCLUSION, ORGANIC INCLUSION

Durkheim (1930) accurately saw that in modern societies, with their growing complexity, an evolutionary process is initiated, namely, that the fundamental forms of solidarity in traditional societies, "mechanical" or through resemblance, increasingly give way to solidarities that are "organic" or effected through complementarity. But the latter bring with them a growing individualism, which comes into conflict with the priority traditionally given to the social whole.

The dynamic character of our present-day societies is emphasized, but so is the permanent challenge that confronts them. Thus, there are greater risks of social dissociation than in traditional societies but also increased possibilities, because of their organicity, of integrating the new and alien.

Societies characterized by mechanical solidarity are strongly integrated but cannot admit "foreign bodies." When they exclude, they do so in radical fashion and are often incapable of assimilating the new. Modern societies have a very broad capacity for inclusion but, on the other hand, are in danger of putting apart by creating enclaves within themselves.

In societies with mechanical inclusion, the individual is a constituent of an indestructible whole. He or she has a fixed place, given at birth, and in this sense is fully integrated, a cog in the overall works. There is no question of changing place, which would disrupt the global mechanics, leading the society to defend itself against the defective part that no longer performs its task and punish it. Thus, integration can be defined as a place—a single, fixed place—in a whole that has no plans to change. The person who does not have a place of this type is literally not part of the society. This person is the stranger, excluded by negation and not through a positive act. Barbarians could not become Romans; foreigners could not (except through a special procedure) become citizens of Athens, and so on. A positive act of exclusion, on the other hand, can occur in cases where an individual questions his "integration."

In societies featuring organic solidarity, the individual tends to be isolated. He or she cannot count on a place assigned by tradition and culture. Integration is a long road and a constantly reimposed obligation to take further steps, because the division of labor and social division entail the continuous refinement of legislative, institutional, and financial procedures, so that individuals are not exposed to the rigors of competition and isolation. When these procedures are relaxed, individuals risk being set adrift. There are no longer sufficient common measures to maintain the social link. In addition, there need to be enough shared representations on the global level that these procedures are maintained.

Everything has contributed to the formation of societies that, relying only on themselves and on the strength of their members, have become entirely responsible and accountable for people "living together." We must recall the "autonomization" of society with regard to any reference to the transcendent (a characteristic of modernity) and the autonomization of the individual (Weber 1920). This also explains such societies' vulnerability; the risks of marginalization, even of social abandonment or exclusion, are substantial.

THE PROCESS OF NORMALIZATION

One of the principal procedures in the attempt to effect integration is normalization. Here it is a matter of defining averages, comparing discrepancies with these averages, and then trying to close the distance to come as close to the average as possible.

For children with mental impairments to be admitted to schools, for example, they must be able to follow along in class and thus reach the required level of competence, failing which they are placed in separate institutions that are supposed to bring them (back) to the norm. In the event that this proves impossible, they risk being segregated for almost their entire lives. For disabled adults to gain employment in the business environment, they must acquire personal autonomy and vocational competencies equivalent to, once again, the average. It is on this idea of deviation from the conventional norm that the notions of the first International Classification of Impairments, Disabilities and Handicaps, proposed by the World Health Organization in 1980, are based. Here we can recall Goffman (1963), who quite humorously described the average American by showing how anyone who deviated in any respect from the standard was considered defective and more or less to blame.

The will toward normalization is tied to another force active throughout contemporary societies: the attraction of the universal. Modern Western societies, which are driven by the necessity of establishing on their own the conditions of inclusion to further cohesion and reduce inequalities, consider their forms of sociability to be the most advanced.

From this follows the preference for the *assimilation* model.

The point of departure is the undeniable universality of humanity. The human species is a unity. The

other can only be another I. There are, in principle, no limits to the rights of human beings as such. This is the great achievement of democratic revolutions. But we move very quickly from a recognition of equality to a desire for identicalness. It is this discourse that more or less is generated by the assimilation model: There are common values, common objectives, canons of conduct—averages that we must strive to approach. One must agree to live according to these norms, and this kind of public space can become "blind to differences." The critical point is this: If we fall into what might be called "assimilationism," we end up denying others their irreducible differentness, their right to be themselves, just the way they are.

In contrast to the assimilation model, a *differentiation* model has been formulated. The first form of the differentiation model is the "hierarchical" one. It is a way of integrating differences by holding them together in a coherence, which is at the same time a system of submission. For example, man and woman represent two ways of being human but, because of the traditional relationship of dominance, the social roles associated with these two ways of being have resulted in one having precedence, greater dignity, and greater worth than the other (political vs. domestic role, productive vs. nurturing role, authoritative vs. affective role). The hierarchical model makes it possible to control differences. Still in the universe of differentiation, we meet a second model: that of "juxtaposition." The recognition of a difference is pushed far enough that each individual remains on his or her own, a stranger in the midst of strangers. With the juxtaposition model in its extreme form, which can be called differentialism, it is said: You are another but you have nothing to do with me unless it is to submit to a scale of value on which I am more perfect than you. Juxtaposition, like hierarchy, is a way of putting some people at the top and giving the impression that they alone represent the universal.

THE DIFFERENT FORMS OF EXCLUSION AND INCLUSION

The doubtless most dynamic notion of inclusion leaves room for the work of adjustment, acceptability, and social participation, while the idea of integration presupposes conformity, an alignment that is always experienced as domination, even oppression, by the group that defines the norms or of the majority over the minority. Being included can signify a situation of which one is organically a part, without being necessarily obliged to behave according to a rigid norm. On the other hand, inclusion, like insertion, can prove to be weak and may merely be synonymous with simple presence, simple admission, simple tolerance. You can be tolerated without being recognized. You can be admitted without being incorporated.

On the other hand, exclusion may reference several phenomena: radical exclusion from society, segregation within society, discrimination, also within, concerning access to goods and social spaces, disaffiliation, and an exit from the social exchange system.

Varying according to cultural practices (Ingstadt and Reynolds 1995) and historical periods (Stiker 1999), inclusion and exclusion may assume different meanings; they are not univocal and are not historically fixed. There is diversity in exclusion and diversity in inclusion.

We can observe that each of these kinds of exclusion, even if it has been generally characteristic of a given ancient society, nonetheless displays survival in contemporary Western societies. Establishing a typology of the different forms of inclusion and exclusion that can be observed in the social treatment of disability is comparable to a construction in terms of ideal-type according to Max Weber. An ideal-type is always a mixture of abstract relations and contingent data. By raising practices, albeit empirically different and historically separated, to the point where they can be subsumed in an abstract characterization, we try to associate possible configurations with some conjectural behavioral outcomes.

The Elimination Model

The most extreme form of social exclusion is death. One of the first identifiable types of exclusion, then, is exclusion through elimination. The elimination of disabled people can be effected directly by putting them to death or indirectly by radical abandonment or the withholding of care. Elimination, less of persons than of disability itself, may also be considered to occur before birth; this raises questions related to the

termination of pregnancy when an impairment is discovered in the fetus, and even before pregnancy with new developments in genetic testing. Eugenicist theories show the possible link in continuity between the social practices of elimination of ancient societies and the practices associated with the most recent advances in technology of contemporary societies. Making this observation is not in contradiction with a legal right to abortion.

The Abandonment Model

The practices of abandonment can be distinguished from those of elimination by the fact that they do not entail death, or at least not in such direct fashion. Practiced in ancient cultures, exclusion through abandonment is also reflected in the contemporary forms of "social death" and social abandonment. Examples of abandonment practices are not lacking: the abandonment of children born deformed, the severely wounded, and very dependent elderly people.

Abandonment may amount to conferring of parental authority on another, leaving the fate of a newborn in God's hands, or in more modern fashion anonymously giving up a child for adoption (Dumaret et al. 1998). Abandonment can also be ceasing to look after people, depriving them of care. Relevant here is the question of passive *euthanasia.* The "surplus population thesis" has been advanced as one of the chief explanations of exclusion through abandonment (Oliver and Barnes 1998).

The Segregation Model

Sequestration and the whole set of practices of putting apart constitute one of the most widespread forms of exclusion. It is also the form of social treatment that, by clearly distinguishing an inside and an outside, offers the best fit with the basic meanings of inclusion and exclusion. The point here is that this putting apart does not necessarily take place outside the community but frequently at its very heart. Lastly, we may note that this segregation may be more or less constraining, with a greater or lesser deprivation of freedoms.

One of the paradoxes is that what is often called a segregating detour, for example, through temporary schooling in a separate institution, is often touted as having integration as its ultimate goal. And indeed today this form of segregation is most often conceived of as a side trip that will facilitate a sound return to the ordinary environment (even if the detour never proves to be a way back). Thus, the will is not to exclude, but to include at a later stage. Segregation is as well an attempt of *deferred inclusion.*

The Assistance Model

The relationship with work invites consideration of another form of exclusion: exclusion through assistance, an "economic" form of exclusion that been a social issue since the end of the Middle Ages.

Assistance is a form of close protection and concerns those who, through their inaptitude for work, cannot meet their own needs. Assistance admittedly creates a weak form of participation in society. It confers social substatus. But to assist is not to exclude in the strongest sense of the term, since those helped are part of society simply by virtue of society's concern for them. Those so assisted are part of society on the condition that they stay in their place. Georg Simmel (1908) has convincingly shown that poverty lies not in being without means but rather in being assisted, such assistance itself being a means to ensure social cohesion. The ideal-type that assistance represents can be expressed by the idea of *conditional inclusion.* On one hand, it is still a form of exclusion, because the disabled person is not allowed to acquire a status equivalent to that of the able-bodied and other social groups, but on the other hand, it is a form, albeit weak, of inclusion.

The Marginalization Model

In the precise meaning of the term, *marginalization* is the process of moving to the side through the refusal of, or the impossibility of accepting, current recognized rules of social functioning. The marginalized are defined by transgression of, or protest against, commonly held values and habits, whether this is a decision to become an outsider or rejection by the dominant group. What has been at stake in rehabilitation has thus been to reduce this deviation from the norm. The action on the individual who is to be reintroduced into the mainstream is therefore

informed by the goal of effacing differences. The individual should "act like" others even if this necessitates technical aids, devices, or prostheses.

But it is this same concern for a reduction of the deviance that lies at the ground for the normalization developed by Wolfensberger (1972) with regard to people with mental retardation. Here we can see, more clearly than previously, that even a position on the margin can be qualified as *inclusion through normalization.*

The Discrimination Model

To discriminate is to distinguish or to separate out a social group and restrict its rights. These distinctions made in social life at the expense of disabled people may be judged unacceptable because they violate social norms and the principle of equality before the law, even though in other societies and at other times they may be current practice.

To define discrimination as the action of treating equal individuals inequitably shows to what extent the concept is tied to modern society, which puts equality at the center of its value system.

With the development of civil rights, most modern democracies instituted judicial protections against intentional negative discrimination based on criteria relative to the impairments of an individual. Nonetheless, forms of statistical discrimination are no less evident (Ravaud, Madiot, and Ville 1992), and these are much more difficult to contend with.

Discrimination can also be positive and have the restoration of equality as its goal. Positive discrimination can be effected by social assistance measures in cases with an extrinsic character (e.g., income). It can be effected through authoritarian measures (which raises the question of personal freedoms) or finally by preferential measures (e.g., employment quota policies that favor disabled workers). It can be conceived of as a compensatory measure and defended on the basis of distributive justice.

CONCLUSION

The principal question posed today in Western countries is the nature of the citizenship that can be exercised by disabled people. Modern policy excludes the possibility of distinguishing among different categories of people in the public sphere. Behind these questions of discrimination and exclusion we discern the principle of equality rights of citizens as a moral ideal of a democratic nation.

Exclusion needs to be seen from a global perspective that comprises both the views of the excluded people and those of the entity that rejects them. For, contrary to contemporary representations now in circulation, exclusion is not an abstract phenomenon, implacable, agentless, in its extreme form a fatality resulting from the entry into a new global economy. Exclusion is clearly also inscribed in the social relationships of power (Elias 1965).

It seems impossible to ignore the fact that the two poles are always in evidence: civic universalism, on the one hand, and differentiated groups and individuals, on the other.

—Jean-François Ravaud and Henri-Jacques Stiker

See also Democracy; Normalization.

Further Readings

Dumaret, A.-C., C. De Vigan, C. Julian-Reynier, J. Goujard, D. Rosset, and S. Aymé. 1998. "Adoption and Fostering of Babies with Down Syndrome: A Cohort of 593 Cases." *Prenatal Diagnosis* 18:437–445.

Durkheim, É. 1930. *De la division du travail social.* Paris: Presses Universitaires de France.

Elias, N. 1965. *The Established and the Outsiders.* London: Frank Cass.

Goffman, E. 1963. *Stigma: Notes on the Management of Spoiled Identity.* Harmondsworth: Penguin.

Ingstadt, B. and Whyte S. Reynolds. 1995. *Disability and Culture.* Berkeley: University of California Press.

Oliver, M. and C. Barnes. 1998. *Disabled People and Social Policy: From Exclusion to Inclusion.* Social Policy in Britain Series. London: Addison Wesley Longman.

Ravaud, J.-F., B. Madiot, and I. Ville. 1992. "Discrimination towards Disabled People Seeking Employment." *Social Science and Medicine* 35(8):951–958.

Ravaud, J.-F. and H.-J. Stiker. 2001. "Inclusion/Exclusion: An Analysis of Historical and Cultural Meanings." Pp. 490–512 in *Handbook of Disability Studies,* edited by G. L. Albrecht, K. D. Seelman, and M. Bury. Thousand Oaks, CA: Sage.

Schnapper, D. 1998. *La relation à l'autre, au coeur de la pensée sociologique.* Paris: Gallimard.

Simmel, G. 1908. *Der Arme.* Munich: Duncker & Humblot.

Stiker, H.-J. 1999. *A History of Disability.* Translated by W. Sayers. Ann Arbor: University of Michigan Press. Original version *Corps infirmes et sociétés.* 1982. Paris: Aubier (Dunod, 1997).

Weber, M. 1920. *Gesammelte Aufsatze zur Religionssoziologie.* Tübingen, Germany: Mohr.

Wolfensberger, W. 1972. *The Principle of Normalization in Human Services.* Toronto: National Institute on Mental Retardation.

INCLUSIVE EDUCATION

The concept of inclusive education is grounded in the principle of "normalization," which asserts that individuals with disabilities have a right to access the same opportunities, including the same daily experiences and routines, as persons without disabilities. Inclusive education has been strongly endorsed by the international community. Article 23 of the United Nations Convention on the Rights of the Child states:

> A mentally or physically disabled child has the right to a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate active participation in the community. The state shall provide special care, free of charge, whenever possible, to ensure that the disabled child receives education, training and services leading to the fullest possible social integration and individual development.

This stance by the United Nations represented a major leap forward in establishing education as a "right" of children with disabilities. The UN convention did not, however, provide a definitive statement regarding inclusion. The international community has adopted a vision of "education for all" (EFA), which means that every child, regardless of status, is entitled to an education. The World Declaration on EFA was first adopted in Jomtien, Thailand, in 1990 by more than 1,500 persons representing the international community, including government officials, members of nongovernmental organizations, policy makers, researchers, and key international donors such the World Bank. (UNESCO, the lead UN organization for special needs education, was one of five organizations that convened the Jomtien conference and continues to work with other international agencies and nongovernmental agencies to achieve the goal of providing equal access to education to children with disabilities.) Subsequent conferences, such as the Salamanca World Conference on Special Needs Education in 1994 and the Dakar World Education Forum in 2000), reaffirmed the goal of EFA, and the international community has increased its commitment to promoting policies that support educational opportunities for all.

According to the Salamanca Statement, every child has a fundamental right to an education, and schools should develop a child-centered philosophy to accommodate the needs of all children. The design of education systems and programs needs to account for the wide diversity of child characteristics, including those of a range of children with disabilities, gifted children, street children, working children, children from remote and nomadic populations, children from minority groups (whether linguistic, ethnic, or cultural minorities), and children from other disadvantaged areas or groups.

According to the Salamanca Framework for Action:

> The fundamental principle of the inclusive school is that all children should learn together, wherever possible, regardless of any difficulties or differences they may have. Inclusive schools must recognize and respond to the diverse needs of their students, accommodating both different styles and rates of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use and partnerships with their communities. (UNESCO 1994:11, para. 7)

The Salamanca Statement advocates educating children with disabilities within regular schools and eliminating, as much as possible, the use of segregated special schools for these children.

DEFINITIONAL ISSUES

Within the international community, the notion that every child is entitled to an education is not debated. Inclusive educational policies are those that address the specific needs of every child of school age regardless of gender, race, ethnicity, language, culture, economic status, or disability. However, where the education is provided continues to be confounded by disability classifications. The International Classification of

Functioning, Disability, and Health (ICF), developed by the World Health Organization (WHO 2001) is the dominant tool used for defining disability in policy and research. This classification system focuses on the types and levels of interventions appropriate for individuals with disabilities within specific contexts, such as in education. Its purpose is to assist in the development of inclusive policies and research through refinement of classification. Yet the idea that children with disabilities need to be categorized has been challenged by some in the international community because of concerns about the stigmatizing effect of labeling children. For example, in many countries, a child's ICF classification can determine whether or not the child will be allowed to stay in a regular public school. Thus, the preferred approach is not to focus on the disability and instead create schools that can meet the needs of any child.

However, this is not a universal goal. To illustrate: Consider students who have physical and sensory disabilities and no cognitive or intellectual impairments. Children with these types of disabilities will likely require some adaptations to their physical environment in order to be able to access education. These can include accessible facilities as well as transportation. Students with sensory impairments may also require specially designed interventions and curricular materials (e.g., interpreters, large-print or Braille materials). While all such interventions may be provided within regular schools and classrooms, advocates for some of the sensory disabled populations question the capacity of regular schools and/or classrooms to provide interventions for individual children who may be hearing or visually impaired. Advocates for the deaf and hearing impaired also maintain that it is important for children with these impairments to be educated with others like themselves so that they are included in Deaf culture. They assert that equality of educational opportunity is best achieved in specialized settings, such as special schools.

Children with intellectual and learning disabilities have special educational needs, although the latter are not universally recognized as having a disability. For children experiencing difficulties learning to read as well as those children with marked levels of cognitive and developmental disabilities, inclusive education means individually designed and child-centered pedagogy. However, where that education is provided may be subject to debate. For example, in the United States and Canada, where learning disability is recognized as a classification, advocates question whether the regular classroom can provide the intensive instruction these students need to access and progress in the curriculum (McLaughlin & Jordan forthcoming). For students with moderate to severe intellectual disabilities, inclusive education is often interpreted as both individualized and provided in regular classrooms. Education for these students places great emphasis on developing communication strategies and social competencies that will permit these students to interact with and be integrated into the community at large.

EMERGING ISSUES

Several issues have emerged in recent years concerning inclusive education in countries with and without well-developed special educational systems. First and foremost, *every* child with a disability must have access to public education. Within developing countries, there is growing acknowledgment that a paucity of data are available pertaining to childhood disability. The WHO and the United Nations generally agree that approximately 10 percent of the world's population is affected by some kind of physical, mental, or sensory impairment (Metts 2000). However, reported estimates on the proportion of disabled persons in the population have ranged from 5.2 percent to as high as 20 percent. The WHO has stated that it is not possible to determine the percentages of individuals with disabilities more accurately because of differences among the classification systems used to determine who is disabled. For example, children with severe disabilities are sometimes not included in estimates because they are hidden from society and excluded completely from the educational system. These children may also reside in institutions or, as is the case in many developing countries, may be receiving care or education in one of a number of small community organizations supported by various charitable organizations (Peters 2003).

Another emerging issue concerns increased demand for educational accountability in the form of higher levels of student academic achievement. Greater attention to educational productivity is challenging schools to improve the performance of

students with disabilities in specific academic content areas (McLaughlin & Jordan forthcoming). Whether accountability demands will lead to improvement or restriction of the education of students with disabilities in regular schools and classrooms remains to be seen. Some believe that increased scrutiny of the academic achievement of students with disabilities, and other subpopulations of at-risk students, will motivate schools to implement curricula and pedagogy that will address diverse learners. Others are concerned that such scrutiny will lead regular schools and classrooms to become less tolerant of students who require extensive support or adaptations and to see these students as better served in more specialized settings.

Inclusive education, in all of its meanings, is not a specific program that can be implemented. Rather, inclusion is a philosophy and a process that must be implemented at many different levels of the educational system (Hegarty 1995). Inclusion requires the restructuring of the physical environment, the broadening of instructional strategies and curricula, and changes in the social and psychological attitudes of teachers, administrators, and students.

—Margaret J. McLaughlin

See also Education, International; Education, Primary and Secondary; Education and Disability.

Further Readings

Hegarty, S. 1995. *Educating Children and Young People with Disabilities: Principles and the Review of Practice.* Paris: UNESCO.

McLaughlin, M. J. and A. Jordan. Forthcoming. "Push and Pull: Forces That Are Shaping Inclusion in the United States and Canada." In *Contextualizing Inclusion,* edited by D. Mitchell. London: Routledge Falmer.

McLaughlin, M. J. and M. Rouse. 2000. "Introduction: The Struggles for Reform." Pp. 1–10 in *Educational Reform in the United States and Britain,* edited by M. J. McLaughlin and M. Rouse. London: Routledge.

Metts, R. L. 2000, February. "Disability Issues, Trends and Recommendations for the World Bank" (World Bank, Social Protection Discussion Paper No. 0007). Retrieved May 12, 2005 (http://www.worldbank.org/sp/disability/documents_online/world_bankdocuments).

Peters, S. 2003. *Inclusive Education: Achieving Education for All by Including Those with Disabilities and Special Education Needs*. Washington, DC: World Bank, Disability Group.

Rioux, M. 2001. "Bending toward Justice." In *Disability, Politics and the struggle for change,* edited by L. Barton. London: Fulton.

UNESCO. 1993. *The Standard Rules for the Equalization of Opportunities for Persons with Disabilities.* Retrieved April 30, 2005 (http://www.independentliving.org/STANDARDRULES/StandardRules1.html).

———. 1994. *The Salamanca Statement and Framework on Special Needs Education.* Retrieved April 30, 2005 (http://www.unesco.org/education/educprog/sne/salamanc/index.html).

Wolfensberger, W. 1975. *The origin and nature of institutional models.* Syracuse, NY: Human Policy.

World Health Organization. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

INDEPENDENT LIVING

ESSENTIAL DEFINITIONS

The term *independent living* refers to the emancipatory philosophy and practice that empowers disabled people and enables them to exert influence, choice, and control in every aspect of their lives. Independent living is an ideology as well as a social and political movement. Originally inspired by the example of the American civil rights movement and also by the growth of the women's movement, participants in the independent living movement see it as a civil rights movement of disabled people.

The Washington Declaration, which came out of a global summit on independent living held in Washington, D.C., in 1999, defines the principles of independent living as follows:

> That all human life has value and that every human being should have meaningful options to make choices about issues that affect our lives;
>
> That the basic principles of Independent Living Philosophy are human rights, self-determination, self-help, peer support, empowerment, community inclusion, cross-disability inclusion, risk-taking and integration.

Within this broad understanding, the concept of independent living has developed a different character in different regions of the world.

HISTORY

Some of the ideas inherent in independent living predate the naming of the first center for independent living (CIL). Within the United Kingdom, for example, disabled people with sensory impairments were uniting to press for rights to education and to paid work as early as the nineteenth century. Most people, however, accept that the birth of the modern independent living movement took place in Berkeley, California, in the 1970s. There a group of physically impaired students rebelled against the notion that they should accept living in a nursing home and united to demand the right to an accessible living environment and to paid aides to give them the personal assistance necessary for them to lead normal daily lives.

This group, originally called the Rolling Quads, worked to support other disabled students at Berkeley. The group swiftly extended its services to the community, and the Berkeley Center for Independent Living was born. The concepts that underpinned the Berkeley initiative—of accessible environments, affordable technology (e.g., a wheelchair repair service), personalized daily living support (personal assistance), and peer advice (disabled people supporting and helping each other)—have remained central in the independent living movement. The CIL came into being at an institution with a reputation for social radicalism, in an era of social radicalism. So the other characteristic it embodied was a political dimension, an identification with struggles for social justice.

SPREADING THE IDEA

The CIL concept was exported to Europe in the late 1970s through the work of a few well-traveled disabled activists. The concept was taken up enthusiastically in northern Europe, including the United Kingdom. Activists from these countries and from the United States took the idea to other parts of the world. There is now a global independent living movement.

The movement has developed in various ways from region to region. In most of the developing world, independent living has been associated with economic independence, so the movement has focused on employment opportunities, often linked to providing services to other disabled people. In Zimbabwe, for example, a wheelchair manufacture business provides both work and a service for disabled people as well as generating income for the CIL.

AGAINST INSTITUTIONS

In Western Europe the independent living movement has focused on ensuring that disabled people have alternatives to residential care institutions. Most European CILs, as well as the European Network on Independent Living (ENIL), focus on personal assistance as a key component of independent living. This is because lack of personal assistance is closely linked to individuals' being forced to live in institutional care. ENIL was set up in 1989 at a conference held in Strasbourg. The conference resolution (known as the Strasbourg Resolution) states:

> This conference has focused on Personal Assistant Services as an essential factor of Independent Living, which itself encompasses the whole area of human activities, e.g. housing, transport, access, education, employment, economic security and political influence. . . .
>
> We condemn segregation and institutionalisation, which are direct violations of our human rights, and consider that governments must pass legislation that protects the human rights of disabled people, including equalisation of opportunities.
>
> We firmly uphold our basic human right to full and equal participation in society as enshrined in the UN Universal Declaration of Human Rights . . . and consider that a key prerequisite to this civil right is through Independent Living.

This resolution locates independent living firmly within the framework of human rights. This is not about doing good to disabled people, or providing them with welfare. It is about ensuring that disabled people can exercise their human and civil rights equally with nondisabled people. The Strasbourg Resolution expresses independent living philosophy in a form that governments can understand.

DIRECT PAYMENTS

One of the tools that disabled people have developed as a way of achieving the control and choice that

characterize independent living is direct payments. This is a method of giving disabled people cash to pay for personal assistance instead of having assistance arranged on their behalf by local authorities. Direct payments have been popular in Europe, including the United Kingdom, because they provide an alternative to home care or residential care. The fact that direct payments give disabled individuals control over the budget and over hiring (and, if necessary, firing) the people who assist them has been a major challenge to the prevailing welfare philosophy.

In the traditional mode of service provision, disabled people are seen as dependent precisely because they need help with daily tasks such as getting dressed. With direct payments, disabled persons can take control over these daily tasks. More important, when they can accomplish such basic tasks as getting dressed or washed efficiently, disabled people can use their time doing more productive and enjoyable things, such as working, bringing up children, and going to art galleries.

Some welfare professionals have opposed direct payments, stating concerns that users may spend the money on the "wrong" things or hire the "wrong" workers. Such concerns are born of a belief that disabled people are vulnerable, that they need professionals to hire the "right" workers for them. These concerns also reflect a belief that public money should be spent only on activities sanctioned by professionals. Both these ideas are based on a view of disabled people as less than wholly adult, not able to make their own decisions and take their own risks. Direct payments challenge this view. However, supporters of direct payments do not pretend that disabled people do not need help in making choices or implementing decisions. They argue that CILs, run by and for disabled people, can provide this help. A number of CILs in operation today started as peer support groups for people using direct payments.

A COMPREHENSIVE PHILOSOPHY

Independent living is more than an individual aim. It encompasses a change in social relations. It is both a philosophy and a practical approach. It brings disabled people together to work for civil and human rights. They espouse equal opportunities for everyone as well as self-determination for themselves. The basic meaning of independent living can be expressed very simply: "Independent Living means that disabled people want the same life opportunities and the same choices in everyday life that their non-disabled brothers and sisters, neighbours and friends take for granted" (Ratzka 1996). This simple definition encompasses all of social and economic life. Many disabled people are still denied the opportunity to grow up alongside nondisabled siblings, to go to the neighborhood school, to use the same buses and get the same kinds of jobs as their nondisabled friends. The independent living movement says that they can attain these simple aims through collective action.

CHANGING SOCIAL RELATIONS

The independent living movement wants to change the social relations of disabled people, particularly to remove enforced reliance on family members as primary caregivers. Simon Brisenden wrote one of the most memorable criticisms of being forced to rely on a family member for assistance: "It exploits both the carer and the person receiving care. It ruins relationships between people and results in thwarted life opportunities on both sides of the caring equation" (quoted in Morris 1993:27).

This view is not universally accepted—some people see giving assistance to a family member as an expression of love or of wider familial duty—but it is one that underpins much of the work of the independent living movement. Nasa Begum has described the "burden of gratitude" placed on people who are always beholden to others for simple things such as taking a bath; the independent living movement attempts to remove that burden by making assistance into a straightforward working relationship, rewarded with appropriate wages, delivered in ways chosen and directed by the disabled person. This approach does not reject the family—rather, it values family members in their own right, as wives, fathers, sisters, sons, rather than forcing them into the role of unpaid attendant.

INDEPENDENCE IS NOT ISOLATION

Some critics of independent living have argued that it is an individualistic philosophy, that the focus on

supporting individual people ignores the wider social and economic pressures facing disabled people. This claim ignores the whole culture of independent living.

At the 1999 global summit on independent living mentioned above, delegates noted:

> The Independent Living Philosophy recognizes the importance of accepting responsibility for our own lives and actions, and at the same time, the importance of community to foster Independent Living.

Achieving the social aims of independent living requires collective action. Independent living is developed through the self-organization of disabled people. The movement is based on collectively developed solutions to individually experienced barriers. The movement recognizes that many disabled people will not manage to achieve independence on their own, that the system we live in puts too many obstacles in the way. "The cornerstone of Independent Living Philosophy is . . . control and choice. . . . Systems advocacy is of ultimate importance because some choices for disabled people still need to be created" (Holdsworth 2000).

This recognition, that society needs to create choices for disabled people, is one of the reasons disabled people have come together to set up their own organizations, including centers for independent living. CILs are always controlled by disabled people; often all of the voting members on the governing boards of CILs are disabled people. This is not because of hostility toward nondisabled people. Rather, it is an expression of a necessary step toward independent living. As Adolf Ratzka (1992) notes: "Disabled people need to be in charge of their own lives, need to think and speak for themselves without interference from others." This is as true in organizations as it is in the lives of individuals.

INDEPENDENT LIVING AND THE SOCIAL MODEL

In the United Kingdom, the philosophy of independent living is closely linked to the ideas embodied in the social model of disability. Some of the theorists of the social model were pioneers of the U.K. independent living movement. This model shows us that (a) historically, society's reaction to impairment (and failure to meet needs relating to impairment) has undermined disabled people's human and civil rights; and (b) this is not inevitable—in other words, impairment does not have to determine life chances. Biology is not destiny.

The social model recognizes that disabled people are different from nondisabled people in that they have *additional requirements,* such as mobility needs and needs for communication assistance or personal assistance. These additional requirements stem both from experiences of impairment and from the disabling barriers of negative attitudes and unequal access.

The pioneers of independent living in the United Kingdom identified 7 "basic needs" of disabled people—that is, essential additional requirements that must be met if disabled people are to achieve independent living and thus equality of opportunity with nondisabled people. That initial list was later extended to the following 12 basic needs:

- Full access to the environment
- A fully accessible transport system
- Technical aids (equipment)
- Accessible adapted housing
- Personal assistance
- Inclusive education and training
- Adequate income
- Equal opportunities for employment
- Appropriate and accessible information
- Advocacy (toward self-advocacy)
- Counseling
- Appropriate and accessible health care provision

This list echoes similar priorities identified a few years previously at the CIL in Berkeley.

INDEPENDENT LIVING AND INCLUSION

Historically, CILs have struggled to provide services for all sections of the disabled community. In most cases their founders have been people with physical impairments, but they have always taken an inclusive approach to disability, aiming to serve all disabled people, regardless of the nature of their impairments. Some CILs have had problems in fulfilling their inclusive aims, often because of limited material and

human resources. CILs' success in achieving such aims can also be affected by entrenched opposition from vested interests within agencies that provide traditional disability services. For example, some traditional service providers have castigated CILs in the United Kingdom for being insufficiently knowledgeable about the communication needs of people with learning difficulties (intellectual impairments) while at the same time jealously guarding their own knowledge. In such cases, the concept of sharing knowledge in order to make the service better is not put into practice.

Some disability activists, particularly in the United Kingdom, where social model thinking is especially influential, have adopted the terms *integrated living* and *inclusive living* in place of the original *independent living* to characterize the philosophy on which their activities are based. By doing so, they demonstrate their recognition that humans are by definition "social" beings, and that *all* humans, regardless of the degree and nature of impairment, are interdependent and, therefore, a truly "independent" lifestyle is inconceivable. This recognition is especially important to the independent living movement in regions where interdependence is a strong part of the culture, such as in Southeast Asia.

GLOBAL SUMMIT

As noted previously, in 1999 a global summit on independent living was held in Washington, D.C. The summit brought together activists from more than 70 countries. Despite regional variations in how independent living was being developed around the world, the delegates agreed on a set of basic principles. These principles, which are laid out in the Washington Declaration, include a restating of the basic needs identified by CILs in the United States and United Kingdom: "that we recognize the importance of equal and inclusive education, employment opportunities and entrepreneurship, assistive technology, personal assistance, accessible transportation and a barrier free environment to promote Independent Living." The principles also restate the movement's aspiration to universality:

> that the Independent Living Principles and Philosophy have applications on a global scale and are to be implemented on the local, national and international levels without regard to disability, sex, religion, race, language, ethnic background, political affiliation, age or sexual orientation.

INDEPENDENT LIVING IN THE TWENTY-FIRST CENTURY

Current concerns in the independent living movement center on sustaining the movement, on creating real independent living opportunities in the developing world, and on promoting the link between independent living and human and civil rights. These concerns are interlinked. Activists who meet at global and regional gatherings devoted to the topic of independent living have noted that many of the pioneers of the movement are aging and that no large cohort of younger activists is replacing them. One result of the success of independent living in the United States and Europe has been that more disabled people can now take it for granted that they can get education, get assistance, get a job. They thus have less direct motivation to devote time to managing and supporting independent living organizations. The movement is looking for ways to sustain its collective base in an era when individual consumerist culture is the dominant mode.

One method by which advocates of independent living are sustaining a wider perspective is found in Scandinavia, where national disabled people's organizations support independent living projects in several developing countries. By emphasizing the global links among disabled people, they are helping to create a sense of community.

Finally, the movement is revisiting the philosophical roots that informed the first CIL in Berkeley, stressing that disabled people have the same civil and human rights as everybody else. Independent living is a tool for achieving these rights. Activists are now challenging residential institutions, not just because they stifle individual autonomy but because they rob those who live there of essential human rights. In the United States, the Free Our People campaign uses the direct action tactics developed by Adapt. In the United Kingdom, the government-sponsored Disability Rights Commission is backing a campaign for a right to independent living on the grounds that it is essential

to enable disabled people to enjoy civil rights. This reaching out from disability organizations to the wider world of civil and human rights has been the hallmark of the independent living movement and distinguishes it from other, welfare-based approaches to meeting disabled people's needs.

Independent living can be summed up in two words: freedom and participation. Independent living gives disabled people the freedom to make choices and the means to participate in their communities, taking both opportunity and responsibility.

—Frances Hasler

See also Activism; Advocacy, International.

Further Readings

Center for Independent Living Inc. n.d. "Mission and History." Retrieved April 30, 2005 (http://www.cilberkeley.org/text/history.htm).

European Network on Independent Living. 1989. "The Strasbourg Resolutions." Reproduced in *Tools for Power: A Resource Kit for Independent Living,* edited by Adolf D. Ratzka. Retrieved April 30, 2005 (http://www.independentliving.org/docs2/enilstrasbourgresolutions.html).

Holdsworth, Cassie. 2000. "Vision Statement." Commissioned by Birmingham Centre for Independent Living, Birmingham, England.

Martinez, Kathy. 2000, March. "Global Perspectives on Independent Living for the New Millennium: An International Summit Conference on Independent Living." *Disability World.* Retrieved May 1, 2005 (http://disabilityworld.org/March2000/English/ilconferencearticle.htm).

Morris, Jenny. 1993. *Independent Lives? Community Care and Disabled People.* London: Macmillan.

Ratzka, Adolf D., ed. 1992. *Tools for Power: A Resource Kit for Independent Living.* Retrieved April 30, 2005 (http://www.independentliving.org/toolsforpower).

———. 1996. "Introduction to Direct Payments for Personal Assistance." Presented at the HELIOS Study Visit on Independent Living and Personal Assistance, June 7–9, Stockholm. Retrieved May 27, 2005 (http://www.independentliving.org/docs5/IntroDirectPayments.html).

"Washington Declaration" (in Spanish). 2003. Pp. 315–318 in *El Movimiento de Vida Independiente,* edited by J. Vidal García Alsonso. Madrid: Fundación Luis Vives.

Websites

Center for Independent Living (Berkeley, CA), http://www.cilberkeley.org

European Network for Independent Living, http://www.enil.eu.com

Independent Living Institute (Sweden), http://www.independentliving.org

National Centre for Independent Living (UK), http://www.ncil.org.uk

INDIA

See Disability in Contemporary India; Disability Policy: India; Experience of Disability: India; India, Impact of Gender in; India, Marriage and Disabled Women in

INDIA, IMPACT OF GENDER IN

Historically, disability has been defined as a medical condition and perceived as the personal tragedy of the "affected" person. However, slowly but surely disabled people have come to question this understanding. As the disability movement has gained impetus, the experiences of marginalization and multiple exclusions associated with disability have come to be comprehended as the results of social oppression. It has become clearly evident that factors such as widespread inaccessibility in the built environment, segregation in education, rampant unemployment, unavailability of alternative formats of communication, and a general lack of acceptance in society have been responsible for the subjugation of the disabled. Disability therefore is in reality a social construction and not a natural category.

Gender, on the other hand, has historically been synonymous with sex. In the 1970s, however, the concept of gender as different from sex made its appearance in feminist discourse. Since then, the term *sex* has been understood to refer to the biological characteristics that make men and women different, and *gender* has been conceived as referring to the social and psychological characteristics related to femininity and masculinity. To the feminist world, this distinction is extremely significant in that it underlies the different forms of domination experienced by women universally. According to feminist theorists, every societal configuration has a sex-gender system—a set of arrangements by which the biological raw material of human sex and procreation is shaped by desired social interventions. Sex is related to what was bestowed by nature, and gender is

related to what results from nurture. Within the emerging feminist understanding of the 1970s, this distinction was significant as it avoided the underpinning of *women* as a natural category. It thus became evident that femininity and masculinity are to be understood as acquired characteristics with social significance.

Despite a clear enunciation of the gendered character of societal parameters, mainstream feminism went on to replicate the inequities of the patriarchal society by leaving out of its ambit many categories of women who are marked by given systems as "different" and are oppressed due to factors such as class, ethnicity, caste, and physical or mental diversity. Implicit in mainstream feminism was the idea of universal sisterhood, which signified that all women experience similar oppressions; however, this idea was contested by those who felt that their unique life conditions were not reflected in the collective experience. Disability was one of the categories excluded from deliberations within the evolving awareness of feminism.

The inevitable fallout of this reasoning was that the disability movement mirrored the gendered nature of larger society, making the female members uncomfortable habitants of the resistance that the disability movement has been putting up against the hegemony of the normality. Even sensitive students of disability have focused on disability as a singular concept and have taken it to be not merely the primary status, but apparently the exclusive status of disabled people. Disability is not the only social marker of distinctiveness, as gender coalesces and makes the experience increasingly doubly oppressive. Thus, both disability and gender are social constructions, endorsing the cultural inscriptions on the bodily impairment and the biological sex, respectively. The realization that both identities are similar in that they are biological entities that are assumed to become problems when placed in a hostile social context has become crystal clear. It is precisely this understanding that has rendered the lives of disabled women across the globe invisible and devoid of any control.

The process of discrimination against disabled people starts at birth. It is not uncommon in some parts of the world for disabled infants and very young children to be killed or left to die. In India, technological advances that allow the determination of the sex of the fetus have created a eugenics movement that might be unheard of in the West. The widespread desire for male offspring has translated into the abortion of many female fetuses. While activists in the West have been vehemently protesting against the killing of disabled infants in India, the preference for sons has resulted in the lowest ratio of female to male births ever. Although feminists have engaged in plenty of debates about the ethical contradictions involved in the selective killing of female fetuses, as well as the right to abort, the use of new technologies for prebirth genetic screening to predict disability has not been addressed. Coupled with the predominant negative presumptions held about impairment and disability, it is not in the least surprising that the abortion of impaired fetuses is not even mentioned in these debates.

The survival to birth of a disabled girl child, however, does not guarantee her a struggle-free existence. The road she will have to traverse is not easy. In any nation, a disabled girl child is likely to experience inequities in terms of basic entitlements (such as food, health care, education, and employment opportunities) and often has little hope of being included in the cohesive net of the family. Although most if not all disabled girls around the world are subject to such difficulties, a majority of disabled girls who live in developing countries are currently living lives in which every one of their human rights is being violated.

In the early 1980s, feminists in the West drew attention to the danger inherent in applying the feminist critique of patriarchy to disabled women's experiences. They realized that this critique would not offer an adequate account of the oppression of disabled women, as disabled women have not been "ensnared" by many of the social expectations feminists have challenged. In reality, this "freedom" from expectations signified the loss of traditional roles that provided living space to women marked as disabled. The constant privileging of "normal" women worsened the situation of disabled women. The intimidation of hegemony that worships physical and mental perfection has a definite impact on the resistance that disabled women can put up against their recurrent marginalization.

In such a context, it is not easy to think of viable strategies. Despite swift social, cultural, and economic changes and the current drive toward a global society, women are still defined in terms of their

connectedness with traditional social roles. For instance, in India, throughout her life, a woman is largely defined by her roles as daughter, wife, and mother. Any position she holds outside the home is not considered to be her primary role. However, disabled women are not considered "marriageable" because their impairments are seen as "imperfections" that could be passed on to their children. Their ability to fully look after a home and family is also questioned.

The incidence of marriage for disabled women is lower than that for disabled men throughout the world, but it is lowest in cultures where traditional roles are highly valued. In a similar vein, whereas specific cultural taboos may vary, the universal reality is that disability and motherhood are not perceived as complementary. Even in cultures where single motherhood is acceptable, disabled women often find it difficult to express their desire for this role. The denial of traditional roles thus adds to disabled women's vulnerability and desolation.

Much of the uncertainty about disabled women's suitability for the role of motherhood stems from assumptions concerning their physical capacity to carry pregnancies. If disabled women do manage to be reproductive, grave doubts still exist in most societies about their competence as mothers. The emotional strength that they can provide their children is viewed as inconsequential, as the stereotypical image of disabled women is that of dependency. That disabled women can be caretakers too is often missed in the dialogue of care. This appears in contrast with more emancipated "normal" women, because of the limitations imposed on disabled women, who cannot become partners in this celebration because they do not have opportunities to participate in the more productive activities of a given culture.

The economic strain and isolation created by the relatively few opportunities disabled women have for productive work or gainful employment lead to a lack of participation in the labor market, producing and reinforcing the dependency that is assumed to be characteristic of disabled women. In this sense, feminist positions are guilty of amplifying the importance of women's employment until it has become a standard of womanhood against which disabled women shrink into invisibility. Striving for equality not only with men but also with "normal" women induces in disabled women a desire to be recognized as persons first and then as being female.

In many societies, women who are considered intellectually disabled frequently encounter the severest form of oppression in the form of forced sterilization. Without their consent or even their knowledge, they are provided with an "effortless" and "realistic" solution to their "predicament." Sterilization is said to "relax" the disabled woman, as she no longer has to manage menstrual hygiene or deal with pregnancy or the "risk" of bearing a disabled child. It is often argued that sterilization protects a woman from sexual abuse. Although sterilization is imposed predominantly on women who are intellectually different, many women with physical and sensory disabilities are also subjected to this inhumane treatment.

This is quite paradoxical, as it is popularly assumed that disabled women are asexual. This contradiction places them in an extremely perilous situation. In a society that imposes ruthless standards for attractiveness and desirability, disabled women require a sort of physical legitimacy in order to obtain love and acceptance, with a certain sexual model as the entrée to both. This creates confusion, as disabled women obviously cannot adhere to rigorously defined standards of acceptable body dimension, weight, and physical competence with the ability to be sexual. This becomes a discouraging and inexorable process for those who don't measure up to the normative standards. The consequences for these women are feelings of guilt, shame, and fear when they are confronted with the possibility of sexual intimacy. Slowly but surely, this conveys messages of unattractiveness as well as leads to a state where it seems that the body has lost the potential to respond to sexual cues. Thus, all these measures are designed to control disabled women rather than to address the societal arrangements that do not provide security and support for these women.

The oppression and invisibility that disabled women experience have negative impacts on their self-esteem. Stigmatized from birth, through neglect they grow up with the tyranny of a society that demands perfection. In addition, disabled women—especially those who are severely disabled and fully dependent on the assistance of others to accomplish their day-to-day life activities—have to contend with

caregivers who objectify disabled women, often completely disregarding their feelings and their right to decide on matters concerning them.

The difficulties that disabled women experience are rooted in the meanings that impairment has for nondisabled people. If the nondisabled view the difference of disabled women as deviance, this has a negative impact on disabled women's internal strength and resistance. It is not easy to acknowledge and retrieve one's agency to resist dominant patterns when the signals communicated to one by others are those of dismay, fear, and pity. The right to self-definition and an evolving worldview is a fundamental political right that is denied to many disabled women. As disabled women confronting their recurrent exclusion, they are deprived of the right to have expertise regarding their own lives. Thus, disabled women must struggle not only to assert their own identities but also to assert their difference and to account for the injustices done to women that have not found expression in the language of feminism.

The stigma attached to disabled girls and women does not leave their mothers unblemished. A form of torture accrues to them for having given birth to disabled daughters. Once again, the feminist discourse in India has paid scant attention to the issues faced by women who are the mothers of disabled children, especially girls. Women who cannot validate their social status as mothers who have borne healthy children for their husbands' families, such as those who have given birth to disabled children, are condemned to live in shame. There have been instances in India of women being divorced or even tortured because they gave birth to disabled children. Given the preference for sons, "mother blaming" is even more severe when the disabled child is a girl.

In addition to such direct onslaughts—which are always met with protests—disabled women have to contend with the use of their life situations as a metaphor to illuminate the issues and concerns of nondisabled women. The genesis of this probably lies in the fact that the sociocultural meanings ascribed to female bodies and those assigned to disabled bodies are similar. Excluded from full participation in public and economic spheres, both are conceived in opposition to a norm that is assumed to possess natural superiority. Such comparisons can be both emancipatory and oppressive. If the objective of invoking such comparisons is to understand the lived experiences of people and grasp their legitimacy, the potential is immense. However, when the underlying realities of the categories serve only at a metaphorical level, this can lead to a total erasure of the category that is being invoked. The consequent effect is that whereas one category gets "valorized" the other is very often "suppressed" in the process. Consequently, when nondisabled women are portrayed as experiencing social disability, the strategic advantage of the metaphor gets lost.

A shift from the theoretical/metaphorical to the material, which is essential to render visible the "cultural constructions" that have supported the currently flawed conceptualizations of disability and womanhood, is critical. A careful analysis of metaphors that use disability as explanatory categories is required to unearth their meanings and functions, if their power is to be subverted. Until the popular refrain that "being a woman is the biggest form of disability" operates, the road to empowerment is going to be a difficult one. Another significant issue to remember is that disabled women are also divided by many factors, such as class, caste, ethnicity, rural/urban divide, sexual orientation, and type of disability. In the context of the relationship between disability and gender, we must understand how these marginalizing aspects play a significant role.

For disabled women to resist the hegemony of normality, both advocacy and research are essential. Within India what is perhaps needed is an interrogation of the normative standards that construct disabled women as passive and dependent. However, given the cultural context, this cannot be accomplished through an emphasis on "independence and autonomy," as family structures are interdependent in Indian society. Whereas women in the West have attained a reasonable amount of success in challenging the "perfection-driven norm," this has been a result of a significant attitudinal change that has led to a more accessible built environment and changes in other structural inequalities. Research in developing countries needs to focus on actual living conditions so that it can accurately assess the impact of disabling conditions associated with gender. Researchers need to resist the tendency to borrow from the Western understanding, as the local reality is extremely important.

The cause of disabled women in India would be greatly supported by cross-cultural research that listens to diverse voices and recognizes that there is no single grand narrative of "the disabled woman." Thus, the idea of universal sisterhood, while sound in principle, will remain a myth if researchers overlook the nuances of specific realities in order to arrive at broad generalizations. Although rhetorically the women's movement may be represented as inclusive, the reality belies the claims. Encapsulating diversity within every universal category can be a daunting task, but the initiation has to come from the grass roots. It is only then that the necessary agency can be located and the hegemonies of both the disability movement and the women's movement can be challenged.

—Anita Ghai

See also Disability Policy: India; Experience of Disability: India; India, Marriage and Disabled Women in.

Further Readings

Fine, Michele and Adrienne Asch, eds. 1988. *Women with Disabilities: Essays in Psychology, Culture, and Politics.* Philadelphia: Temple University Press.

Ghai, Anita. 2003. *(Dis)Embodied Form: Issues of Disabled Women.* New Delhi: Haranand.

Kittay, Eva, Anita Silvers, and Susan Wendell, eds. 2001. "Feminism and Disability" [Special issue]. *Hypatia* 16(4).

Mairs, Nancy. 1996. *Waist-High in the World: A Life among the Nondisabled.* Boston: Beacon.

Thomas, Carol. 1999. *Female Forms.* Buckingham, UK: Open University Press.

INDIA, MARRIAGE AND DISABLED WOMEN IN

A study of the literature on disabled women reveals that the issue of marriage has been addressed very little from an empirical perspective. Most of the claims about the marital status of disabled women are based on estimates rather than actual research conducted with large samples. In countries such as the United States, Canada, and the United Kingdom, where disability studies is evolving as an independent discipline, a significant body of literature discusses gender, feminism, personal experiences, and the sexuality of women with disabilities. This literature briefly alludes to the issue of marriage, but it does not move beyond giving a selected group of women with disabilities the choice between remaining single or getting married. In developing countries such as India, hardly any research has been conducted on this issue, and therefore very little archival material, if any, is available. The subject of marriage and disabled women in India needs to be critically and thoroughly researched and documented. This entry is offered with the hope that it will provide scholars with some leads into the issue.

Before this discussion can begin to approach the significance or insignificance, and the availability or nonavailability, of the institution of marriage for disabled women, it must briefly address the basic question of the importance of marriage for women, the changing perception of the institution in the wake of awareness generated by the feminist movement, and how a single woman is looked at in a volatile yet strongly traditional Indian society. Also, marriage is addressed here as it exists between men and women; the topic of same-sex marriage is not considered, as this practice is not a norm and therefore uncommon in India. Of late, however, some deaf lesbian women have come out, but it is beyond the scope of this entry to delve into multiple issues; the focus here is primarily on the traditional institution of marriage and its availability to women with disabilities in India.

It is pertinent to note that, owing to the diversity of India's population and the country's colonial history, which has been questioned as not allowing subalterns sufficient voice, this entry does not seek to offer a monolithic picture of the issue. While some aspects of the topic may fall into a linear singular pattern, others may be contextualized and located in diverse cultural, educational, regional, religious, caste, and socioeconomic realities. Although the experience of discrimination, deprivation, and exclusion is common to most disabled women in India and cuts across different contexts, the primary focus here is on Hindu women. This entry attempts to trace a recurring pattern of experiences of disabled women in the majority Hindu community because constraints of time, space, and scope as well as the availability of literature on the experiences of Hindu women make it most feasible to concentrate on this group.

IMPORTANCE OF MARRIAGE FOR WOMEN IN INDIA

In Hindu society, even today, one of the key roles a woman is expected to subscribe to is that of a wife. In fact, from the time of birth itself, the girl child is groomed, trained, and prepared to take this role after marriage. By and large, the feminist literature in India has regarded marriage as an oppressive institution, as it operates to strengthen patriarchy and perpetuate women's exploitation. Women are expected to conform to the laws or rules laid down in the Laws of Manu—the ancient lawgiver—and the ideals of womanhood described in several other ancient Hindu religious scriptures, epics, mythological tales, rituals, and practices. According to Desai and Krishnaraj (1987), these prescribe an ideal of womanhood that confines the woman to the roles of devout wife and doting mother. In these roles she does not function as an entity independent of her husband or children. Together, these roles put women in a lower, dependent position. Many writers, including Rao and Rao (1982), Dhruvarajan (1989), Bumiller (1990), Bagchi (1995), Nair and John (1998), Gandhi (1942), and Sharma (2002), have endorsed similar views, stating that a woman's career path is oriented toward marriage, which is arranged by parents in more than 90 percent of cases. It is the religious and social responsibility of parents to "settle" their daughters in marriage. Fruzzetti and Östör (1992) have observed that marriage is central to the lives of Bengali women. They note: "Daughters are not meant to remain permanently in their father's house. It is expected that all women will marry and leave for their husband's place. Marriage completes the cycle of cultural expectation for women" (pp. 39–40). In conjunction with such expectations, it is difficult to find aspirations or models for single women in this society. This practice of placing a premium on the virtues of wifely duty and maternity is followed in other cultures and religions in India as well, including Sikhism, Jainism, and Christianity.

In a 1953 study, Margaret Cormack found that single women were considered unholy and inauspicious in Hindu culture. This may not be an absolute truth today, because with changing times the numbers of women choosing to remain single have increased, but they still constitute a minuscule minority. In fact, a recent study conducted by economists of the London School of Economics found that among Indian cities Mumbai has the largest number of single women; based on their findings, the researchers projected that with growing economic and social independence, many Indian women may prefer not to marry (cited in Mukhopadhyaya 2004). In discussing the reasons some women remain single, Cormack observes that a majority of single women do not have the option of getting married for one or more of the following four reasons: They may be considered unattractive, they may be too qualified and hence cannot find husbands with higher qualifications than themselves, their parents may be unable to provide sufficient dowry, or they may not be able to find the "right man." In urban areas of India, a small proportion of women are found to be wedded to their careers and professions, which brings some amount of respect. A career provides some buffer because unmarried women without good careers are treated as objects of pity or lead lives of social exclusion and stigma.

Despite the feminists' reprobation against the age-old institution of marriage, it is imperative to understand why such a premium is still placed on it, especially for women in Indian culture. Marriage, for women, is seen as an institution that confers certain entitlements, privileges, status, respect, and access to other life accomplishments, such as motherhood, family life, and experience of sexuality. It is a means of gaining social acceptance in society; hence, it ensures participation and inclusion. These avenues become shut off to women who never marry. In most cases, marriage is also a route to economic and financial security. Although the Hindu Succession Act of 1956 gives equal rights to women to inherit parental property, as Kishwar (2004) points out, in practice women have little access to property.

EXPERIENCES OF DISABLED WOMEN IN INDIA

If marriage is perceived as the ultimate destiny of nondisabled women, then why is the destiny of disabled women different from that of their able-bodied counterparts in India? This is not to suggest that marriage should be the destiny of disabled women,

but rather that disabled women might have the alternative of choosing—that is, of deciding their destiny vis-à-vis marriage. A considerable literature indicates that disabled women are less likely to be married than are disabled men or able-bodied women. The 1996 report on the National Conference of Disabled Women put the proportion of unmarried disabled women in India at that time at 80 percent. Another report on the status of blind women in India, published by the Women's Committee of the Asian Blind Union in 2000, put the proportion of unmarried blind women at 73 percent. However, the latest findings of the National Sample Survey Organisation of India, brought out in December 2003, project a completely different picture. They show a higher number of disabled women being married than disabled men, but the percentage of widowed, divorced, or separated disabled women is about 30 to 31 percent, in contrast with 7 to 8 percent of disabled males. This pattern is observed in both urban and rural areas.

Researchers need to probe further into the reasons behind these higher rates of widowhood, divorce, and separation among disabled women in comparison with disabled men. This difference suggests problematic partnerships and devaluation of status for women after marriage. It could be possible that young disabled women are married off to men much older than themselves, or another possibility could be that they are tied to ailing men and therefore suffer a higher rate of widowhood. The higher rate of divorce and separation postmarriage for disabled women is again indicative of the fact—as Jeeja Ghosh and Shampa Sengupta (2003) projected based on the findings of a study in West Bengal, India—that they are often abandoned or physically and mentally abused, treatment associated with their disability. It is a situation of double bind: Whether disabled women are unmarried or married, they are in a disadvantageous position because the stigma of disability is permanently marked on their bodies. They either cannot get married because of their disability or, if they do marry, disability makes the survival of a happy marriage difficult.

At times, having disabilities opens several avenues for women in India that may otherwise be denied to them, such as education, employment, and subsequent financial independence. But such benefits come at the cost to disabled women of having it instilled in their minds that the avenue of marriage is closed to them and that it is futile even to think of it. According to Anita Ghai, this nonavailability of the traditional roles puts disabled women in a state of rolelessness. In her book *(Dis)Embodied Form: Issues of Disabled Women* (2003), she presents case studies in which she examines in detail the experiences of disabled women within and outside marriage. Ghai asserts that while feminists analyze the oppression of able-bodied women within the traditional role of wife and mother, they have chosen to ignore the oppression that disabled women feel due to the unavailability of traditional roles. She notes that in India marriage and motherhood have a cultural value, and that when disabled women are denied these markers of womanhood, the result is "a social obscurity and annulment of femininity" (p. 68).

Many educated and professionally accomplished disabled women refuse to marry disabled men or men who are not their equals in professional terms. The same holds true for disabled men as well. From my personal experience I can corroborate that professionally qualified disabled men prefer less than equal, able-bodied woman as partners to qualified and accomplished disabled partners. Marriage entails many compromises for disabled women that are humiliating. To begin with, due to the lack of choice they have owing to disability, they are left with no option but to accept spouses who are socially, economically, and intellectually not their equal. Sometimes they are physically and mentally abused and tortured, disability again being a major cause of their victimization. As indicated by the proceedings of the National Conference on Empowerment and Mainstreaming of Women with Disabilities, held in Jaipur, India, in August 2002, given such realities, many educated disabled women are choosing not to marry.

Where disabled women have little or no education or any skills that allow them to be productive and contributing members of society and thus improve their chances of marrying, they are treated by their families as a burden, and at times like damaged property that can be bargained in the matrimonial market. In a bizarre incident reported recently in the *Times of India* (Farooqui 2003), a father who had failed to find a groom for his disabled elder daughter, Preeti, who is a wheelchair user, laid the condition that he would give

the hand of his younger, nondisabled daughter, Ragini, to any man who would marry his disabled daughter as well. The marriage of both the daughters to one man was solemnized with Amarnath Verma—who has been lauded by many people for setting a precedent in rehabilitating a helpless disabled woman—on November 25, 2003; and, to the shock of everyone, the feminists remained silent toward this open practice of bigamy, something that is prohibited by Hindu Personal Law. This incident raises many questions about the options and choices available to disabled women, especially in India. Disabled women have no role models and little access to any community in India. The issues of their education and employment, their sexuality, and the violence, abuse, exploitation, and denial of rights and deprivation to which they are subject are rarely talked about or raised by disability activists or scholars. The disability movement has kept these issues under wraps, and disabled women activists as well as scholars hesitate to address them. India's disability movement is dominated by men with disabilities who set the agenda. And the agenda is based on the issues that concern them. Disabled women activists just follow that agenda. One disability activist recently had the following to say on this subject:

> Though we come across as strong activists shouting slogans, fighting for our rights . . . who takes care of our right to be loved (emotionally and physically), to be a life partner, to be mother and so on? Yes one can never force someone to love. It is the most natural process of life. But sadly it is dependent on the outward looks of a human. . . . I have kind of become numb and immune to these feelings though I am very emotional, sentimental and romantic at heart but I don't have the strength and guts to go through any pain. . . . And besides there is no future (marriage) even if I got involved with someone cause I can't manage things the way other women do. And our culture and traditions don't allow live-in relationships or have affairs w/o marriage . . . so there's no point. Of course, I feel lonely and crave for a companion but I can't do anything about it. (personal communication, November 5, 2003)

The yardstick used to measure a disabled woman's eligibility for matrimony is set by the traditional precedence of an able-bodied woman's roles of wife and mother. In an anthropological study conducted in rural South India, Erb and Harris-White (2002) found that disabled men are not interested in marrying disabled women because they feel such women will not be able to perform household or work tasks and undertake child-rearing activities. These researchers also found that disabled women decide against marriage due to fear of childbirth and fear of being abandoned. This may be seen as their internalization of disability oppression. In fact, the myths that disabled women are not sexually active, do not marry, and therefore do not even become mothers keep them out of the purview of government family and child welfare programs as well as reproductive and child health care programs. Although feminists criticize these programs for relegating women to the role of mother, the programs' exclusion of disabled women deprives them of access to marriage by perpetuating the myth that disabled women are incapable of becoming mothers and thus succeeding in family life. This also puts them in a cycle of economic deprivation, for, in India, marriage is also sometimes a route to financial empowerment (although the high percentage of widowed, divorced, and separated disabled women indicates otherwise).

Although some disabled women in India have made successful marriages, disabled women have no role models or ideals in this area to emulate. Those disabled women who have been successful in marriage tend to negate their disability identity; as Ghai (2003) has observed in her examination of Meekosha's work, they are "reluctant to share their personal stories, in fear that they might be seen as spectacles" (p. 100).

For the status quo to change, so-called privileged disabled women must come out of their closets and prove by example that disability is not a barrier to experiencing sexuality, motherhood, love, and family life. The news and entertainment media need to be enlightened on this issue and motivated to play a more active role in challenging the stereotypes of disabled women by bringing to light positive instances and precedents. And above all, disabled women activists and scholars should discuss the issue of marriage more openly, lobby for the inclusion of disabled women in reproductive and child health programs, and seek to revise the feminist agenda so as to shatter the myths that disabled

women are incapable of motherhood and of taking part in child-rearing activities. In India, marriage is as much a route to social rehabilitation for women with disabilities as it is an issue of their right to have family lives and to be mothers. Marriage is a rights issue for disabled women in developing countries as much as it is in developed countries. The only difference is that in developed countries, disabled women themselves have taken up the issue more forthrightly.

—Meenu Bhambhani

See also Disability Policy: India; Experience of Disability: India; India, Impact of Gender in.

Further Readings

All India Peoples' Science Network. 2004. *Globalization and the Indian People.* Hyderabad: Prajashakti Book House.

Bagchi, J., ed. 1995. *Indian Women: Myth and Reality.* Hyderabad: Sangam.

Bhabha, H. K. 1994. *The Location of Culture.* London: Routledge.

Bumiller, E. 1990. *May You Be the Mother of a Hundred Sons: A Journey among the Women of India.* New York: Random House.

Cormack, M. 1953. *The Hindu Woman.* New York: Columbia University, Teachers College, Bureau of Publications.

Desai, N. and M. Krishnaraj. 1987. *Women and Society in India.* Delhi: Ajanta.

Dhruvarajan, V. 1989. *Hindu Women and the Power of Ideology.* Granby, MA: Bergin & Garvey.

Erb, S. and B. Harris-White. 2002. *Outcast from Social Welfare: Adult Disability, Incapacity and Development in Rural South India.* Bangalore, India: Books for Change.

Farooqui, M. 2003, November 25. "Kalyug ki Shaadi: Ek Phool Do Mali." *Times of India.* Retrieved May 18, 2005 (http://timesofindia.indiatimes.com/cms.dll/articleshow?msid=302029).

Fruzzetti, L. and Á. Östör. 1992. "Bad Blood in Bengal." In *Concepts of Person: Kinship, Caste, and Marriage in India,* edited by Á. Östör, L. Fruzzetti, and S. Barnett. Delhi: Oxford University Press.

Gandhi, M. 1942. *Women and Social Injustice.* Ahmedabad, India: Navajivan.

Ghai, A. 2003. *(Dis)Embodied Form: Issues of Disabled Women.* New Delhi: Shakti.

Ghosh, J. and S. Sengupta. 2003. *Socialization of Women with Disabilities: A View from West Bengal, India.* Kolkata: ActionAid India.

Kishwar, M. 2004. "The Paraya Dhan Mindset." Retrieved May 18, 2005 (http://www.outlookindia.com/full.asp?fodname=20040413&fname=madhu&sid=1).

Lang, R. 2001. "Understanding Disability from a South Indian Perspective." Pp. 290–322 in *SDS 2001 Proceedings,* edited by W. Kinsner. Chicago: Society for Disability Studies.

Mukhopadhyaya, S. 2004, January 7. "Many Indian Women May Prefer Not to Marry, Say Economists: Dangerous Curves Ahead for the Indian Male." *Financial Express.* Retrieved May 18, 2005 (http://www.financialexpress.com/fe_full_story.php?content_id=49959).

Nair, J. and M. E. John, eds. 1998. *Question of Silence: The Sexual Economies of Modern India.* London: Zed.

National Conference of Disabled Women. 1996. *A Report on the End of the Long Silence.* New Delhi: NAB-CBR Network.

National Sample Survey Organisation (India). 2003. *Disabled Persons in India: Report No. 485, 58th Round July-Dec. 2002.* New Delhi: National Sample Survey Organisation.

Puja. 1999. "Words from the Silence." In *Facing the Mirror: Lesbian Writing from India,* edited by Ashwini Sukthankar. New Delhi: Penguin.

Rao, P. V. V. and N. Rao. 1982. *Marriage, the Family, and Women in India.* Columbia, MO: South Asia.

Sharma, A. 2002. *Women in Indian Religions.* New Delhi: Oxford University Press.

Supraja, C. 2004. "Marriage sans Statutory Warning." Retrieved May 18, 2005 (http://www.boloji.com/wfs2/wfs226.htm).

INDIVIDUALIZED EDUCATION PROGRAM (IEP)

According to Section 300.15 of the U.S. Department of Education federal legislation, the acronym IEP stands for *individualized education program.* Since the passage of the Education for All Handicapped Children Act (P.L. 94-142) in 1975, the IEP has been a mechanism for ensuring that students with disabilities up to the age of 21 receive a free appropriate public education (FAPE) in the least restrictive environment (LRE) that is individualized to meet their needs. The IEP process is also intended to hold educational systems accountable for student progress. An IEP initiates a process that is completed and guided through the creation of a document that communicates legal intent. In the United States, the Individuals with Disabilities Education Act (IDEA) of 1997 requires that an IEP be developed for every student with a disability who receives special education and/or related services.

Before any student is identified as having a disability, a comprehensive evaluation must be completed. This evaluation includes an assessment of the student's potential and achievement, home and social environment, biological development, and (if related areas of

difficulty are observed) speech and language ability and fine and gross motor skills. An IEP is developed only if the identified disability has a negative impact on the student's learning and/or academic progress. In cases where the disability does not have such an impact, a section plan may be developed for the provision of accommodations and modifications in accord with Section 504 of the U.S. Rehabilitation Act.

A student's IEP is developed with information gathered by an interdisciplinary team through a comprehensive evaluation of the student. The IEP is designed to ensure that a student with any type of disability that affects his or her progress in learning receives specialized and individualized instruction. These outcomes are reached primarily through the development of annual goals and quarterly benchmarks. Goals and objectives are linked to individual student progress and are not based primarily on available professionals' services. Goals and objectives are developed with parental and student involvement and consider individual student strengths and needs. The parents are required members of the IEP team, and the student is also encouraged to attend and participate in planning sessions. Special education experts recommend that a student's IEP goals and objectives, not his or her disability diagnosis, be used to determine the service delivery setting. Furthermore, the model calls for services to be provided in the LRE, ensuring that students with disabilities are not segregated from nondisabled peers as a direct result of their disabilities.

The IEP process provides an opportunity for the individualization of educational services for students with disabilities. The IEP details individualized services and teaching that focus on the attainment of goals and objectives. Attention to individual student progress on set goals and objectives is intended to ensure that educators and service providers address the student's learning needs. Well-developed IEPs have the power to have a positive impact on students' learning if the services are implemented and interventions and progress are reviewed and revised on at least an annual basis. Although individualized education plans are not mandated for students in general education, many educational systems recognize the benefits that IEPs afford and are beginning to adopt such strategies for general education settings.

The IEP model is used in early childhood, elementary, and secondary school education. Thus, adults with disabilities do not benefit from IEPs in workplaces or in institutions of higher education. However, careful attention to including secondary school students with disabilities and their families in the IEP process can help to prepare these students to access services later, as adults with disabilities. Furthermore, adults with disabilities can use the IEPs developed during their school years to provide proof of disability when they desire to access services and resources from adult service agencies. The information contained in an IEP can potentially guide the creation of supports within higher education and/or employment settings.

The implementation of the IEP model has not been without challenges. Primary among these has been the ability of schools to include parents and students in the IEP process and obtain students' perspectives on transition issues. This issue of meaningful involvement arises in part because IEP team meetings often are held on weekdays, while the parents of affected students are at work. Parents may lack familiarity with the law and/or the school system and thus may be unaware of their rights. As students with disabilities approach adulthood, it is also increasingly critical to prepare them for their adult lives. While the IEP can establish a mechanism to promote this goal, affording students with disabilities an equal voice in the process demands a change in the culture of the school, which can be more deliberate than speedy.

Other significant concerns include creating individualized plans that are adjusted annually and changing schools so that students with disabilities learn in the least restrictive environment. School professionals who head IEP development are often responsible for many students, and it is frequently extraordinarily difficult for them to allocate sufficient time to the creation of goals that are adequately individualized to each student and updated regularly. A national teacher shortage in special education only adds to the difficulty of addressing this problem. Finally, school systems have been slow to develop environments that do not segregate students with disabilities from other students solely because of disability. It is important to note that the IEP process can be powerful in overcoming this challenge, at least at an individual level.

—Teresa Garate and Jose Mendez

See also Individuals with Disabilities Education Act of 1990 (United States); Special Education.

Further Readings

Bos, S. B. and S. Vaughn. 1998. *Strategies for Teaching Students with Learning and Behavior Problems.* Needham Heights, MA: Allyn & Bacon.

Cutler, B. C. 1997. *You, Your Child and Special Education.* Baltimore: Paul H. Brookes.

Websites

Council for Exceptional Children, http://www.ideapractices.org

INDIVIDUALS WITH DISABILITIES EDUCATION ACT OF 1990 (UNITED STATES)

The Individuals with Disabilities Education Act (IDEA) is the title of legislation passed by the U.S. Congress in 1990 guaranteeing the right to free and appropriate education for children and youth with disabilities. The IDEA was the reauthorization of the Education for All Handicapped Children Act (EHA), which was passed in 1975 as the first separate federal legislation authorizing special education for children and youth. Previous legislation had included the legal basis for special education as early as 1965, but it was included in acts pertaining to elementary and secondary education. The EHA was reauthorized in 1986 and later as the IDEA in 1990 and 1997. As federal legislation, it requires states to provide specific services to eligible individuals with disabilities who are ages 3 to 21 and to have procedural safeguards in place to ensure that those services are in fact provided in an equitable and nondiscriminatory manner. Under the IDEA, children with disabilities are entitled to evaluations of their needs as the basis for individualized education plans (IEPs) and placement in the least restrictive environment (LRE) for their education. They are also entitled to the provision of related services, such as transportation, therapies, medical support, and assistive technology, to ensure that they receive maximum benefit from the educational experience.

Procedural safeguards are built into the legislation in the form of requirements for parental involvement in evaluation, planning, and placement activities; parental consent to school decisions; and parents' right to appeal decisions made about their children's placement. For children under three years of age, the 1986 reauthorization encouraged states to extend services under the IDEA to children from birth to age three, encompassing early intervention and support for families in their caregiving roles.

HISTORY OF THE IDEA

Prior to 1975, children and youth with disabilities in the United States were either denied education altogether or did not receive education appropriate to their needs. Children did not have a right to education, and schools could selectively refuse to admit any children they judged to be ineducable. The consequence was that only a fraction of children with disabilities were provided an appropriate education. In the 1960s and early 1970s, parents and advocates challenged the exclusion of children with disabilities from public education under the provisions of the equal protection and due process clauses of the Fourteenth Amendment of the U.S. Constitution. Two key cases were brought before the courts to argue for the rights of children with disabilities to equal access to education—*Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania* (1971) and *Mills v. Board of Education of the District of Columbia* (1972). The success of these cases was incorporated into the passage of the EHA in 1975, defining a free and appropriate public education for children with disabilities from the ages of 5 to 21.

The first reauthorization of the EHA occurred in 1986, with two important modifications. The first was the downward extension of the age range from five to three years of age for eligibility for special education. The second was the formalization of early intervention services for infants and toddlers from birth through age two years. In 1990, the EHA was reauthorized as the Individuals with Disabilities Education Act. The most recent reauthorization was in 1997, and it is likely that the reauthorization process will be repeated at regular intervals. Although the IDEA does not compel states to provide free and appropriate education for children with disabilities, it does require states to adhere to the specific elements of the act if they wish to receive federal funds.

ELEMENTS OF THE IDEA: SPECIAL EDUCATION

In the 1997 reauthorization of the IDEA, provisions are divided into four parts: Part A defines the various terms used in the law, Part B spells out the special education services required for children and youth ages 3 through 21, Part C describes requirements for the provision of early intervention services for children birth through 2 years of age, and Part D constitutes the capacity-building component of the law, in terms of how education and related agencies in states need to ensure the provision of special education and early intervention to all children needing such services. Part D also specifies the ongoing role of the federal government in ensuring the preparation of personnel by institutions of higher learning, the development of new instructional approaches and technology, and the conduct of research on effective practices.

The rights of children with disabilities as defined in the IDEA can be summarized as falling within the following major themes: eligibility, assessment, parent involvement, the IEP, LRE, and related services. In order to receive special education services under the IDEA, a child must meet the criteria for assignment to 1 of 13 categories defined in the act. Eligibility determination is based on individualized assessment carried out by qualified specialists and approved by a school-based team.

Eligibility Determination and Categories

Under the IDEA (1997), eligibility for special education encompasses children who are defined as

> (i) . . . children with mental retardation, hearing impairments, deafness, visual impairments including blindness, deaf-blindness, multiple disabilities, speech and language impairments, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments or specific learning disabilities and (ii) who by reason thereof, need special education and related services.

Following referral by a parent or by health care or school professionals, a child is given an evaluation appropriate to the referral to determine whether he or she meets the criteria for 1 of the 13 categories. Eligibility was expanded beyond these 13 categories in the 1997 reauthorization to include children ages three to nine years

> (i) experiencing developmental delays as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development or adaptive development and (ii) who by reason thereof, need special education and related services.

In contrast to the 13 categories, the use of developmental delay as the basis for special education eligibility is at the discretion of individual states and is variably implemented.

Assessment

Comprehensive assessment is carried out to identify the nature and extent of a child's need for special education. Such assessment involves a school-based team, the members of which include a school psychologist; physical, occupational, and speech therapists; and teachers in both regular and special education. The assessment may involve the use of standardized tests, observation, parent interview, and professional judgment. Every child who is found to be in need of special education is reevaluated at three-year intervals to determine whether he or she continues to be eligible for one of the categories and thus eligible to receive special education services.

Individualized Education Plan

The IEP provides a yearly specification of goals for the child and a road map for the services the child needs in order for appropriate learning to occur. The IEP is produced by the school-based team in conjunction with the child's parents and the child whenever possible. It is a living document that is used for periodic review of the child's progress. In addition, the IEP should be seriously reviewed each year in which the child is in need of special services, as it is important that the next year's plan reflect evaluation of the child's progress each year. If the child has not made progress, it is important that the IEP reflect changed expectations, alternative educational interventions, or a combination of the two.

Parent Involvement

Parents are deemed to be partners with school staff in crafting the child's IEP. They are supposed to be involved at each step of the process, and the IDEA provides them with recourse to school- or system-based mediation if they have differences with the school over the child's plan. If resolution is not achieved through these means, differences between parents and the school can be dealt with through due process.

Least Restrictive Placement

The IDEA's underlying principle for student placement is full inclusion—that is, a child is to be placed in the setting that will allow him or her the greatest participation with peers of the same age without disabilities. The nature and extent of inclusion of the child's placement is spelled out in the IEP.

Related Services

In addition to direct instructional accommodations to meet the child's educational needs, other services that are needed to improve the child's performance in school are also provided under IDEA. These services may include physical, occupational, and speech therapy as well as the provision of assistive technology. Environmental accommodations may also be provided under Section 504 of the act.

IMPLEMENTATION ISSUES

Accountability

Under the IDEA, documentation that special education is beneficial for children and youth with disabilities has taken two forms. The first is the monitoring of each child's progress on an annual basis with a review of the goals spelled out under the IEP. This typically leads to revision of the goals defined for the child in the IEP. The second form of accountability is the expansion of the participation of children and youth with disabilities in the large-scale assessments carried out for general education students. In this context, special accommodations may be made for students with disabilities; for example, they may be provided with additional time and/or modified materials to allow them to complete the annual tests taken by all students. As noted earlier, due process is another form of accountability for the child.

Transition

In addition to education services, students with disabilities are also eligible under the IDEA for individualized transition plans to assist them in making the move from school to the community. This is a crucial process and may begin during early adolescence although children may continue in special education through the age of 21 years.

—Rune J. Simeonsson and Donald J. Lollar

See also Education, Primary and Secondary; Education and Disability; Individualized Education Program (IEP); Special Education.

Further Readings

Individuals with Disabilities Education Act, 20 U.S.C. 1401–1485.

Martin, Edwin W., Reed Martin, and Donna L. Terman. 1996. "The Legislative and Litigation History in Special Education." *Future of Children* 6(1): 25–39.

Mills v. Board of Education of the District of Columbia, 348 F. Supp. 866 (1972).

Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania, 334 F. Supp. 1257 (1971).

Telzrow, Cathy F. and Kathy McNamara. 2001. "New Directions in Assessment for Students with Disabilities." *Work* 17:105–116.

Websites

National Information Center for Children and Youth with Disabilities, http://www.nichy.org

Office of Special Education Programs, U.S. Department of Education, http://www.ed.gov

INDUSTRIALIZATION

Industrialization is the process by which manufacturing displaces agriculture and commerce to become the dominant economic activity in a society. Driven by inanimate sources of power, industrialization allows the concentration of machines in factory settings and their regular, reliable deployment. In Britain—the first

industrialized nation—this transformation was initially understood as a cataclysmic event. Subsequent interpretations have stressed the long-term origins in the breakdown of the feudal system and the emergence of capitalist modes of production and exchange, particularly associated with the growth of towns since the late seventeenth century. Revolutions in commerce, transport, and agriculture consolidated these developments. During the 40 years after 1660, Britain's foreign trade increased by more than a third, generating unprecedented prosperity. By 1760, long before the mid-Victorian railway boom, an impressive network of canals and turnpike roads was springing up, and simultaneous improvements in agricultural productivity not only freed up labor for industrial purposes but also prevented inflationary food prices, thus releasing surplus income for the purchase of manufactured consumer goods.

Entrepreneurs, who thrived in Britain thanks to the stimulus of religious nonconformity and the potential for social mobility, faced few constraints in exploiting these economic conditions. The lax enforcement of apprenticeship regulations, for instance, aided the recruitment of new workers, and landowners and merchants had little difficulty in financing ambitious projects despite legislation intended to discourage irresponsible speculation. Consequently, for almost a century prior to 1780—the traditional starting point of the Industrial Revolution—real national income in Britain was expanding at an average rate of 0.70 percent each year. This indicator peaked at a mere 1.97 percent during the decades of fastest growth between 1801 and 1831. None the less, the accumulated effects of this gradualism were dramatic. In 1760, agriculture and related economic activities accounted for 37 percent of British national income; by 1871, the proportion had slumped to 14 percent. Conversely, manufacturing, mining, and building had escalated in importance, explaining just 20 percent of national income in 1760 compared with 38 percent in 1871. The factors shaping this particular experience were not exactly replicated elsewhere. In the second half of the nineteenth century, however, the Industrial Revolution spread to other areas of Europe, the United States, and Japan, ending Britain's tenure as the "workshop of the world."

Industrialization has been pivotal to the social model of disability and its location of disability—as opposed to impairment—in the material and ideological organization of modern societies. In 1980, Vic Finkelstein blamed new productive technologies for the rise of the segregated institution; the production lines of big industry were designed to fit able-bodied norms and thus shut out disabled people, who had previously been integrated and socially active members of their classes and communities. Michael Oliver (1990) later put forward a more detailed case, arguing that whereas full-fledged capitalism was exclusive, agriculture and small-scale industry did not prevent most disabled people from being economically active. Most recently, Brendan Gleeson (1999) has suggested that bodily impairment, an accepted and constituent element of medieval peasant life, became problematic only when industrial workplaces severed the connection between home and employment and began to discriminate against uncompetitive workers.

Like the heroic reading of the Industrial Revolution, however, the assumption that premodern societies were friendly to disabled people neglects the significance of incremental change. Long in advance of industrialization, the religions and cultures of ancient Greece and Rome, and the art and literature of Renaissance Europe, were constructing impairment in a pejorative light. Work was also a preoccupation before the Industrial Revolution. In early modern Britain, for example, the Tudor Poor Law struggled to distinguish "deserving" from "undeserving" or work-shy applicants. Similarly, letters recommending patients for admission to eighteenth-century hospitals such as the General Infirmary at Bath stressed the contributions of these individuals to their households' economies. For men, the emphasis was on paid employment: For instance, Newton Highhorn, a painter of 20, had been "greatly afflicted" by lead poisoning and had "so far lost the use of his hands as to be disabled from working at his trade or earning his bread." For women, the emphasis was on family responsibility: Mary Coombs, a married woman of 32, had experienced severe rheumatic pains for six months and was "now in great measure disabled and incapable of performing the usual labour for the support of her family" (Bath City Record Office 1750–1758). Regardless of gender, impairment was

represented as a deficiency with damaging economic consequences.

Although disabled people were economically marginalized before the Industrial Revolution, the raft of changes that followed in the wake of industrialization transformed their predicament. Economic changes were themselves a cause of impairment because industrial enterprises polluted the human environment and led to workplace injuries and diseases. Furthermore, the inequalities that motivated the capitalist economy bred impairments that were correlated with social deprivation, such as rickets, tuberculosis, and infantile paralysis. Governments wedded to the virtues of private enterprise were slow to regulate the harmful effects of industrialization, and disabled people disadvantaged in the labor market had no option but to exist on meager incomes or parsimonious poor relief. The Great Depression of the 1930s compounded their financial difficulties. Conversely, World War II temporarily opened up job opportunities as able-bodied workers joined the armed services. After 1945, however, the employment policies implemented in industrial societies were largely ineffective in achieving economic inclusion. Even the British welfare state—celebrated for its health provision—offered little more than a minimally enforced quota of disabled employees.

The industrial societies that were inhospitable to impairment underwent profound social and political changes, although the changes were sometimes slow in coming. One example is found in the social implications of the factory system, often regarded as the emblem of the Industrial Revolution. As late as 1851, only 6 percent of the total labor force was working in textile factories, the sole employment sector where this mode of production had made significant inroads, and principal cotton workers continued to recruit their relatives to factory teams, preserving a reduced economic role for the formerly self-sufficient preindustrial family. Nevertheless, the adoption of heavy machinery did ultimately entrench a geographic separation of home and work that became a defining feature of industrial societies.

Andrew Scull (1993) has linked such change in family life to the rise of the segregated institution. Examining madness in nineteenth-century Britain, he concluded that the relatives of the mentally ill were compelled to incarcerate them because industrialization had eroded families' capacity to provide care. In sprawling industrial cities social networks were fragile, but smaller industrial towns developed complementary support mechanisms through workplace clubs, friendly societies, and cultural groups. Therefore, factors aside from industrialization explained the asylum, not least the appearance of a psychiatric profession with a scientific discourse on insanity and, later, mental deficiency. Other medical specialists endorsed the confinement of physically disabled people, reinforcing the influence of the eugenics movement. The voluntary sector was a pioneering supplier. As industrial states became more interventionist, however, the health and welfare professions increasingly collaborated with the public sector to deliver institutional solutions.

Although industrialization did not invent the work ethic, its protection through low taxation was perceived as essential to a thriving economy. In the "developing" world, where the modern plants that permitted extensive industrial production were not widely dispersed, the resources had never been available to build expensive institutional infrastructures. In the industrialized world, however, from the second half of the twentieth century concerns about costs encouraged community care as a cheaper, and more humane, alternative to institutional provision. At the same time, industrialization was entering a new phase. Manufacturing was being overtaken by the service industries, the benefits of limitless economic growth were being challenged, and innovative technologies were transforming the acquisition, processing, and distribution of information. Sociologists debate whether these postindustrial societies are now postmodern. Work has indeed been reconfigured by the information revolution, the welfare state has been fragmented into a mixed economy with charitable and commercial as well as statutory inputs, and professional power has been weakened by a loss of faith in scientific rationalism. But for disabled people there is no escape from the discrimination that is a characteristic of industrialization.

—Anne Borsay

See also Employability; Employment.

Further Readings

Bath City Record Office, Royal National Hospital for Rheumatic Diseases (formerly Bath General Hospital), 4/1, Casebook, 1750–1758.

Borsay, Anne. 2005. *Disability and Social Policy in Britain since 1750: A History of Exclusion.* Basingstoke, UK: Palgrave.

Finkelstein, Victor. 1980. *Attitudes and Disabled People: Issues for Discussion*. New York: World Rehabilitation Fund.

Gleeson, Brendan. 1999. *Geographies of Disability.* London: Routledge.

Oliver, Michael. 1990. *The Politics of Disablement.* London: Macmillan.

Scull, Andrew. 1993. *The Most Solitary of Afflictions: Madness and Society in Britain, 1700–1900.* New Haven, CT: Yale University Press.

Teich, Mikuláš and Roy Porter, eds. 1996. *The Industrial Revolution in National Context: Europe and the USA.* Cambridge, UK: Cambridge University Press.

Websites

Victorian Web, http://www.victorianweb.org

INFANT STIMULATION PROGRAMS

Infant stimulation is a form of sensory enrichment that is used with clinical populations (i.e., at-risk and disabled) of infants as well as nondisabled (i.e., healthy) infants. For at-risk infants, infant stimulation is a process of providing supplemental sensory stimulation in any or all of the sensory modalities (visual, auditory, tactile, vestibular, olfactory, gustatory) to an infant as a therapeutic intervention. The intervention uses supplemental stimulation to compensate for the lack of normal/typical environmental sensory stimulation or the presence of abnormal/atypical environmental sensory stimulation. For example, sick infants born prematurely and hospitalized in a neonatal intensive care unit (NICU) are exposed to high levels of intense and aversive sensory stimulation related to necessary medical care (e.g., venous and arterial punctures, heal sticks, injections) and the general NICU environment (e.g., intense lights and alarms). Further, these sick infants do not receive the same caregiver stimulation and interaction that healthy full-term infants generally receive from their parents in the home environment.

Infant stimulation programs are instituted to compensate for the atypical sensory stimulation of NICU hospitalization. Such programs include the administration of sensory stimuli—including tactile (e.g., touching, rubbing, massage), vestibular (e.g., rocking, positioning, picking up), auditory (e.g., soft music, human voice), and/or visual (e.g., high-contrast pictures, mobiles) modalities—by nurses or therapists. The stimulation may be unimodal or multimodal and is usually presented on a regular schedule for specific amounts of time (e.g., 30 minutes per day for 20 days). The most frequently used stimulations are tactile, vestibular, and/or auditory, administered to approximate the stimulation the infant would have received in the womb. As the sick infant gets older and healthier, visual stimulation is added, and the program is modified to approximate the typical sensory environment of the home and caregiver.

Much of the research that has evaluated the efficacy of these types of infant stimulation procedures (e.g., regularly scheduled presentation of sensory stimuli) with sick preterm infants has generally been of poor scientific quality (e.g., use of heterogeneous groups, lack of control groups), and even the most scientifically sound studies have found little evidence of effectiveness. Thus, infant stimulation programs are currently evolving to be more "infant centered" and to have an important "social-psychological component" (SPC). Infant-centered programs focus on the infant's communication to the caregiver about the types and amounts of sensory stimulation the infant can tolerate (e.g., an infant's eye-to-eye contact with a caregiver indicates tolerance of the stimulation, whereas the infant's looking away from the caregiver indicates lack of tolerance). This allows the caregiver to cease stimulation of the infant prior to the infant's becoming "overloaded" (homeostatically challenged and dysregulated); additionally, the caregiver can recognize the signals of the infant's readiness for stimulation. The SPC of infant stimulation programs includes the use of the infant's own primary caregiver (e.g., mother, in contrast to nurse or therapist) as the provider of the sensory stimulation. The caregiver administers stimulation interactively with the infant, modulating the stimulation by reading the infant's communication of tolerance levels and preferences for the sensory

stimuli. This component adds a more natural interaction between the caregiver and infant and facilitates the caregiver's understanding of the infant's behavioral capacity and potential. The infant-centered focus and SPC of NICU infant stimulation programs are also applicable to impoverished infants and their families, as well as other at-risk subgroups.

For healthy infants, infant stimulation enrichment programs generally include early experiences with classical music, being read to, educational play, home schooling, and participation in organizations such as Parents-as-Teachers. One of the major rationales for infant stimulation programs for both atypical and typical infants is based on the plasticity of the nervous system. Neuroplasticity is the ability of the nervous system to change throughout the lifespan. Research with a variety of species, including humans, indicates that the brain can change (e.g., growth of nerve cells, generation of new nerve cells, increases in neural connections and circuits) as a function of use and experience (e.g., using fingers to learn computer keyboarding, being challenged by enriched and complex environments). The ability of sensory experience to modify the nervous system has been shown to be greater for infants than for adults, because of the high nervous system growth rates already present during early development. There is also evidence that certain sensory experiences are required during important periods for normal development of the nervous system. The visual system, for example, requires "early visual experience" for normal structural and functional development of the visual cortex that enables form and depth perception. Research also indicates that sensory stimulation is important for brain and behavioral development of brain-injured populations. Thus, the importance of infant stimulation is becoming well established; current research questions are focusing on evaluating different types of stimulation, when and how stimulation should be administered, how much stimulation infants should receive and how often, and who is best suited to provide the stimulation, for different infant populations.

Infants, as well as adults, are constantly being bombarded with sensory stimulation during both waking and sleeping hours. Nevertheless, infant stimulation programs seem particularly beneficial for at-risk and disabled infant populations, and these programs continue to be an important focus of clinical and research attention as well as public interest. Although infant stimulation programs often supplement sensory stimulation to counter sensory deprivation, they may also focus on reducing sensory stimulation based on sensory appropriateness.

Modern interest in infant stimulation programs was energized in the 1940s when Rene Spitz showed that long-term hospitalization of infants with little or no stimulation was associated with abnormal behavioral development. Similarly, in the 1950s Harry Harlow showed that monkeys raised in isolation (i.e., without maternal stimulation) displayed abnormal development. These findings, coupled with the relatively long-term hospitalization of sick infants in NICUs, indicated a potential need for infant stimulation programs to promote normal development. However, hospitals and agencies throughout the world differ considerably with regard to their use of infant stimulation programs.

As therapeutic interventions in NICUs, infant stimulation programs became relatively popular in the 1970s. However, these programs began to evolve dramatically during the 1980s, and that evolution continues today. In the 1970s, medical practice was expanding to allow increasing use of infant stimulation programs, especially for infants born prematurely who were isolated within NICUs. This was based in part on two realizations: that the long-term hospitalization of infants born prematurely was generally associated with a high frequency of invasive medical procedures that were disruptive and painful to these infants (e.g., aversive conditioning or learning) and that the general hospital environment was associated with forms of environmental stimulation that were considerably different from those found in the home and family environment. Thus, early stimulation programs with preterm infants were designed to overcome the abnormal sensory environment of the NICU. The earliest programs focused either on mimicking the environment of the womb (e.g., use of water beds to provide for tactile and vestibular stimulation) or on correcting the sensory deprivation or abnormality of the NICU environment. An important finding of early research was that some types of stimulation procedures (including typical medical procedures) could actually be

harmful to infants (e.g., producing hypoxemia). Such findings led to major changes in the form of infant stimulation programs. Since the 1980s, and continuing through the present time, programs have been moving away from the simple presentation of unimodal or multimodal sensory stimulation to infants on some arbitrary timing and intensity schedule. In recent years, many infant stimulation programs have moved toward infant-centered and SPC approaches. Another important change, brought about by the movement toward infant- and family-centered care in the NICU, has been the reorganization of the timing of medical procedures and nursing care. Rather than having medical procedures administered to infants at any time throughout the day, these procedures are now grouped together within short periods so that infants can experience longer periods without aversive stimulation and increased time in interaction with caregivers.

Thus, the evolution of infant stimulation programs toward infant- and family-centered approaches is providing infants with meaningful sensory stimulation with a social-psychological component within the NICU environment. Such programs maximize the opportunity for attenuation of aversive sensory stimulation to facilitate optimal growth and development. Future research on infant stimulation programs will include a focus on determining the effects of infant- and family-centered approaches on the short- and long-term development of at-risk infants.

—C. Robert Almli

Further Readings

Anastasiow, Nicholas J. and Shaul Harel, eds. 1993. *At-Risk Infants: Interventions, Families and Research.* Baltimore: Paul H. Brookes.

Cooperative Extension Service, Purdue University. 2002. "Come Play with Me: Play Activities and Infant Stimulation." Retrieved March 17, 2004 (http://www.ces.purdue.edu/extmedia/CFS/CFS-175.html).

Gunzenhauser, Nina, ed. 1987. *Infant Stimulation: For Whom, What Kind, When, and How Much.* Skillman, NJ: Johnson & Johnson Baby Products.

Health First. 2004. "Infant Stimulation." Retrieved March 17, 2004 (http://www.health-first.org/health_info/your_health_first/kids/infant_stim.cfm).

Kolb, Bryan and Ian Q. Whishaw. 1998. "Brain Plasticity and Behavior." *Annual Review of Psychology* 49:43–64.

Lipkin, Paul H. and Mitchell Schertz. 1996. "An Assessment of the Efficacy of Early Intervention Programs." Pp. 525–547 in *Developmental Disabilities in Infancy and Childhood,* Vol. 1, *Neurodevelopmental Diagnosis and Treatment,* edited by Arnold J. Capute and Pasquale J. Accardo. Baltimore: Paul H. Brookes.

van Praag, Henriette, Gerd Kempermann, and Fred H. Gage. 2000. "Neural Consequences of Environmental Enrichment." *Nature Reviews: Neuroscience* 1:191–198.

INFANTICIDE

The ancient Greeks and Romans practiced exposure, the discarding of unwanted infants. Because it is often assumed that disabled babies were unwanted babies, the issue of exposure is intimately connected to the question of physical disability in the ancient Graeco-Roman world. That the Greeks, especially the Spartans, regularly disposed of newborns with visible physical anomalies was commonly accepted in nineteenth- and twentieth-century scholarship and popular culture. For example, in *Should the Baby Live? The Problem of Handicapped Infants* (1985), Helga Kuhse and Peter Singer write that infanticide was common among the Greeks and Romans, and that the recommendations of the philosophers to destroy defective infants "would not have seemed anything out of the ordinary to their contemporaries" (p. 111). A deeper inquiry, however, reveals that the source material is far too thin to support the drawing of such certain conclusions. More important, it is misleading to superimpose modern social, economic, religious, and military assumptions about the value of disabled people on the ancient world.

The Greek material that discusses or alludes to the exposure of deformed infants is limited, comprising five short passages ranging from the fourth century BCE through the second century CE. Two of these passages are from the works of Plato, and there is one each from Aristotle, Plutarch, and the second-century physician of the Roman imperial period, Soranus. The sources that discuss deformed offspring in the ancient Greek world are too sparse to support the conclusion that the exposure of such infants was standard practice; in fact, there is evidence that children born with disabilities survived. For example, the fifth-century BCE tragedian Sophocles has the chorus in *Oedipus at Colonus* ask

Oedipus if he had been born blind (lines 148–149). Roman primary sources are also scant. Robert Garland (1995) finds instances of "defective" babies' survival, and adds that "there are . . . indications of a somewhat sympathetic attitude towards deformed infants in the Roman Imperial period" (p. 18).

For discussion of the exposure of children with physical disabilities in the ancient Greek world, see my book *The Staff of Oedipus* (Rose 2003), and regarding the Roman world, see Robert Garland's *The Eye of the Beholder* (1995). Good literature on ancient infanticide in general includes articles by Marc Huys (1996) and Cynthia Patterson (1985). Ruth Oldenziel (1987) traces and discusses the secondary literature on infanticide in Greece in her chapter in a collection titled *Sexual Asymmetry,* and John Boswell summarizes the literature for Rome in his book *The Kindness of Strangers* (1988:40–41, n. 96).

Modern assumptions about the economic worth and aesthetic appeal of deformed people, cloaked in the standards of medical health, do not provide an appropriate framework of interpretation for the evidence about the lot of anomalous infants in the ancient Graeco-Roman world.

—M. Lynn Rose

See also History of Disability: Ancient West.

Further Readings

Boswell, John. 1988. *The Kindness of Strangers: The Abandonment of Children in Western Europe from Late Antiquity to the Renaissance.* New York: Pantheon.

Garland, Robert. 1995. *The Eye of the Beholder: Deformity and Disability in the Graeco-Roman World.* Ithaca, NY: Cornell University Press.

Huys, Marc. 1996. "The Spartan Practice of Selective Infanticide and Its Parallels in Ancient Utopian Tradition." *Ancient Society* 27:47–74.

Kuhse, Helga and Peter Singer. 1985. *Should the Baby Live? The Problem of Handicapped Infants.* New York: Oxford University Press.

Oldenziel, Ruth. 1987. "The Historiography of Infanticide in Antiquity: A Literature Stillborn." Pp. 87–107 in *Sexual Asymmetry: Studies in Ancient Society,* edited by Josine Blok and Peter Mason. Amsterdam: J. C. Gieben.

Patterson, Cynthia. 1985. "'Not Worth the Rearing': The Causes of Infant Exposure in Ancient Greece." *Transactions of the American Philological Association* 115:103–123.

Rose, Martha L. 2003. *The Staff of Oedipus: Transforming Disability in Ancient Greece.* Ann Arbor: University of Michigan Press.

INFECTIOUS DISEASES

Infectious diseases and disability are intricately linked in terms of both causal relationships and complicating factors. In considering these issues, it is helpful to distinguish between those infectious diseases that cause disability and those that complicate preexisting disability.

Ample evidence links certain infectious diseases to the onset of disability in previously able-bodied individuals. Well-known examples include the profound central motor and cognitive neurological disabilities resulting from viral brain infections (e.g., St. Louis encephalitis and West Nile virus infection) and from overwhelming bacterial infections of the brain and/or its coverings (e.g., syphilis, meningococcal infection, and Rocky Mountain spotted fever). Certain other infections when suffered in pregnancy are implicated as important causes of long-term disability in the neonate, such as the so-called TORCHES group of infections (toxoplasma, rubella, cytomegalovirus, herpes simplex virus, syphilis). A progressive inflammation of the nerves (e.g., an ascending polyneuropathy such as Guillain-Barré syndrome) is often seen as a postinfectious complication following a viral or bacterial infection (classically seen after campylobacter diarrhea). Additionally, some investigators have proposed an infectious etiology for such disabling illnesses as multiple sclerosis, diabetes mellitus, and chronic fatigue syndrome, although these linkages are controversial. Finally, it is important to note the disabling nature of chronic, long-term infectious syndromes such as AIDS, hepatitis C, tuberculosis, and certain parasitic diseases such as filariasis or malaria, which clearly have negative impacts on quality of life and impair sufferers' ability to perform daily activities.

Perhaps more immediate and of greater day-to-day consequence for both patient and clinician is the extent to which disability predisposes individuals to acute and chronic infections. In general, disability serves to impair the normal host's natural defense

mechanisms against invasion by microorganisms, thereby increasing the likelihood of colonization and subsequent pathogenic transformation. Integrity of the body is dependent on satisfactory functioning of host defense strategies. When these are impaired, infectious complications commonly develop. Bacterial colonization of normally sterile sites leads to acute and chronic infection. Repeated treatment with antibiotic medications preferentially selects for the persistence of resistant organisms, making future treatment more difficult. Conditions that impair the host immune response (e.g., diabetes, cancer, AIDS) place the individual at increased risk for infection with unusual or difficult-to-treat organisms.

Respiratory, genitourinary, and integumentary systems are most crucially at risk for infection in the disabled, with those structures at particular risk being dictated by the nature of the host disability. For example, clearance of bacterial pathogens from the upper respiratory tract is facilitated by adequately functioning cilia, and individuals with impaired ciliary function (as in chronic obstructive pulmonary disease) are at greater risk for bacterial colonization and development of recurrent lung infections. Genitourinary tract integrity is preserved through the maintenance of urine production and flow through the kidneys, ureters, and bladder. Impairment of flow leading to urinary stasis (as in persons with neurogenic bladder due to spinal cord injury) predisposes the individual to bacterial colonization and urinary tract infection. Catheterization of the bladder is another complicating factor, inasmuch as bacteria adhere to and are introduced into the urinary tract with the catheter. In general, the use of an indwelling catheter presents a greater long-term infectious risk than chronic intermittent catheterization for those patients requiring repetitive bladder drainage. Finally, disability may predispose skin and soft tissue structures to breakdown due to chronic pressure on particular dependent or insensate areas of the body. Ulcerations that develop at these pressure sites are at risk for colonization and invasive infection and may lead to deep-seated infection of underlying structures (e.g., osteomyelitis).

Treatment of infections among the disabled should be tailored to the particular circumstances of the host and should take into consideration the nature of the host disability, the body system involved, the specific pathogen being targeted, and the acute versus chronic nature of the infection. Certain infections, once established, may become very difficult to cure, requiring instead suppressive therapy to control and limit progression. Other infections may require combined medical and surgical approaches to achieve cure. With this in mind, caregivers need to anticipate potential infectious complications and seek to implement preventive measures to avoid serious outcomes.

—Bradley P. Stoner

See also Disease.

Further Readings

Hughes, Richard A. C. and Jeremy H. Rees. 1997. "Clinical and Epidemiologic Features of Guillain-Barré Syndrome." *Journal of Infectious Diseases* 176 (Suppl. 2): S92–S98.

O'Dell, Michael W. 1996. "HIV-Related Neurological Disability and Prospects for Rehabilitation." *Disability and Rehabilitation* 18:285–292.

Schendel, Diana E. 2001. "Infection in Pregnancy and Cerebral Palsy." *Journal of the American Women's Association* 56:105–108.

Trautner, Barbara W. and Rabih O. Darouiche. 2002. "Prevention of Urinary Tract Infection in Patients with Spinal Cord Injury." *Journal of Spinal Cord Medicine* 25:277–283.

INFERTILITY

Infertility is typically defined as the inability to become pregnant after a year of having intercourse without contraception. The American Society for Reproductive Medicine (ASRM) and RESOLVE, the principal advocacy organization for the infertile, describe infertility as a "disease" that hinders "the body's ability to perform the basic function of reproduction." Ordinarily, however, infertility is considered a *condition* that might be caused by one or more diseases. In women, some examples of such diseases are endometriosis (in which the tissue that lines the uterus grows outside the uterus), polycystic ovary syndrome (in which the follicles in which the woman's egg is enclosed mass together to form a cyst, and no mature egg is released), and premature ovarian failure (in

which a woman under age 40 no longer produces ova). Among men, infertility can result from mumps experienced after puberty, certain infections (e.g., prostatitis, orchitis), and diseases of the pituitary or hypothalamus, all of which can reduce or destroy the capacity to produce sperm. Various testicular injuries as well as chromosomal abnormalities and those of the testes, such as cryptochrodism (failure of the testes to descend into the scrotum), cancer, and direct trauma, are also among a range of conditions that can cause male infertility. Infertility is distinct from surgical sterilization, which was once used as a form of state-sponsored social control, but today—at least in the United States—is more often a voluntary procedure.

The term *infertility* is of relatively recent origin. American colonists in the seventeenth and eighteenth centuries used the word *barrenness* to describe the inability to bear children. Only a woman could be barren; any man capable of sexual intercourse was automatically deemed fertile. In the nineteenth century, especially as gynecologists became more prevalent in treating the condition, the term *sterility* came into common use. The terminology was important; *sterility* conveyed the growing medical conviction that men as well as women were affected. As early as the 1860s, a few physicians advocated the microscopic analysis of semen, and by end of the nineteenth century several prominent gynecologists began to urge husbands to be tested, although many men refused to subject themselves to what they considered an outrage against their masculinity. *Infertility* gradually replaced the older term in the 1940s and 1950s, as optimism about treatment soared. Most experts currently believe that about a third of infertility cases are caused by conditions that affect men and another third are caused by those that affect women, with the rest attributable to both halves of the couple. About 20 percent of cases, overall, remain unexplained.

Authorities nowadays generally agree that infertility affects about 10 percent of the population. In spite of a widespread perception that infertility rates rose dramatically in the late twentieth century, the 10 percent figure is consonant with estimates made in the late nineteenth and early twentieth centuries. The national fertility studies begun in the United States in 1965 put the infertility rate at 11.5 in the 1960s and 8.5 in the 1980s, albeit with a rise in primary infertility and a decline in secondary infertility. (*Primary infertility* is the term used to describe those couples who have never been able to conceive or carry a pregnancy to term. *Secondary infertility,* once called *one-child sterility,* describes couples who have borne children but are no longer able to do so.)

Most cases of infertility are treatable by conventional medical techniques, including surgery, artificial insemination (practiced since the nineteenth century), and the use of ovulation-inducing therapies. However, an estimated 15–17 percent of the infertile make use of assisted reproductive technologies, 99 percent of whom undergo in vitro fertilization using their own or donor eggs. In vitro fertilization may be accompanied by ICSI (intracytoplasmic sperm injection), a technique that seeks to compensate for male subfertility through the injection of a single sperm directly into the woman's egg. Whether the treatment is low-tech or high-tech, about two-thirds of the infertile are able to achieve biological reproduction. The other third may circumvent their condition through adoption or surrogacy or learn to live with it.

Infertility can have profound social, cultural, and psychological effects on those who have the condition. Societies everywhere assume that women want to become mothers, and women who choose not to have children, or who fail to express maternal feelings, frequently face social opprobrium. In turn, those who long for children and are unable to bear them often feel that they have been denied a fundamental right, the "right" to reproduce. Although infertility affects men just as often as it does women, social scientists have discovered that women in infertile unions often find their situation intolerable, a threat to their fundamental identity as women. Men, in contrast, tend to be disappointed but not devastated. Many who fruitlessly yearn for children often internalize a profound feeling that their bodies have betrayed them. In this sense, then, infertility might be viewed as a psychological disability as well as a social and medical condition.

—Margaret Marsh

See also Gender; India, Impact of Gender in.

Further Readings

American Society for Reproductive Medicine. n.d. "Quick Facts about Infertility." Retrieved May 7, 2005 (http://www.asrm.org/Patients/faqs.html).

Marsh, Margaret and Wanda Ronner. 1996. *The Empty Cradle: Infertility in America from Colonial Times to the Present.* Baltimore: Johns Hopkins University Press.

May, Elaine Tyler. 1995. *Barren in the Promised Land: Childless Americans and the Pursuit of Happiness.* New York: Basic Books.

Sandelowski, Margarete. 1993. *With Child in Mind.* Philadelphia: University of Pennsylvania Press.

Websites

American Society for Reproductive Medicine, http://www.asrm.org

National Women's Health Information Center (U.S.), http://www.4woman.gov

INFORMATION TECHNOLOGY

Information technology (IT) may be seen as both enabling and disabling. From the earliest days of computers, people with disabilities have been integrally involved with this technology, yet it has continued to be shaped by nondisabled norms. As computers and other IT developed and became ubiquitous features of work, education, home, and everyday life, they developed a profound role in the shaping of ability and disability. People with disabilities began to make their mark as users of IT with the advent of the personal computer (PC), although the accessibility of the technology was limited. Although accessibility has increased, barriers remain, and new forms of IT have been disabling as well as enabling. Disableism is ever present in the ideologies, structures, and power relations that are part of, and inform, IT. Nondisabled designers often incorporate disability in the technology through taken-for-granted norms.

THE RISE OF THE PERSONAL COMPUTER

The early computers that featured in the advent of commercial computing after World War II operated with punch cards, which required of users the manual dexterity associated with card readers and other input devices. Herman Hollerith, who devised the punch cards used for processing and tabulating data in the 1890 U.S. Census, is said to have had great problems learning spelling, something that might be regarded today as a learning disability. In 1896, Hollerith founded the Tabulating Machine Company, which later became International Business Machines (IBM).

In the early 1970s, the invention of the microprocessor displaced both mainframe and minicomputers and led to the rise of the personal computer in 1974–1975. The PC's development paralleled the increasing role of IT in everyday lives. The basic PC unit was built around particular norms of design, code, and input and output, requiring people to conform to those norms. The PC needs of people with disabilities led to a set of contests regarding three key technologies: hardware, operating systems, and applications.

Specialized assistive technology, both hardware and software, emerged for people with disabilities. This showed the potential range of input and output devices that could be used in conjunction with computers, such as Braille embossers to create documents readable by blind people and hardware and software for speech synthesis (e.g., the 1976 Kurzweil Reading Machine). Yet such developments also raised the political and practical question of whether disability demands special or mainstream solutions. The consumer and disability movements took an early lead, for example, when they formed the Committee on Personal Computers and the Handicapped in Illinois in 1981.

Breakthroughs in the accessibility of mainstream computing proved elusive. Apple introduced the Macintosh computer in 1984, and although many acclaimed its graphical user interface as user-friendly, and it greatly influenced the development of its now ubiquitous Windows counterpart, for some users with disabilities, such as blind users, it was not ideal. However, Macintosh took an early lead in incorporating accessibility into its operating system.

In contrast to the graphical interface, the MS-DOS operating system was a text-based platform that worked in conjunction with text-based programs such as early versions of Word and WordPerfect. Computer users who were blind or vision impaired could use screen readers that would speak the text of DOS files.

Many hailed Microsoft's relatively late introduction of a graphical user interface with Windows

(especially its successful 1990 Windows version 3) as a breakthrough, but blind and vision-impaired users viewed it as a great threat. The move from text-oriented DOS-based to graphical Windows-based computer operating systems resulted in serious losses in access and jobs for persons using speech or Braille for communication.

Corporate initiative alone was not sufficient to stimulate the development of products to increase IT accessibility for people with disabilities, so activists used other strategies, such as lobbying for legislative protections. One result was the inclusion of IT requirements in the Americans with Disabilities Act (ADA) of 1990. Also critical was Section 508 of the 1973 Rehabilitation Act, which requires that information technology procured, developed, maintained, and used by federal agencies must be accessible to people with disabilities unless such requirement imposes an undue burden. Effectively, U.S. federal and state governments could use their purchasing power to encourage companies to make IT accessible. Activists in Massachusetts took the lead, lobbying the state government to use Section 508 to require the purchase of accessible computers.

The IT industry took several years to develop adequate accessibility strategies for Windows software, with little interest among mainstream software developers. In the early 1990s, Microsoft had only one person working on accessibility issues. Even as late as 1998, the company shipped Internet Explorer 4.0 with fewer accessibility features than had been in the previous version. The disability movement had to fight pitched battles with Microsoft before the company began to incorporate accessibility features in its operating systems and programs.

Despite positive corporate moves in this area, accessibility remains a threshold issue. Accessibility is vital for the incorporation of people with disabilities into computing technology, and thus the information society.

COMPUTER NETWORKING

The networking of computers through telecommunications to share resources, exchange data, and facilitate communications developed from the 1960s. In the 1980s, with the growth of bulletin boards, private networks such as America Online (AOL) and Compuserve, and the spread of the Internet, people with disabilities started to communicate and to share computer files online. Blind people as well as other people with disabilities were among the early Internet pioneers.

Disability accessibility has been a key issue for networked IT. In one important test case, a group of blind people invoked the ADA to force AOL to adopt accessibility measures. After requesting that AOL provide accessible Internet services for a number of years, the National Federation of the Blind filed suit against AOL in November 1999. Negotiations commenced, and the suit was suspended in July 2000 when AOL agreed to make its software accessible by April 2001.

Accessibility has been an integral feature of the design and deployment of the World Wide Web since the launch of the World Wide Web Accessibility Initiative (WAI) in April 1997. The WAI has raised the level of awareness of disability accessibility issues within the Internet community, especially among those who design and implement web pages. In principle, information on how to make web pages accessible is easily available—online. W3C is a consortium of organizations that work together consensually and issue recommendations regarding online accessibility. However, it is left to others to implement those recommendations, and many organizations do not. Hence the accessibility of the Internet for people with disabilities remains quite precarious (as is illustrated by the 2000 case of *Maguire v. Sydney Organising Committee for the Olympic Games*).

IT EVERYWHERE

IT has become pervasive in everyday business and private life in developed countries, and it is arguably a more subtle form of colonization in developing countries. Computer processors feature not only in PCs and modems, but also in media and communications devices (from televisions and radios to personal digital assistants, cameras, and mobiles), household appliances (refrigerators, ovens, alarms, lights, heaters), cars, and clothes (wearable computers). The average home in the twenty-first century is soon likely to contain hundreds of computer processors, with many of these devices likely to be connected to computer networks.

Information technology now actually has impacts on every major form of technological system utilized in Western society, incorporating norms that are rarely critically examined. The vision of the "smart home" and the "information society" is slowly being realized, and the convergence of the different sorts of IT involved presents important disability-related issues. To date, some IT companies, designers, and policy makers have reluctantly gained an understanding of the diverse expectations and needs of various people with disabilities. As IT is increasingly woven into the fabric of everyday life, accessible technology becomes all the more imperative because other alternatives may disappear. A further difficulty lies in the proliferation of different IT devices and applications, only some of which incorporate accessibility.

DESIGNING IT FOR DISABILITY

People with disabilities are often mentioned as being among the primary beneficiaries of IT, yet more often than not they are actually neglected in IT development. Sophisticated use of IT is providing smart homes and enabling lifestyles for people with severe disabilities, but such technology remains costly for individuals and society. In general, the potential uses of IT by people with disabilities are not systematically incorporated into the design, implementation, and marketing of IT products. Accessible IT still tends to be achieved through costly and tardy specially built solutions and retrofitting rather than through development that envisages disabled users and builds accessibility into mainstream design. Some innovative work has occurred around disability and design, including under the banner of universal design, but the issues of designing IT for all people with disabilities are complex, requiring an integrated approach, from invention and standards setting to manufacturing, procurement, promotion, marketing, product delivery, and training.

—Gerard Goggin and Christopher Newell

See also Accessibility; Accessible Internet; Assistive Technology; Augmentative Communication.

Further Readings

Goggin, Gerard and Christopher Newell. 2003. *Digital Disability: The Social Construction of Disability in New Media.* Lanham, MA: Rowman & Littlefield.

Websites

Trace Research and Development Center, University of Wisconsin–Madison, http://www.trace.wisc.edu

Web Accessibility Initiative, World Wide Web Consortium, http://www.w3.org/WAI

INSPIRATION

Inspiration is a popular-culture ritual that signifies the partial, ambivalent identification of normals with disabled people based on the willful "overcoming" of the putatively devastating effects of disability. In ubiquitous, stylized media stories presented by and for a normal perspective, disabled people are held up as (pseudo-) role models for refusing to quit against the overwhelming odds assumed to be posed by their own disabilities; rather, inspirers courageously mobilize their wills to superhuman heights, persevere, and overcome their disabilities, thereby pointing to and proving the existence of the "power of the human spirit." Neither the specific activities themselves nor the skill with which they are performed is important to the inspirational relation, which can be invoked any time normals encounter disabled difference. Disabled people may thus be marked as inspirational for any participation whatsoever, from mountain climbing while blind to playing the piano with a mental illness diagnosis to shopping while using a wheelchair. All such activities represent the contradiction of patterned social expectations, namely, that the "normal" response to disability would be bitter, angry surrender.

To *inspire* literally means to "breathe into" another person, to have an animating or exalting influence on, and the concept of inspiration surely exists in some form in all societies. Traditionally, inspirational forces were traced either directly or indirectly back to the divine, but the secularizing trends of modernity have centered the unified, self-directing will of the individual. Stories about inspirational role models (e.g., Martin Luther King Jr., Mother Teresa) stand in for

the divine in their selfless transcendence for the common good. Identification with such inspirers supposedly allows admirers to achieve by overcoming resistance, both external and internal.

Disability inspiration became prominent in the twentieth century and appears (its history has not been written) to draw on facets of nineteenth-century Victorian sentimentalism and the ideology of the freak show. From the latter, inspiration preserves conformist normality's horror before otherness—indeed, it collapses without it—along with an identificatory fascination regarding "How do they do it?"; from the former, it continues the narcissistic self-congratulation of beneficence before social inferiors while subtly shifting its point of identification from empathic understanding to willful overcoming.

In its valorization of a similar, if extraordinary, human will thought to reside within its objects of admiration, disability inspiration reflects a generalized advance in social status for people with disabilities. Although cross-cultural comparisons await, it would seem unlikely that disability inspiration can exist in societies in which disability presents as uniformly and overwhelmingly negative.

Nevertheless, as scholars such as Paul Longmore (2003) and Beth Haller (1999) have noted, disability inspiration places a drag on the quest for equality: It functions to deny *social* oppression by individualizing disability and maintains deviance by presuming an inability that must be "overcome" through "supercrip" achievement. Disabled people tokenized as inspirational also become ideological hammers against the rest of the group, for if one can succeed, why can't the rest? Inspiration is thus fundamentally reactionary and works against political solutions. In the end, inspiration reveals itself as a relationship of bad faith, wherein what disabled people supposedly overcome is precisely what has been done to them in the first place.

—John B. Kelly

See also Normality; Normalization; Representations of Disability, Social.

Further Readings

Haller, Beth 1999. "News Coverage of Disability Issues: Final Report for The Center for an Accessible Society." Retrieved December 1, 2003 (http://www.accessiblesociety.org/topics/coverage/0799haller.htm).

Kelly, John B. 2003. "Inspiration." *Ragged Edge* 24(1): 11–14, 26–27.

Longmore, Paul K. 2003. "Screening Stereotypes: Images of Disabled People in Television and Motion Pictures." Pp. 131–146 in Paul K. Longmore, *Why I Burned My Book, and Other Essays on Disability.* Philadelphia: Temple University Press.

INSTITUTIONALIZATION AND SEGREGATION

The writer Jack London once noted that "the chief horror of leprosy obtains in the minds of those who do not know anything about the disease." The same can be said about many conditions that affect the ordinary physical appearance of a person and confer visible physical distortions in the body together with obvious physical disabilities. In this entry, leprosy, particularly in colonial South India, is used as a context within which the characteristics of institutionalization and disability are examined.

LEPROSY AND DISABILITY

Knowledge about leprosy and the reasons for the physical damage it can cause has increased significantly since the late nineteenth century, although much about the illness remains a mystery. *Mycobacterium leprae,* the bacillus that causes leprosy, was discovered in 1873 by Gerhard Henrik Armauer Hansen, from whom the common name for leprosy, Hansen's disease, comes. Even so, the action of the bacteria was not understood until medical science advanced further in understanding the role of bacteria in causing illness and even disability. The advent of sulfa drugs in the 1940s offered the first effective medical cure for leprosy. However, the emergence of drug-resistant strains of the disease by the 1960s swiftly returned leprosy to the status of an intractable illness. Only with the development of a consistently effective form of multidrug therapy in the 1980s did a cure for leprosy again become viable.

Owing to the persistent difficulties with the diagnosis and treatment of leprosy through to the 1980s, together with the physical disfigurement and accidental

damage to limbs anesthetized as a consequence of the body's immune response to the disease, those with leprosy have tended also to suffer disabilities.

In the context of modern rehabilitative medicine and occupational therapies, leprosy has been studied as a cause of physical disabilities that can to some extent be minimized and managed even if not entirely remedied by treatment and physical therapy. Typically, a person with leprosy experiences a range of physical disabilities according to the type, severity, and duration of the illness. The hands often become clawed as fingers are foreshortened and lose sensation, resulting in loss of fingers through ulceration and accidental damage. Similarly, feet lose nerve sensation, and bones and joints deteriorate. Toes and even whole feet can be lost through accidental damage and ulcerating infection. It is not unusual for a person with leprosy, particularly when left without treatment or care, to have only stumps where hands and feet once were. Damage to eyes, nose, and palate also occurs in some forms of the disease, inhibiting and even destroying the capacity for sight, smell, and speech.

Stigma

In many, although not all, societies and times, those suffering from leprosy, like those with many disabilities, have been stigmatized because of their physical appearance. The external manifestation of leprosy in facial deformity, loss of limbs, and blindness has made the leprosy sufferer vulnerable to social ostracism and segregation from the economic, religious, and domestic life of their communities. During the nineteenth century, horror at the appearance of leprosy sufferers contributed to the establishment of systems for the isolation and segregation of those with the disease as much as did concerns about the contagiousness of the illness.

Segregation

Segregation and institutionalization of leprosy sufferers has occurred in a variety of countries throughout the history of the disease. The Hawaiian island of Molokai, where Father Damien lived and died among the leprosy sufferers, and the later island settlements of Makogai in Fiji, Peel Island off the Queensland coast of Australia, and Quail Island in New Zealand's South Island port harbor of Lyttleton are all famous examples of state efforts throughout the late nineteenth and twentieth centuries to segregate leprosy sufferers completely from the world. In each of these instances, the response to leprosy of the indigenous population was not necessarily the same as that of the white colonial or settler government. However, principally because of settler fear of contagion and the horrific appearance of those suffering the disease, complete physical separation and confinement of leprosy sufferers within the physical space of an island was believed necessary.

Institutionalization

Dedicated residential care for leprosy sufferers in institutions, often termed *asylums* in the nineteenth century, was also a typical response of colonial authorities to the disease. It was not, however, unique to British and other colonies. In the United States, a national leprosarium was completed in 1922 at Carville, Louisiana, on the Mississippi River to provide the best available medical treatment, rehabilitation, and assistance in living for those disabled by the physical effects of the illness. Built on 4,000 acres of land, it also provided accommodation as effective as the island settlements in segregating those with leprosy from the larger community.

Attempts to institutionalize leprosy sufferers occurred in a broader social as well as medical context. Systematic confinement of the sick, including leprosy sufferers, and the creation of *cordons sanitaires* to contain disease were the results of plague experience in fifteenth-century Europe. In nineteenth-century Europe and America, prisons, mental hospitals, workhouses, and almshouses emerged concurrently, providing, in an age of reform and social change, apparent solutions to both the social problems of crime and disorder and the demands of charity. Although in the late eighteenth century the doctor Philippe Pinel in Paris and the Quakers in Northern England instigated supportive care as an alternative to incarceration of the "insane," institutional confinement prevailed as the preferred medical and social

means of managing those perceived as "deviants and dependents"—that is, people who did not conform to social and economic "norms."

The French intellectual Michel Foucault (1975, 1988) has written on marginalization and the confinement of ostracized groups, including leprosy sufferers and the insane. The value of Foucault's work lies in his invitation to consider the symbolic significance of those who are excluded and marginalized and to understand confinement as a logical progression from other forms of complete isolation, such as island segregation. Through Foucault's eyes we are drawn to see institutional confinement and isolation more as a consequence of the symbolic status of the poor, the leprosy sufferer, the mentally ill, and the criminal than as any direct result of a societal concept of the best way to provide economic or medical care or administer justice.

The rise of institutions in the nineteenth century reflected not only changes in psychiatric and social thinking but also greater reliance on government and law, rather than private philanthropy and religious organizations, to resolve social problems. A strong relationship developed between the provision of residential facilities for health care and administration of justice and the emergence of legislation compelling both quarantining of the unfit and institutional confinement.

INSTITUTIONAL CONFINEMENT OF THE DISABLED

Leprosy Sufferers in Nineteenth-Century South India

In the light of contemporary medical understanding, the physical disability of leprosy sufferers is seen as the effect of leprosy but not essential to the disease. This has not always been the case. In nineteenth-century India, for example, leprosy was conceptualized in traditional Hindu and colonial British culture as both disease and infirmity. Both Hindu and British concepts of infirmity included those suffering physical disabilities such as blindness and lameness as well as those with physical signs of leprosy. It is the historical position of the leprosy sufferer as infirm/disabled in both the Indian and British traditions that makes a focus on the experience of the leprosy sufferer in colonial India suitable for this exploration of the confinement and institutionalization of those with disabilities.

Not all physical infirmities attracted confinement and institutionalization in colonial India. Although the Lepers' Act, a form of vagrancy legislation, was passed in 1898 to enforce the confinement in asylums of leprosy sufferers who were poor and vagrant and thus visible on the streets, others who were vagrant and lame, deaf, or blind (the principal forms of disability recognized in both colonial and Hindu Indian culture) were not similarly targeted. The legislation, developed after years of debate, was virtually impossible to enforce, but it did confirm the tenor of nineteenth-century social, medical, and governmental thinking on the social status of the leprosy sufferer in India.

Vulnerability to confinement was not a consequence of the disability itself, nor even of the contagiousness of the leprosy causing the disability, but of societal perception of the disabled. In the case of leprosy in India, the fact that the condition was incurable raised for colonial government and medical authorities the issue of contagion as a factor in their decision making concerning whether or not leprosy sufferers should be confined. Ultimately, however, socioeconomic issues were the deciding factor. The vulnerability of leprosy sufferers to institutionalization increased as their socioeconomic status declined. Despite being known to run the highest risk of spreading infection, those who lived and were supported within their families or were still able to earn their own living were not the subject of legislation. Rather, the poor and vagrant, those who posed the least risk of communicating infection through close personal contact, were targeted. Those who were so disabled that they were not able to support themselves became the subject of police and, later, legal attention.

Further, part of the justification for removing leprosy sufferers from the streets had less to do with health than with aesthetics. Leprosy sufferers, ravaged in appearance by the disease, were considered offensive to the eye and disturbing by both Indian and British in the colony. The value of the disabled leprosy sufferer was thus measured in both socioeconomic terms—according to his or her place in the family and capacity to earn a living—and aesthetic terms. While

often arousing compassion, the horrific physical appearance of the leprosy sufferer resonated strongly with British concepts of morality and stigmatizing illness and with Hindu ideas of the karmic responsibility of the individual for his or her condition. For both leprosy sufferer and the community, the physical degradation of the body was felt to reflect a deeper spiritual and moral decay.

The Nature of the Institution

The government institutions developed for leprosy care in nineteenth-century colonial India could not be termed *total institutions* in the sense defined by the sociologist Erving Goffman (1987). Rather than the complete separation of patients/inmates from family and community ties—an essential element of Goffman's concept of the total institution—these institutions featured constant interaction between patients and their families and the outside world. Although visiting hours were restricted at the Madras Leper Hospital, patients were permitted to leave the hospital, and there was little restraint on their continued social and personal interaction. As the hospital's surgeon in charge noted in 1889, some aspects of family life remained. Husbands and wives could visit each other, and many babies were born to inpatients.

Even so, tension and confusion existed concerning the true nature of these institutions, whether they were hospitals for patient care or prisons to ensure the confinement of a diseased and disfigured population. Linked with these issues was ambivalence over the status of leprosy sufferers, whether institutionalized individuals were patients or prisoners.

The issue of compulsion was never far away from attempts to institutionalize leprosy sufferers, and it aroused complex intercultural and class-related questions concerning the nature of medical care and the purpose of segregation. India was not acculturated to any form of institutional care for the sick or disabled. Rather, the family and community, supported by religious beliefs and indigenous medicine, were the context for care. Thus, any form of institution, even where compulsion to remain was not a factor, could be perceived as a prison. The building of the Madras Leper Hospital in 1816, with its high surrounding wall, made fear of imprisonment in the hospital inevitable.

Experience of Institutions

Despite considerable confusion as to whether the leprosy asylum was a prison or a hospital, until the passage of the 1898 Lepers' Act, there was no law in India under which leprosy sufferers could be forcibly confined in institutions. The difficulties in implementing the act meant, however, that enforced institutionalization was the experience of only a few with leprosy, notably those who were also imprisoned for criminal offenses and occupied the Leprosy Hospital at Port Blair in the Andaman Islands penal colony and, later, the Criminal Leper Ward of the Madras Leper Hospital. For most leprosy sufferers, institutionalization was a temporary experience that they resorted to by choice to obtain food and shelter when family and friends were unable to support them and destitution overcame them. The hospital was rarely seen as a place for cure, although at times rumors of leprosy cures did bring people into the hospital.

The ambiguous status of leprosy sufferers living in institutions had implications for their experience of institutional life. Some climbed the wall to escape the Madras Leper Hospital, not realizing that voluntary departure was an option. Medical staff were well aware of the voluntary nature of institutionalization, however, and in the interests of attracting and retaining patients for long enough to at least improve their physical condition, they tried to make hospital life acceptable and even appealing.

Hospital staff recognized that incentives were necessary, not just to lift patient morale and encourage compliance with the treatments available, some of which were painful and unpleasant, but to prevent leprosy sufferers from leaving the institution for the more stimulating, if hazardous, life of begging, pilgrimage, and relative freedom. Patients who had families to support and crops to tend found it impossible to enjoy the benefits of hospitalization for long. The need to find money and food, even by begging, and the seasonal demands of cultivation and harvest made flight from hospitals a necessity for the survival of the whole family.

Institutions made considerable efforts to meet the spiritual and cultural needs of leprosy patients in order

to encourage them to stay. South Indian institutions made provisions to enable patients to practice their religion and for patients of different castes to live according to their cultural requirements. Generally, the staff of leprosy institutions recognized the tedium and routine irritations of hospital life, and to counteract this, in some hospitals they encouraged patients to cultivate plots of land and to sell for their own profit any garden produce they could raise.

Living conditions for those with leprosy in institutional care were generous in comparison with what was available to other hospital populations. Basic clothing, fuel for fires, and lamp oil enabled patients to follow ritual practices and to cook for themselves according to caste rules if necessary. A diet rich in protein and fats was provided, with the additional luxuries of betel nut to chew and tobacco allowances. The generosity of the diet was matched, however, by its monotony. In 1878, in an incident that indicates the negotiating power of the patients within the institution, Indian patients at the Madras Leper Hospital convinced the surgeon in charge that the benefits to patient happiness, improved discipline, and greater treatment compliance would far outweigh the additional cost of providing greater variation in the evening meal.

As noted above, patients were free to leave the Madras Leper Hospital; however, certain areas of discipline were enforced with the threat of discharge. Patients were permitted only hospital food and were forbidden to give food away or to take food out of the hospital. Similarly, except in cases where patients were bedridden, smoking was not permitted in the wards. Generally, discipline was in place to maintain the routine working and safety of the institution and to ensure that patients received the benefits of good food, treatment, and healthy activity rather than to coerce or demean them. Even so, staff sometimes applied pressure to patients to enforce cooperation, using the threat of reduced privileges or diet.

The agency of the patients within the Madras Leper Hospital in the face of such pressure is evident in the action taken by a group of inpatients in 1873 in protest against a request from the surgeon in charge that they take on some work, including light labor, tailoring, and running messages. The surgeon considered such work to be both a beneficial diversion for the patients and a means of reducing the need for salaried help in the hospital. The rebel group disagreed, however, and, given the ultimatum of compliance or reduction to a "spoon diet"—broth for the European patients and rice porridge for the Indian—left the hospital to take their protest directly to the local magistrate at the Madras Town Police Office. The magistrate heard their complaint but upheld the surgeon's request. The patients returned to hospital and took up the work, having asserted both their freedom to leave without restraint and their right to negotiate, even if unsuccessfully, the types of conditions under which they wished to receive treatment in the institution.

FUTURE DIRECTIONS

In the last decades of the twentieth century, institutionalization again became less attractive in the "developed" world as a means of managing issues of health and justice. The decline in the growth of institutional "solutions" has as much to do with the often high capital value of institutional land and the costs of institutional care as with shifts in ideological and cultural understandings of the benefit of institutions to either the individual or society. Disability care has followed the trend of deinstitutionalization, although leprosy care in India has been slower to follow suit.

In "developed" countries today, individuals with moderate to severe disabilities are more likely to receive government or insurance funding for independent living within the community than to be offered institutional care. The movement away from institutional care toward independent living has been further supported by public advocacy through disabled support groups, increased government awareness, and the development of antidiscrimination legislation. Individuals with disabilities have also benefited from technological advances in computers and other devices designed to assist in daily life and work as well as from developments in physical and occupational therapeutics. Today, public perception of disability is moving toward recognition of those who face its challenges as worthy of respect and admiration rather than as requiring separation from society and community in institutions.

—Jane Buckingham

See also Deinstitutionalization; Experience of Disability: India; Inclusion and Exclusion; Stigma.

Further Readings

Bloombaum, M. and T. Gugelyk. 1970. "Voluntary Confinement among Lepers." *Journal of Health and Social Behavior* 11(1): 16–20.

Buckingham, Jane. 2002. *Leprosy in Colonial South India: Medicine and Confinement.* London: Palgrave.

Foucault, Michel. 1975. *The Birth of the Clinic: An Archaeology of Medical Perception.* New York: Vintage.

———. 1988. *Madness and Civilization: A History of Insanity in the Age of Reason.* New York: Vintage.

Goffman, Erving. 1987. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates.* London: Peregrine.

Gussow, Zachary. 1989. *Leprosy, Racism, and Public Health: Social Policy in Chronic Disease Control.* London: Westview.

Parascandola, J. 1998. "An Exile in My Own Country: The Confinement of Leprosy Patients at the United States National Leprosarium." *Medicina nei Secoli* 10(1): 111–125.

Rothman, David J. 1971. *The Discovery of the Asylum: Social Order and Disorder in the New Republic.* Boston: Little, Brown.

Strange, Carolyn and Alison Bashford, eds. 2003. *Isolation: Places and Practices of Exclusion.* London: Routledge.

U.S. Department of Health and Human Services, Bureau of Primary Health Care, National Hansen's Disease Program. n.d. "History of the National Hansen's Disease Programs." Retrieved May 1, 2005 (http://bphc.hrsa.gov/ nhdp/HISTORY_MAIN_PAGE.htm).

Websites

Global Project on the History of Leprosy, http://www.leprosyhistory.org/index.htm

Leprosy Mission, http://leprosymission.org.nz

Wellcome Library, MedHist, http://medhist.ac.uk/browse/mesh/detail/C0023343L0023343.html

INSURANCE

See Risk and Risk Selection Related to Insurance

INTERDISCIPLINARY TEAM

Within the medical model of disability, clinical activities have been broken down into professionalized disciplines, such as nursing, occupational therapy (OT) and physical therapy (PT), and social work. The interdisciplinary team is a managerial concept that has as its goal the efficient execution of care by team members through cooperation, communication, and identity as a unit within a larger structure.

Currently, four models of "team" dynamics exist: (a) the strict medical model, in which the physician maintains all authority for both communication and referral to "team" members in a strictly vertical hierarchy; (b) the multidisciplinary model, in which the physician coordinates all communication, usually vertically, but occasionally horizontally, among consulting services (e.g., PT, OT); (c) the interdisciplinary model, in which communication takes place laterally between consulting services as well as vertically through the physician; and (d) the transdisciplinary model, in which individuals are trained in several disciplines, encompassing their own interdisciplinary team. Each model has disadvantages and advantages, and consequently each is valuable in some situations but not in others. Too little research has been conducted to allow an "objective" delineation of the differences.

The "team" has traditionally followed the hierarchical medical model, with the physician "leading" it, but recently broader social shifts have made the pyramid of authority less vertical, encompassing interdisciplinary and transdisciplinary models. The concept of the team is based on a Western model, and so it is examined here in that milieu.

The idea of an interdisciplinary team necessitates the existence of disciplines. In the West, medicine—the area of expertise of the putative leader of the medical team, the physician—appeared as a discipline during the high Middle Ages. With the birth of the medical universities came an increasingly verticalized pyramid of authoritative health care. Physicians, in concert with civil and religious authorities, often sought out means to regulate broader medical care. From its inception, physician-coordinated regulation also implied that the physician would be working with other kinds of health care providers. Nursing, too, had its start in late antiquity and the Middle Ages, although the modern incarnation of nurses as professionals dates at the latest from the 1860s, when Florence Nightingale, the "Lady-in-Chief," applied statistical and managerial techniques to create a nursing hierarchy. This movement established nursing "teams" inside broader medical teams. Within nursing,

the "team" concept has remained an especially potent paradigm from Australia to the United States. Social workers, occupational therapists, physical therapists, dieticians, psychologiss, and others joined the ranks from the last quarter of the nineteenth century into the late twentieth. With such a panoply of disciplines, it is not surprising that the concept of the interdisciplinary team did not become formally voiced until the mid-twentieth century.

Similarly, a location for these workers to come together and function as a team in actuality was not necessitated until the rise of the modern hospital. An early form of the hospital started in antiquity and got on its feet during the Middle Ages; the hospital reached its apotheosis at the end of the nineteenth century and the beginning of the twentieth. The hospital as the home of the operating theater, expensive equipment, and the locus for controlling patients and staff has been particularly nurturing to this form of organization.

In the English medical literature, at least, during the nineteenth century it was uncommon to find the word *team* unless in reference to accidents occurring with runaway horse teams. By the first two decades of the twentieth century, even before World War I, the term appeared most frequently in reference to surgical teams, although Cooter (2004) suggests that it entered medicine from social work through Harvard physician Richard Cabot's 1909 book *Social Service and the Art of Healing.* The war certainly accelerated diffusion of the team concept into the medical profession through the experience with military organization. Thereafter, it appeared in literature from psychiatry to general practice to dentistry to public health to hospital ward care, finding particularly fertile ground in anesthesia and the surgical suite. World War II enhanced that association. By the 1960s, medical literature was rife with descriptions of psychological and sociological characterizations of medical team dynamics from the operating room to the schoolroom. Increasingly, too, business-oriented management techniques and educational concepts have infiltrated the military connotations.

In rehabilitation care, particularly in institutions, the team model also became popular. The metaphorical power of the body's systems working together as a "team" often entered the language of early advocates of team care, such as the pioneering British orthopedist Robert Jones (1857–1933). As it was used in the 1920s and 1930s, the word *team* was applied equally to groups of people with disabilities working together and to health care professionals providing multidisciplinary care. In the late 1940s and early 1950s, however, physiatrists increasingly employed this concept to describe their role in rehabilitation. They envisioned directing the many multidisciplinary ("integrated") activities of the health care providers surrounding those with disabilities. It became one more tool in their professionalizing armamentarium.

To take a specific example, in pediatric care, the rudiments of the team model undoubtedly started in the mid-nineteenth century in institutions such as the Hôpital des Enfants Malades in Paris and the Great Ormond Street Children's Hospital in London, among others. The laicization and professionalization of nursing and the creation of training programs specifically in pediatric nursing reinforced this process. In the first third of the twentieth century, medical care providers for children with cerebral palsy included physicians, social workers, nurses, teachers, psychologists, and therapists. The full model, if not the term, was pioneered in New York through the Society for the Ruptured and Crippled and in Boston at the Children's Hospital. The stated goal of these pioneers was usually the reintegration of the child into an educational setting; this necessitated work with teachers as well as with early social workers to apply new techniques in social engineering. Developmental psychology, which was becoming increasingly influential in the clinics, in research halls, and in the popular press, also demanded that pediatricians work alongside psychologists. In the eyes of some interdisciplinary pioneers, the inherent dependence of the developing child, with or without disabilities, necessitated careful coordination among professionals.

By the middle of the twentieth century, interdisciplinarity became the founding mantra of professional organizations such as the American Academy of Cerebral Palsy, was the subject of testimony before the U.S. Congress, and inspired celebratory articles in the lay press about patients who had been saved by the team process. Governmental agencies sponsoring both clinical research and health services redesign also began sponsoring team models in the last half of the century.

In the United States this occurred through the Veterans Administration and eventually Medicaid/Medicare; in the United Kingdom it took place through the National Health Service. U.S. national accreditation standards now require that rehabilitation facilities maintain interdisciplinary teams. Multidisciplinary clinics, however, in which multiple specialists saw children with disabilities simultaneously, offering families efficiencies of time, were rejected by U.S. governmental reimbursement models in the late 1980s.

In some measure, the impulse of the clinical team model paralleled the growth of ever-specializing "team science" in the biomedical sciences. Since the mid-nineteenth century, the reductionist style of laboratory science provoked knowledge production models in which workers (technicians and students) are supervised by the manager (the scientist). The parallel processing inherent in the system increased productivity, but it also sparked many of the false steps of capitalist production models in general. In physiology, for example, conflicts at times arose around the team or "factory" model, in which there are many laborers but one person gets the credit. Thus, Ivan Pavlov's candidacy for the Nobel Prize in physiology was hampered by the Nobel committee's concerns about who really generates knowledge in a large laboratory model.

In the clinical realm, at times, physicians have directly altered the constituency of teams, even at the level of redirecting already established disciplines. Thus, in a highly resource-rich rehabilitation network in Brazil the directors have favored developing their own in-house universal therapist, replacing the traditional occupational, physical, and speech-language therapists while creating new managerial flexibility outside the bounds of traditional disciplinary teams.

As a management paradigm, the team has proliferated, from the transplant procurement team to the hospital restructuring team to the palliative care team, all joining the surgical and rehabilitation teams. However, the application of the term *team* in multiple situations has also given it a protean expression, sometimes valuably. For example, in many settings, the "patient" has finally joined the model formally as a nearly full participant in his or her care and in the literature about team dynamics. In addition, the pressure of, for example, interdisciplinary team structures has led to a change in language—from "prescriptions" written for PT and OT, implying a hierarchical status, to "referrals," implying a coequal relationship. Although the *Oxford English Dictionary* still includes a definition of "team" as yoked beasts of burden, health care systems and organizational centers widely advocate the use of "teams" for their part in reducing the burden borne.

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See also Models; Occupational Therapy; Physical Therapy.

Further Readings

Cooter, Roger. 1993. *Surgery and Society in Peace and War: Orthopaedics and the Organization of Modern Medicine, 1880–1948.* London: Macmillan.

———. 2004. "Keywords in the History of Medicine: Teamwork." *Lancet* 363:1245.

Gritzer, Glenn and Arnold Arluke. 1985. *The Making of Rehabilitation: A Political Economy of Medical Specialization, 1890–1980.* Berkeley: University of California Press.

Hasler, John. 1992. "The Primary Health Care Team: History and Contractual Farces." *British Medical Journal* 305:232–235.

Pound, Pandora, Michael Bury, and Shah Ebrahim. 1997. "From Apoplexy to Stroke." *Age and Ageing* 26:331.

Todes, Daniel. 2002. *Pavlov's Physiology Factory: Experiment, Interpretation, Laboratory Enterprise.* Baltimore: Johns Hopkins University Press.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH (ICF/ICIDH)

Since its creation in 1947, the World Health Organization (WHO), based in Geneva, Switzerland, has had the mandate of collecting information about the health of populations around the world to provide input into public health policy. Although the collection of information on causes of death that the WHO undertook initially was useful for calculating life expectancies, the organization recognized early on that information about the lived experience of health would be valuable, and in particular data about levels of functioning in all areas of life. Given the WHO's very broad definition of health ("a state of complete physical, mental and social well-being and not merely

the absence of disease or infirmity"), the collection of complete functional status information was considered to be fully within its mandate. Because functional status is continuous rather than dichotomous, unlike mortality, collecting this information required sophisticated assessment and measurement instruments. But first, a classification of kinds of human functioning was needed, as well as a conceptual map of the complex domain of functioning. These needs led, by 1976, to the initial draft of the WHO's International Classification of Impairments, Disabilities, and Handicaps (ICIDH), a groundbreaking and controversial classification system tentatively released for trial purposes in 1980.

ICIDH (1980)

In the ICIDH, "disablement" (the overall phenomenon of decrements in human functioning) was modeled as a sequence of levels of health experience flowing from disease, trauma, mental illness, and chronic or age-related health conditions. An initial pathological change may lead to awareness of an impairment, defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function." Impairments involve parts of bodies or body systems; they are temporary or permanent differences of structure or function. If an impairment adversely affects a person's range of activities, then the person is said to have a disability, defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." Finally, impairments and disabilities may disadvantage the individual by limiting or preventing the fulfillment of six "survival" roles: orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency. When that happens, the negative social consequences—that is, the social disadvantages of being a person with impairments and disabilities—constitute a handicap, defined as "a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual."

The drafters of the ICIDH wished to incorporate the insights of what is often called the social model of disablement without losing sight of the fact that the concept of disability is grounded in the biomedical reality of impairments and, ultimately, background health condition. They were fully committed to the view that both the existence and the experience of disabilities and handicaps are created in part by the social and physical environment in which the individual lives. The social disadvantage of a handicap is as much a product of demands imposed by the environment as it is of the functional decrement of the impairment itself: "Handicap is thus a social phenomenon, representing the social and environmental consequences for the individual stemming from the presence of impairments and disabilities." Unfortunately, this insight—that the experience of disability is an outcome of an interaction between features of the person and features of the person's environment—was obscured by careless expression. Throughout, the ICIDH refers to the disadvantage of handicap resulting from the individual's "being unable to conform to the norms" of his or her social universe, as if the "problem" lies exclusively with the individual rather than with the norms.

The ICIDH had a negligible impact on disability statistics or data collection, because the classifications were viewed as incomplete, idiosyncratic, or difficult to use. The research community, however, argued that the ICIDH was a vast improvement over the purely medical classifications and assessment instruments that had dominated clinical practice up to that time. Therapists in particular appreciated the fact that the ICIDH acknowledged the role of the person's social and physical environment in both the creation and severity of his or her handicaps. Disability scholars tended to ignore the ICIDH or to dismiss it as little more than a modified medical classification, which is ironic given that, as Mike Bury (2000) has noted, the aim of the ICIDH was precisely to challenge the medical model.

ICF (2001)

By the 1990s it was clear that, at best, the ICIDH was a first attempt, and if it was ever to be of use in data collection or management, it needed to be substantially revised. Disability scholars criticized the ICIDH for defaulting to a medical model in which impairments created disabilities, which in turn created handicaps. They objected that the ICIDH only paid lip service to

the crucial role of the social environment in the creation of disability, and that it was a classification of "inferior" people that would facilitate eugenics and other practices of eliminating people with disabilities. They also asserted that the ICIDH promoted Western imperialism in that it ignored cultural and linguistic differences.

These were substantial and damning criticisms, yet the urgent need for an international classification of human functioning remained. By 1993, an international collaborative process to revise the ICIDH had begun. In the end, the revision clarified the underlying model of disability, reconceptualized the dimensions, added a complete classification of environmental factors, and expanded, reorganized, and updated the three classifications. Each item was operationally defined within a strict hierarchical structure, and the coding system was revamped. Drafts of the new classification system were subjected to extensive field trials to determine cross-cultural and linguistic applicability of the model and the classificatory structure and language. In May 2001 the renamed International Classification of Functioning, Disability, and Health (known as the ICF) was unanimously endorsed by the World Health Assembly and released for use in international research, surveillance, and reporting.

Time will tell whether the ICF's classifications transform the world's health and disability data collection systems or become the basis for "state-of-the-art" clinical assessment tools. The "biopsychosocial" model of the ICF may well be more influential than the classification system itself in the long run.

Briefly, the ICF identifies three dimensions of human functioning: body function or structure, activity, and participation. Observable or measurable decrements in these are dimensions of "disability" (understood in the ICF as an umbrella term referring to one or more of the three dimensions): impairments, activity limitations, and participation restrictions. Depending on how the ICF is used, the classification provides a coding structure that identifies specific categories of functioning in these three dimensions, with qualifiers to roughly assess severity and to identify whether the category is being understood as a "capacity" (inherent functioning of the person, usually measured in a standardized environment) or "performance" (a description of what the person actually does in his or her actual current environment). The definitions of these elements of the ICF model are presented in Table 1.

Table 1 Definitions of Elements of the ICF Model

Body functions are physiological functions of body systems (including psychological functions).
Body structures are anatomical parts of the body, such as organs, limbs, and their components.
Impairments are problems in body function or structure, such as significant deviations or losses.
Activity is the execution of a task or action by an individual.
Participation is involvement in a life situation.
Activity limitations are difficulties an individual may have in executing activities.
Participation restrictions are problems an individual may experience in involvement in life situations.

Finally, the environmental factors classification sets out in general categories all features of the physical, human-built, social, and attitudinal world that may either create disability (and, in particular, participation restrictions) by acting as barriers or lessen (or eliminate) disability by acting as facilitators. (Another contextual dimension, personal factors, is not explicitly classified in the ICF.) In general structure, as Figure 1 illustrates, disability phenomena (that is, impairments of body function or structure, activity limitations, and participation restrictions) are outcomes of interactions between features of the person, including background health condition, and environmental factors.

This model can be understood as a synthesis of what is useful in both the medical and social models of disability, without making their mistake of reducing the whole, multidimensional notion of disability to one of its aspects. This integration of the biomedical and the social means that "disability" can be disaggregated into its interacting components. The biomedical phenomena inherent within the physiological function of the person can be clearly identified and distinguished from features of the inherent capacity of the person to execute discrete simple and complex actions and from the extent of the person's participation in his or her actual environment, in the full range of socially constructed areas of human life.

Significantly, the ICF model offers no account of how or *why* disability comes about, beyond the statement

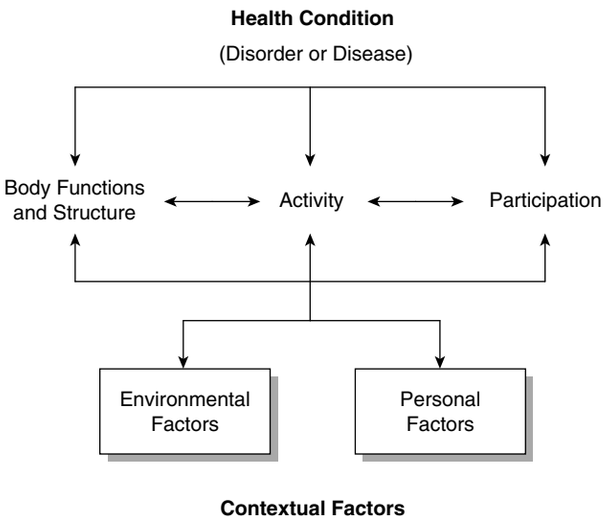

Figure 1 The Structure of Disability Phenomena

that disability arises out of an interaction between person and environment. If a researcher wishes to show, for example, that employment restrictions for people with mobility problems are the product of social prejudice, unaccommodating workplace environments, the underlying impairment, or some combination of these, the researcher can rely on the ICF to collect relevant evidence. The model of the ICF is itself (relatively) theory neutral, in the sense that it is compatible with whatever explanation of how disability arises, at the individual and population levels, that evidence may confirm.

The ICF is thus based on a *multidimensional* and *interactive* model of human functioning and disability. It is nonreductive (in the sense of not assuming that, e.g., the medical dimension is fundamental or "what disability really is") and, as just described, relatively theory neutral. In this sense, the ICF's model is closer to Saad Nagi's influential model, inasmuch as it offers a general structure for functioning and disability phenomena for data collection and management, policy development, and administrative and scientific research rather than an explanatory account of what causes or is responsible for disability, as in the medical model or the model developed by the Union of the Physically Impaired against Segregation (UPIAS).

Another important conceptual feature of the ICF model is universality. This can best be explained in terms of three other principles that guided the development of ICF. The first might be called etiological neutrality—that is, no assumption should be made about the nonenvironmental causal background of any particular functional decrement. For example, "reading" is a complex activity found in the ICF's "Activities and Participation" classification. The operational description of this item makes no reference to any disease, injury, or other health condition, or to specific impairment such as vision or cognitive problems. Problems in a person's capacity to read or in his or her actual reading performance are associated with many potential background health conditions or impairments. There undoubtedly are causal connections, but a classification must not assume these connections. The second principle is that classification is based on parity between the mental and the physical. Indeed, the ICF does not distinguish between "physical" and "mental" disability at all—it is all a matter of human functioning. Finally, in the ICF functioning and disability lie on a continuum, a spectrum from "complete functioning" to "no functioning" with an infinite number of gradations between the two extremes. Depending on user purposes, explicit "threshold" points can be determined (e.g., "mild," "moderate," "severe"), but this is a matter of usage and is not dictated by the ICF itself.

These three principles (etiological neutrality, parity, and continuity) taken together ensure that the ICF is not a classification for or about a particular group of people ("the disabled"); rather, it is about all of humanity. This is truly a paradigm shift in our way of thinking about disability, which is usually construed as an all-or-nothing phenomenon, a medical or social label that applies or not, or a social minority group to which an individual either belongs or does not. The ICF, in contrast, presents disability as a continuum that is relevant to the lives of all people in different degrees and at different times in their lives. Disability is not something that happens only to a minority of humanity, it is a common (indeed natural) feature of the human condition. The ICF is for all people, not just people traditionally referred to as "disabled" and isolated as a separate group.

The ICF thus "mainstreams" the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to the full range of lived experiences, it places all health conditions on an equal footing, allowing us to compare them using a common metric—the ruler of health and disability. From emphasizing people's disabilities and labeling people as "disabled," we now focus on the level of health and functional capacity of each individual. This may be the most important, and politically significant, aspect of the ICF's model of functioning and disability.

—Jerome E. Bickenbach

See also Models; Quebec Model of Disability Creation Process; Rehabilitation Medicine, International.

Further Readings

Badley, E. M. 1993. "An Introduction to the Concepts and Classifications of the International Classification of Impairments, Disabilities, and Handicaps." *Disability and Rehabilitation* 15:161–178.

———. 1995. "The Genesis of Handicap: Definitions, Models of Disablement, and Role of External Factors." *Disability and Rehabilitation* 17:53–62.

Bickenbach, J. E., S. Chatterji, E. M. Badley, and T. B. Üstün. 1999. "Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps." *Social Science & Medicine* 48:1173–1187.

Bury, Mike. 2000. "A Comment on the ICIDH2." *Disability & Society* 15:1073–1077.

Chamie, M. 1990. "The Status and Use of the International Classification of Impairments, Disabilities and Handicaps (ICIDH)." *World Health Statistics Quarterly* 43:273–280.

Fougeyrollas, Patrick. 1989. "Les implications de la diffusion de la classification internationale des handicaps sur les politiques concernant les personnes handicappées." *World Health Statistical Quarterly* 42:281–288.

Minaire, P. 1992. "Disease, Illness and Health: Theoretical Models of the Disablement Process." *Bulletin of the World Health Organization* 70:373–379.

Nagi, Saad Z. 1969. *Disability and Rehabilitation: Legal, Clinical and Self-Concepts and Measurement.* Columbus: Ohio State University Press.

Pfeiffer, D. 1998. "The ICIDH and the Need for Its Revision." *Disability & Society* 13:503–523.

———. 2000. "The Devils Are in the Details: The ICIDH2 and the Disability Movement." *Disability & Society* 15: 1079–1082.

Union of the Physically Impaired against Segregation. 1976. *Fundamental Principles of Disability.* London: Union of the Physically Impaired against Segregation.

World Health Organization. 1980. *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease.* Geneva: World Health Organization.

———. 2001. *International Classification of Functioning, Disability, and Health.* Geneva: World Health Organization.

Zola, I. K. 1989. "Toward the Necessary Universalizing of a Disability Policy." *Milbank Quarterly* 67(Suppl. 2, Pt. 2): 401–428.

INTERNATIONAL DISABILITY ORGANIZATIONS

Supports and services for people with disabilities are recorded as far back as the Old Testament. However, the emergence of organizations of and for persons with disabilities is a much more recent phenomenon, and the emergence of an international disability movement is newer still.

The Stockholm Deaf Club, established in 1868, is the first recorded organization of people with a disability. Since 1922, when Rehabilitation International was established, organizations of and for people with disabilities have been linking together internationally. Interest in sharing information related to disability increased following World War II. The World Federation of the Deaf and Inclusion International were founded in 1951 and 1962, respectively, and the International Association for the Scientific Study of Intellectual Disability (originally the International Association for the Scientific Study of Mental Deficiency) was founded in 1964.

Until the early 1980s, the Council of World Organizations Interested in the Handicapped represented the community of nongovernmental disability organizations in dealings with the United Nations. The council comprised the following organizations, all of which had consultative status with the United Nations: Rehabilitation International, the World Federation of the Deaf, the International League of Societies for the Mentally Handicapped (now Inclusion International), and the World Blind Union. However, in 1981 the creation of Disabled Peoples' International (DPI), with its strong focus on empowering "a voice of our own" for people with disabilities, changed the balance of power in disability organizations' dealings with the United

Nations. DPI played an important role in coordinating the work done during the International Year of Disabled People (1981) and in the subsequent development, together with other international disability organizations, of the World Programme of Action Concerning Disabled Persons and of the International Decade for Disabled Persons (1983–1992).

In 1987, a group of experts evaluated the outcome of the first five years of the International Decade. They determined that too little progress had been made toward the overall goal of "full participation and equality" for persons with disabilities. The international disability organizations therefore requested that the United Nations establish more concrete guidelines. The result was the UN General Assembly's adoption, in December 1993, of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. An important element of the Standard Rules was the creation of an independent and active monitoring mechanism, which included three elements: the UN Commission for Social Development, a special rapporteur whose duties were to conduct the monitoring and report to the commission, and a panel of experts named by the nongovernmental disability organizations. Bengt Lindqvist, a former Swedish cabinet minister, founding member of DPI and leader of the World Blind Union, was named special rapporteur. The panel of experts was composed of five women and five men representing Disabled Peoples' International, Inclusion International, Rehabilitation International, the World Blind Union, the World Federation of the Deaf, and the World Federation of Psychiatric Users (now the World Network of Users and Survivors of Psychiatry).

THE INTERNATIONAL DISABILITY ALLIANCE

During his tenure of three terms as special rapporteur, which ended in 2002, Lindqvist consistently worked with the panel of experts. This not only enabled the disability groups to play a significant role in monitoring the implementation of the Standard Rules, but it also served as an education for the disability organizations about international issues and created a spirit of collegiality among the groups. Individuals who did not have leadership positions within their organizations represented several of the groups, and so the presidents of the various organizations began to hold regular meetings, at first in conjunction with the panel meetings (see Lindqvist 2003-2004). These informal gatherings led to the establishment of the International Disability Alliance (IDA) in Cape Town, South Africa, in 1999.

There was a lapse between the end of Lindqvist's term as special rapporteur and the appointment of his successor, Sheika Hessa K. A. Al-Thani, but the IDA continued to meet. The network became a mechanism for collaboration among the world's major international disability organizations on matters of common concern, especially on matters related to the United Nations and its agencies. Currently, the IDA's member organizations are Disabled Peoples' International, Inclusion International, Rehabilitation International, the World Blind Union, the World Federation of the Deaf, the World Federation of the Deafblind, and the World Network of Users and Survivors of Psychiatry. In order to encourage cross-disability collaboration, and also to support the participation of international disability organizations in the elaboration of a proposed UN convention on disability, the IDA received financial support from the Swedish International Development Cooperation Agency.

Although each IDA member organization has its own mission and objectives, there is a strong commonality of approach among members. Enns (n.d.) summarizes the roles of organizations of disabled people as follows: self-representation, identification of grassroots needs, representation to government service providers and UN bodies, evaluation and monitoring of services, self-development, mutual support and solidarity, provision of a vehicle for self-help projects, provision of networking mechanisms, and promotion of public awareness. The current IDA member organizations are described below (some of these also have their own separate entries in this encyclopedia).

Disabled Peoples' International (DPI)

Disabled Peoples' International, a network of national organizations and assemblies of disabled people, was established to promote the human rights of disabled people through full participation, equalization

of opportunity, and development. DPI has consultative status with the UN Economic and Social Council, the World Health Organization, and the special list of the International Labor Organization.

DPI's mission is to ensure equal representation of its members through a decentralized "regional" structure that also facilitates leadership and strategy development at the local level. DPI currently has approximately 120 national members, more than half of which are in developing nations. Any organization controlled by disabled people can be a member of the national assembly in that organization's country.

A major goal of DPI is the full participation of all disabled people in the mainstream of life, particularly those in developing countries.

Inclusion International (II)

Inclusion International is a federation of more than 200 associations, in more than 115 countries, whose individual members are people with intellectual disabilities, their families, and other supporters. II's vision is a world where people with intellectual disabilities can participate equally and be valued in all aspects of community life. II has consultative status with the United Nations and its agencies.

With its member societies, II is an agent for change based on four main principles affecting the lives of people with intellectual disabilities and their families: inclusion of all persons in all aspects of everyday society, full citizenship for all that respects individual human rights, self-determination and individuals' control over decisions affecting their lives, and family support through adequate services and support networks.

II's Millennium Development Goals use the UN Millennium Development Goals as a framework for expressing the organization's objectives on behalf of people with intellectual disabilities. These goals, which provide a clear agenda and targeted objectives, focus on the following major issues: inclusive education, poverty reduction, children and families, maternal and child health, values and ethics, and human rights.

Rehabilitation International (RI)

Rehabilitation International is a federation of approximately 200 national and international organizations and agencies in 80 nations covering all of the world's regions. RI maintains official relations with the UN Economic and Social Council, the World Health Organization, the International Labor Office, UNESCO, UNICEF, the Organization of American States, the European Union and the Council of Europe, the UN Economic and Social Council for Asia and the Pacific (UNESCAP), and others.

RI develops and promotes initiatives to protect the rights of people with disabilities, to improve rehabilitation and other crucial services for disabled people and their families, and to increase international collaboration toward these objectives. Adopted in March 2000 at the World NGO Summit on Disability, RI's agenda emphasizes working toward the following in regard to people with disabilities: improvement of overall quality of life; reduction of deprivation, hardship, and poverty; improvement of education, training, remunerative work, and participation in decision making; elimination of discriminatory attitudes and practices; elimination of information, legal, and infrastructure barriers; and increased allocation of resources to ensure equal participation.

World Network of Users and Survivors of Psychiatry (WNUSP)

The stated purpose of the World Network of Users and Survivors of Psychiatry is to serve as a global forum and voice through which the users and survivors of psychiatry can promote their rights and interests. The WNUSP began as the World Federation of Psychiatric Users in 1991; it adopted its current name in 1997.

The WNUSP's aims are as follows: to advocate for the advancement of human rights, to provide international representation and consultation to the users and survivors of psychiatry, to encourage the development of national user/survivor organizations, to facilitate effective information exchange among user/survivor organizations, to develop networking opportunities for individual users and survivors of psychiatry, and to carry out any other activities that are consistent with WNUSP's purpose. The organization is also concerned with the advancement of human rights and expresses this concern by preparing, developing, lobbying for,

and supporting human rights work. At the same time, the WNUSP promotes the facilitation of national and international user/survivor networks.

World Blind Union (WBU)

The World Blind Union represents 180 million blind and visually impaired persons from 600 different organizations in 158 countries. The WBU, which has consultative status within UN agencies and the UN Economic and Social Council, is a nonpolitical, nonreligious, nongovernmental, and nonprofit organization divided into six regions, each with its own constitution.

The WBU is based on a commitment to the concept that all persons, including the blind and partially sighted, are born equal and entitled to personal dignity and fundamental human rights. The WBU is working to achieve inclusion of blind and partially sighted people in all UN conventions and covenants in all countries of the world, to increase in number and strength the organizations of the blind and partially sighted, and to take on the role of information provider to society in general. The WBU seeks to promote the interests and societal involvement of all blind and partially sighted people of the world. The organization works to strengthen its close contacts with the United Nations, governments, and national politicians in order to ensure that all blind and partially sighted persons enjoy the same rights and opportunities as others. The WBU uses all available ways and means, including existing laws and regulations, to fight for equal rights and full participation for all blind and partially sighted people through the United Nations, national governments, and nongovernmental organizations, and to provide information to the general public at the international, regional, and national levels.

World Federation of the Deafblind (WFDB)

The World Federation of the Deafblind is an international organization created by and for Deafblind persons in 1988 during the Helen Keller World Conference in Paipa, Colombia. The WFDB is a nonprofit, benevolent society that includes as members national organizations of Deafblind persons, Deafblind individuals, and other concerned individuals. It was organized for the purpose of advancing the economic, educational, and social welfare of Deafblind persons.

World Federation of the Deaf (WFD)

The World Federation of the Deaf is an international nongovernmental organization comprising national associations of Deaf people worldwide. A nonprofit organization, the WFD works for human rights and equal opportunities for Deaf people everywhere. The organization's goals are to improve the status of national sign languages, to improve the education of Deaf people, to improve Deaf people's access to information and services, and to improve human rights for Deaf people in developing countries.

The WFD was established in 1951 during the first World Deaf Congress in Rome, Italy, which makes it one of the oldest organizations in the world for people with disabilities. The WFD's 123 Ordinary Members represent all five continents, and the organization's regional secretariats are as follows: Asia and the Pacific, Central America and the Caribbean, Central Europe, Eastern Europe and Middle Asia, Eastern and Southern Africa, South America, and the Arab Region (Interim). It also has a regional cooperating partner in Europe. The WFD has consultative status with the United Nations.

—Diane Richler

See also Advocacy; Disabled Peoples' International; Rehabilitation Medicine, International.

Further Readings

Clarke, A. D. B. 1991. "A Brief History of the International Association for the Scientific Study of Mental Deficiency (IASSMD)." *Journal of Mental Deficiency Research* 35:1–12.

Enns, Henry. n.d. "The Role of Organizations of Disabled People: A Disabled Peoples' International Discussion Paper." Retrieved May 1, 2005, from Independent Living Institute website (http://www.independentliving.org/docs5/RoleofOrgDisPeople.html).

Enns, Henry and Yutta Fricke. 2003. "The Emergence of a Global Disability Rights Movement. In *In Pursuit of Equal Participation: Canada and Disability at Home and Abroad,* edited by Henry Enns and Aldred H. Neufeldt. Concord, ON: Captus.

Lindqvist, Bengt. 2003–2004. "Final Report of the Special Rapporteur of the Commission for Social Development on Monitoring the Implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities." Retrieved May 1, 2005, from UN website (http://www.un.org/esa/socdev/enable/dismsre1.htm).

Martinez, Kathy. 2000, March. "Global Perspectives on Independent Living for the New Millennium: An International Summit Conference on Independent Living." *Disability World.* Retrieved May 1, 2005 (http://disability-world.org/March2000/English/ilconferencearticle.htm).

Websites

Disabled Peoples' International, http://www.dpi.org
Inclusion International, http://www.inclusion-international.org
International Association for the Scientific Study of Intellectual Disability, http://www.iassid.org
International Disability Alliance, http://www.internationaldisabilityalliance.org
Rehabilitation International, http://www.rehab-international.org
World Blind Union, http://www.worldblindunion.org
World Federation of the Deaf, http://www.wfdnews.org
World Federation of the Deafblind, http://www.wfdb.org
World Network of Users and Survivors of Psychiatry, http://www.wnusp.org

INTERNET

See Accessible Internet

INTERSEX

Intersex is a term used to describe someone who has an anatomy that is not clearly either male or female. Various medical terms have been used to refer to such anatomy, including *androgen insensitivity syndrome, Kilefelter's syndrome, progestin virilization, mixed gonadal dysgenesis,* and *true hermaphroditism.* As these terms suggest, the experience of being an intersexed person is often pathologized through the medical model as a birth defect that should be corrected. Like many disabled people, intersex people often report significant pressures to change their bodies through surgery in order to make them more "socially acceptable" and "normal."

Many intersexed people are forced into surgery to adjust their bodies at very young ages. Common operations of this type include clitoral reduction and vaginoplasty. These surgeries often leave intersexed people feeling ashamed about their bodies as well as confused about their sexuality or their gender. In recent years, intersexed people have responded by starting a political movement to prevent infant surgeries and change medical practices toward children with ambiguous sexual anatomies. The intersex movement challenges dominant social interpretations of bodily differences, such as medical practices that define some penises as "too small," some clitorises as "too large," and the absence of a vagina as meaning a person is "not a real woman." The intersex movement generally objects to anatomy-changing surgery unless it is absolutely medically necessary, such as a lifesaving operation in which a urethra is rerouted so that a child can urinate.

In the past, many intersexed people were labeled "hermaphrodites." However, the category of intersex includes many people who do not conform to the standard medical definitions of "hermaphroditism"—namely, having both ovarian and testicular tissue. It is actually more common among intersexed people for their genitals to be ambiguous, regardless of whether they have ovaries or testes. When there is gender ambiguity, the child is usually allocated a female gender. In this context, it is important to note the social factors that often influence medical decisions—such as the common desire of doctors and family members to assign a gender to the child as soon as possible. The social importance placed on announcing a child's gender at the time of birth, regardless of whether the infant's gender is clear, often places the child and the child's family in uncertain territory in terms of personal identity. Many doctors assert the need to assign gender decisively and irreversibly at birth, but such a pronouncement often belies the complexities presented by intersexed infants. In major medical centers, the medical teams that are involved in assigning gender may include the original referring doctor, an obstetrician, a pediatric surgeon, a geneticist, and a pediatric endocrinologist. Team members may conduct tests and rely on procedures that take months to provide results.

In addition to emotional ordeals, many intersexed people experience physical complications and side effects as a result of the surgeries they have undergone. Although reports of complications from genital surgery are rare in the medical literature, some of the complications that can arise include stenosis (a narrowing of the vaginal canal), scarring, and urinary tract infections.

—Mark Sherry

See also Inclusion and Exclusion; Normality; Sexuality.

Further Readings

Dreger, Alice Domurat. 2000. *Hermaphrodites and the Medical Invention of Sex.* Cambridge, MA: Harvard University Press.

Fausto-Sterling, Anne. 2000. *Sexing the Body: Gender Politics and the Construction of Sexuality.* New York: Basic Books.

Gold, Carl. 2001. "The Intersex Spectrum." Retrieved May 1, 2005, from Nova Online website (http:// www.pbs.org/wgbh/nova/gender/spectrum.html).

Kessler, S. J. 2002. *Lessons from the Intersexed.* New Brunswick, NJ: Rutgers University Press.

INVALID WOMEN

Although the term *invalid* has fallen out of use as a medical category and now colloquially refers to someone who is incapacitated, there was a time when it meant simply weakness and a tendency toward illness. During the nineteenth century, women were presupposed to be weak, and femininity itself was considered akin to illness, so in one sense, all women—no matter their actual state of health—were seen as invalids. This representation of women as ill pervades the literature, art, and medical tracts of the period. Modern feminist critics have understood this phenomenon in four ways: as the result of misogynist cultural conditioning and the patriarchal power to define and control women's bodies, as resistance to such conditioning, as a kind of power in itself, and as a specific manifestation of cultural privilege and power in which illness functions as both power and powerlessness.

The double meaning of *invalid*—that is, both ill and not valid—serves to challenge women's standing as full citizens and was in fact used in arguments against suffrage and equal opportunity for women; middle- and upper-class women were assumed to be too frail to stand up to the rigors of officeholding, voting, or employment, despite the evidence of working-class women's stamina throughout the world. In this way, invalidism paralleled disability: Unfounded assumptions about a group's physical inferiority led to discrimination. Although there are and have been some important differences between invalid women and women with disabilities, quite often the two are indistinguishable, and the cultural associations attached to them are very alike. At the same time, women have sometimes further stigmatized disability in their attempts to deny invalidism. More recently, however, many articulate writers about disability have been women with chronic diseases who have drawn important links between illness and disability and have called attention to the role of gender in thinking about disability.

In the mid-nineteenth century, Edgar Allan Poe (1846) claimed that "unquestionably, the most poetical topic in the world" is the "death . . . of a beautiful woman" (p. 165). Representations of ill and dying women throughout the nineteenth century bear out his claim. Whether in paintings of mad, dead, or dying women (such as Albine and Ophelia), in operatic and dramatic renderings of tragic illness (as in *La Dame aux Camelias, La Traviata,* and *La Bohème*), or in literary depictions like Poe's, the numerous tubercular heroines of sentimental novels, or the delicate ladies fainting on couches that populate many novels and stories, representations of women in this period are often representations of illness and weakness. Nor did such depictions of women end in the nineteenth century. Many contemporary films and other fictional works continue to focus on dramatic episodes of women's illnesses; to mention just a few, one could point to such films as *Girl, Interrupted* and *One True Thing* or to novels such as Ana Castillo's *So Far from God* and Jane Smiley's *A Thousand Acres.*

Explanations of how women came to be understood as invalid usually focus on the cultural conditioning that is part of a patriarchal system. These arguments usually take one of two forms, maintaining either that oppression actually caused the illness or that oppressive norms caused women to be defined as ill no matter what their actual physical condition. Proponents of the former view argue that many expectations of women—that they wear corsets, that they bear numerous children, and that middle- and upper-class women refrain from much exercise—would in fact have led to illness; they point out further that powerlessness over life choices (whether to have a career, whom to marry, how to manage finances, or even whether to play a role in government) would have led to mental and emotional strains that likewise could have caused illness. Proponents of the latter view point out that in the mid-nineteenth century, normal experiences of feminine

physicality (menses, pregnancy, menopause) were coming to be circumscribed by medical intervention.

Critics have addressed female illness not only as an issue of powerlessness, however. Elaine Showalter (1997), for example, argues that female illness in the nineteenth century can be read as resistance to power. She asserts that hysteria, especially, might be read as a mode of protest. Thus, many women who were diagnosed as ill might in fact have been rebellious or politically resistant. Other critics have examined the way that scenes of illness may provide audiences with moral exempla of virtue and stoicism. Finally, it is important to note, too, that not all uses of illness for power are positive; there are numerous examples of female characters who dominate whole communities through feigned illness and demands for attention, probably nowhere more famously than in Harriet Beecher Stowe's *Uncle Tom's Cabin.*

Rosemarie Garland Thomson (1997) points to some important similarities between cultural assumptions about women's bodies and the bodies of people with disabilities. She argues that in many ways, especially if one traces writings about disabilities back to Aristotle, femininity itself can be seen as a disability—Aristotle classified the absence of a penis as a deformity—and that both femininity and disability have been understood as bodily differences that are not simply alternative forms but deficient ones. Thomson points out that by reading disability through a historical lens of discrimination against women, we can see that such oppression is a matter of social "norms" rather than concrete bodily differences.

We cannot, however, make an easy or historically continuous connection between feminist politics and disability politics. In the course of their historical struggle to gain access to political and social rights, women have sometimes argued against their "invalidity" by expressly contrasting themselves to the disabled. Suffragists argued their fitness to vote and hold office by defining their abilities against those of physically, emotionally, and intellectually disabled men. As historian Douglas Baynton (2001) argues, this sets out able-bodiedness as an unquestioned positive value. In many ways, then, the suffragists did not urge a rethinking of the paradigm of invalidism—that it equaled invalidity—they simply argued that they did not fit that paradigm.

In recent years, writers about female illness and disability have thought through the relation between the two in a much more nuanced way. Perhaps the most important of these writers has been Nancy Mairs, whose nonfiction prose collections explore the relationship between femininity—especially as it is connected with sexuality and beauty—and disability, when it takes the form of visible difference, but Lucy Grealy and Anne Finger have likewise grappled in their work with the overlaps between illness and disability. In *The Rejected Body* (1996), Susan Wendell tackles philosophical questions that link feminism, disability, and illness. Most contemporary representations no longer depict women's illness as a result of their own weakness or invalidity, and often do not feature women who are ill as "poetical" or beautiful subjects, either. Contemporary writers and artists are tackling the question of women's illnesses today without casting the ill woman as the invalid. In addition to those mentioned above, one might see the work of Lucille Clifton, Marilyn Hacker, and Margaret Atwood. Many of these representations challenge contemporary culture as the cause of "dis-ease" for women and, as Ann Folwell Stanford (2003) argues, urge a more cultural idea of healing.

—Diane Price Herndl

See also Normality; Sexuality.

Further Readings

Baynton, Douglas C. 2001. "Disability and the Justification of Inequality in American History." Pp. 33–57 in *The New Disability History: American Perspectives,* edited by Paul K. Longmore and Lauri Umansky. New York: New York University Press.

Finger, Anne. 1990. *Past Due: A Story of Disability, Pregnancy, and Birth.* Seattle, WA: Seal.

Grealy, Lucy. 1994. *Autobiography of a Face.* Boston: Houghton Mifflin.

Hippocrates Project, New York University School of Medicine. 2003. "Literature, Arts, and Medicine Database." Retrieved October 1, 2003 (http://endeavor.med.nyu.edu/lit-med).

Mairs, Nancy. 1996. *Waist-High in the World: A Life among the Nondisabled.* Boston: Beacon.

Poe, Edgar Allan. 1846, April. "The Philosophy of Composition." *Graham's Magazine,* pp. 163–167. Retrieved May 2, 2005 (http://www.eapoe.org/works/essays/philcomp.htm).

Price Herndl, Diane. 1993. *Invalid Women: Figuring Feminine Illness in American Fiction and Culture, 1840–1940.* Chapel Hill: University of North Carolina Press.

Showalter, Elaine. 1997. *Hystories: Hysterical Epidemics and Modern Culture.* New York: Columbia University Press.

Stanford, Ann Folwell. 2003. *Bodies in a Broken World: Women Novelists of Color and the Politics of Medicine.* Chapel Hill: University of North Carolina Press.

Thomson, Rosemarie Garland. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature.* New York: Columbia University Press.

Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability.* New York: Routledge.

IQ

IQ stands for *intelligence quotient,* a numerical score derived by combining a person's chronological age with his or her "mental age" as determined by the person's performance on a standardized intelligence test. Intelligence testing has become a standard tool in the diagnosis of two specific forms of disability: learning disabilities and intellectual disabilities (also known as developmental disabilities or mental retardation). Intelligence tests are also used in the assessment of giftedness and in the assignment of students to ability tracks within public schools.

Individual intelligence tests such as the Stanford-Binet Intelligence Scale, the Wechsler Intelligence Scale for Children, and the Wechsler Adult Intelligence Scale are used to provide a single measure of overall intellectual functioning. Intelligence tests are statistically normed so that all scores are distributed according to the pattern of a normal or bell curve. A high number of scores cluster at or near the center around an average value of 100. Fewer scores occur along the two tails of the curve. About 2.3 percent of all scores occur at or below 70, and 2.3 percent occur at or above 130.

Intelligence tests generally consist of two subscales, verbal and performance, each of which comprises five separate tests of specific skills within that domain. Verbal scale tests use language-based items, whereas performance scale tests use visual-motor items, which are less dependent on language skills. The two subscales contribute equally to the individual's total or full-scale score.

Learning disability diagnosis typically involves a formula that sets a specific criterion (often 1.5 or 2 standard deviations) for discrepancy between a total IQ score and a score on a standardized test of academic achievement. The purpose of comparing scores on an intelligence measure and an academic skills test is to uncover any unexplained deficit in a basic area of academic skill (such as reading, mathematics, writing). IQ is viewed as the measure of global intellectual capacity, a gauge of how well a student or other individual is expected to fare on academic tasks. The achievement test provides an actual measure of academic ability in a specific skill area. It is expected that a person scoring in the average range on an intelligence test will score in the average range on an achievement test. When a person scores significantly lower on an achievement test than on an intelligence test, that discrepancy is viewed as a possible indication of a learning disability.

The diagnosis of intellectual disabilities typically involves the use of an intelligence test and other measures of social functioning, such as adaptive behavior scales. An IQ score below 70 is generally interpreted as an indication of a significant intellectual deficit that may (depending on agreement of other measures) be described as an intellectual disability.

Educators and psychologists have often used intelligence tests as part of systems of intellectual stratification that interpret individuals' ability to learn and function in school and society based primarily on IQ. Educators have often categorized individuals across three cognitive levels: educable, trainable, and untrainable. Students classified as *educable* (IQ approximately 50–75) were viewed as being able to learn simple academic skills but not able to progress above a fourth-grade skill level. Children believed to be *trainable* (IQ approximately 25–50) were expected to be able to learn to care for their daily needs but to learn very few academic skills. Children who appeared to be *untrainable* (IQ approximately 0–25) were viewed as totally dependent and in need of long-term care in residential settings.

Psychologists have often used a similar stratification system consisting of either three or five general levels of intellectual disability. The more recent five-level system consists of the following categories: *borderline* (IQ 67–83), *mild* (IQ 50–66), *moderate* (IQ 33–49), *severe* (IQ 16–32), and *profound* (IQ < 16).

Often educators and psychologists have translated intelligence test scores into a concept of a *mental age.* If a score of 100 means that a person is functioning intellectually at the developmental level expected of his or her age peers, then a score of 50 indicates cognitive functioning equivalent to half that person's age. In this way, adults with intellectual disabilities have often been viewed as operating much like children.

For many years, the diagnosis of intellectual disabilities relied solely on the use of a single intelligence test. Also, the usual cutoff score for intellectual disability diagnosis was 80 or 85. In the 1960s, concern arose in the United States about the overidentification of intellectual disability in African Americans and members of other minority groups. Many educators, psychologists, and social critics maintained that intelligence tests were biased against minority and lower-class populations. In 1973, the American Association on Mental Retardation responded by reducing the diagnostic criterion level for intellectual disability (or mental retardation) to 70 to account for problems of bias and measurement error.

In the public schools, a series of court cases struggled with the same issues. In *Larry P. v. Riles* (1979), a California class-action case, it was argued that African American students had been inappropriately placed in educable mentally retarded (EMR) classrooms solely on the basis of IQ scores. The case also claimed that the IQ tests used were culturally discriminatory against African American children. The court found that the IQ tests were culturally biased against African American students. This case and others brought about a shift in public school utilization of intelligence tests, leading to a requirement that no special education diagnosis be made based solely on a single intelligence test.

In 1904, the French minister of public education commissioned Alfred Binet to develop a technique to identify students who could benefit from special education assistance. Binet put together a hodgepodge of tasks and games designed to enable the assessment of a wide variety of cognitive skills. His original insistence that no intelligence test could capture the many human abilities in a single score was generally ignored by the American psychologists who translated and popularized his test.

H. H. Goddard, Lewis M. Terman, and Robert Yerkes were prominent American psychologists who adapted Binet's test for various applications in the early twentieth century. The work of these three men reflected and perpetuated common prejudices of the times. Goddard believed that social problems such as violence, drug abuse, and poverty are rooted in individual mental deficit that is both innate and inherited. His answer was to develop intelligence tests to identify the high-level feebleminded in order to isolate them, thereby segregating social evil in institutions and reducing the chances of defective offspring. Yerkes developed intelligence tests for the U.S. Army during World War I that were given to thousands of soldiers for the purpose of matching individual intelligence with military rank and responsibility. The intelligence data gathered through these tests documented disproportionate levels of mental defect among immigrants and African Americans, providing scientific support for anti-immigrant and racist sentiments among many citizens and leaders. Yerkes's research was instrumental in the passage of the Immigration Restriction Act of 1924, which set strict limits on the numbers of immigrants accepted from Southern and Eastern Europe and Asia. Terman reached similar conclusions in his application of a version of the Binet test (early Stanford-Binet) to schoolchildren in northern California. He found that children of immigrants from Latin American as well as Southern and Eastern European countries fared very poorly in comparison with students of Northern and Western European backgrounds. His work simultaneously introduced intelligence testing to the public schools as a means of sorting students into ability-level groups and supported racist and jingoistic attitudes.

Racial issues returned to the forefront of the discussion regarding intelligence in 1969 when Arthur Jensen claimed in an article in the *Harvard Educational Review* that African Americans typically score lower than white persons on intelligence tests because African Americans are intellectually inferior. This racial argument returned again more recently in Herrnstein and Murray's book *The Bell Curve* (1994). Both of these publications continue a version of a philosophy of intelligence called *hereditarianism,* which was put forth in various ways by Goddard, Terman, and Yerkes. According to this philosophy, intelligence is an innate, unitary mental capacity that is primarily inherited through genetic transmission. Thus, variations

in intelligence scores across different social groups are indications of real differences in intellectual ability between the groups.

The opposing position, which has often been called *environmentalism,* asserts that variations in intelligence scores across social groups occur primarily because of differences in the social and physical environments in which various groups live and in the experiences and kinds of education that individuals within those groups tend to have.

More recently, proponents of a third position, called *multiculturalism,* have maintained that intelligence tests primarily test the extent to which an individual has experienced and learned the language and cultural features of middle-class Anglo-America. According to this stance, low scores achieved by various minority groups and lower-class whites demonstrate a cultural mismatch between the content of the tests and the cultural experience of the individuals.

Despite social critique, intelligence testing has become a mainstay of diagnostic practice among educators and psychologists. A wide variety of institutional authorities—including special education systems, vocational rehabilitation programs, adult disability service providers, and even courts deciding on issues of mental capacity in criminal cases and sentencing hearings—rely on intelligence testing as an authoritative guide to intellectual capacity.

—Scot Danforth

See also Learning Disability; Mental Illness; Mental Retardation, History of; Normality; Special Education.

Further Readings

Chapman, Paul D. 1988. *Schools as Sorters: Lewis M. Terman, Applied Psychology, and the Intelligence Testing Movement, 1890–1930.* New York: New York University Press.

Evans, Brian and Bernard Waites. 1981. *IQ and Mental Testing: An Unnatural Science and Its Social History.* Atlantic Highlands, NJ: Humanities Press.

Gould, Stephen J. 1981. *The Mismeasure of Man.* New York: W. W. Norton.

Herrnstein, Richard J. and Charles Murray. 1994. *The Bell Curve: Intelligence and Class Structure in American Life.* New York: Free Press.

Jensen, Arthur R. 1969. "How Much Can We Boost IQ and Scholastic Achievement?" *Harvard Educational Review* 39(1): 1–123.

IRELAND

See Experience of Disability: Ireland

ISOLATION

In the summer of 1995, more than 700 people died in Chicago during a prolonged heat wave. More than 10,000 individuals died in France under similar circumstances during a three-week period in the summer of 2003. Many of these individuals were elderly and suffering from one or more chronic diseases or disabilities. Of even greater interest to public health officials was the recognition that most of the deceased died alone, isolated from social networks that might have identified their high-risk situations and intervened before the consequences were so severe.

The term *isolation* is used to refer to both voluntary and involuntary lack of contact with others in the community. An individual may be involuntarily separated from others for several reasons. Physical limitations may keep the person from leaving home easily or from accessing facilities where he or she can engage in either business or social activities. Psychological or behavioral conditions may also prevent an individual from establishing satisfactory relationships with others in the community with whom he or she should interact. Some individuals desire solitude and so choose to isolate themselves from the community as much as possible. The majority of isolated individuals, however, do not wish be isolated and often experience physical and emotional impairments because of their isolated status.

In the 1970s, individuals with disabilities were "mainstreamed" from institutions into the larger body of society. This change signified a change in attitudes toward the disabled, but even so, a large segment of this population became segmented from the mainstream. Despite the existence of community training centers and rehabilitation programs, some individuals with disabilities became separated from their communities and isolated in their homes. Reasons for this included limitations caused by disability itself, the limited ability of some individuals to adapt emotionally to the challenges

of their disabilities, and the limited ability of some individuals to communicate with other members of society. Using a broad definition of disability that includes chronic illnesses, researchers who conducted an analysis in 1999 using data from the Survey of Income and Program Participation estimated that one in five American adults suffers from some disability. The major causes of disability were reported to be arthritis, rheumatism, back or spine problems, and cardiovascular disease. Less than 4 percent of those with disabilities reported a mental or emotional problem to be their primary cause of disability, and 20 percent of disabled individuals reported difficulty getting around outside of the home. Individuals over the age of 65 were only slightly more likely to report this difficulty than were those in the 18–64 age group.

Social isolation can result from a number of factors, including physical limitations. The issue of interest resulting from social isolation is the relationship between isolation and social loneliness, or the inability to derive satisfaction from interaction with other individuals or groups. The perception of loneliness results from a discrepancy between the level of those relationships that the individual desires and what he or she can achieve given the level of isolation dictated by the disability.

Several scales have been developed to measure loneliness. Studies using the UCLA Loneliness Scale have found that men are more likely than women to be lonely. In other studies using other scales, females have been found to have higher levels of loneliness. Although there is no consistent agreement on the variables that predict loneliness, an emerging body of literature has begun to link loneliness with poor physical and mental health.

Individuals with disabilities interact with primary health care providers with greater frequency than they interact with providers of rehabilitative or assistive services. This is especially true for individuals living in the community rather than in institutions, where rehabilitative services may be more accessible. There are differences in provision of services by gender as well. For females, most health care provided is related to the disability, and often women's preventive or wellness-based care is ignored. Females are also more likely to present with depressive symptoms.

Some research has attempted to differentiate between isolation and loneliness. Lonely young men and women have both been found to have poorer cardiac function than young people who are not lonely. Loneliness has not been found to be related to poorer health behaviors per se, but it has been found to be predictive of stress and poorer social interactions. In elderly persons with disabilities, attitudes toward social engagement have been found to be more important to overall rehabilitation than actual health condition or type of disability. Attitudes toward social participation related to the use of rehabilitative devices and services are often more predictive of the use of such services than the actual level of disability.

Coexisting psychosocial issues that occur in individuals with physical disabilities may not only increase the effects of their disabilities but also lead to further inability to self-manage as well as increase the incidence of new and preventable physical and emotional problems. Depression in older patients with coronary conditions has also been found to be correlated with poor quality of life, self-report of disability, and decreased physical endurance. Using volunteers who were willing to engage in community-based exercise programs, one study found that exercise improved physical function. Individuals with disabilities have been found to have higher rates of obesity than their counterparts who do not report such conditions. Obesity can aggravate the effects of some disabilities and lead to even less mobility.

Most studies of isolation in the disabled have focused on people with disabilities who live in urban areas. The problem may be even more acute in rural areas. One study found that individuals with HIV/AIDS living in rural areas, where such clients have even greater limitations on access to care than do those in urban areas, were more likely to be isolated and living in poverty. More than one-third of the affected individuals in the rural group reported that they had thought about suicide, and 6 percent seriously considered it to be an option.

Differences in age and the length of time individuals have had to deal with their disabilities may affect their ability to interact socially. As individuals with disabilities get older, they may have a tendency to move away from social interaction and develop self-imposed isolation because of changes in the social

pressures on them to interact with others and because of general societal attitudes toward the elderly.

A major limitation of all of the published research findings to date on isolation among people with disabilities is that estimating the true number of individuals who are isolated is difficult, whether the isolation is caused by limitations associated with disability itself or by individuals' inability to function in social networks. The problem of isolation is receiving worldwide attention, however, and programs have been developed on every continent to address the problem. Approaches to the management of isolation have centered on case management and the use of telehealth and technology to assist the disabled in maintaining contact with society.

Most efforts to date have centered on community-based programs that provide home-based services, monitoring, and/or arrangements for specialized transportation. Although such approaches have assisted a great number of isolated disabled individuals, many more have been missed for a number of reasons. For example, health care providers may fail to recognize the special needs of their disabled clients, insurance may not cover the provision of specialized services, or disabled individuals may have ceased contact with the health care system because of their inability to leave home and make initial contact with health care providers. Disabled individuals residing in rural areas are especially vulnerable to isolation and inability to receive services.

In recent years, approaches to reaching the population of isolated individuals with disabilities have incorporated the use of various communication technologies. Social service organizations and health care facilities have used the telephone to establish contact with homebound individuals; such contact may be made by employees of these organizations or facilities, but this work is often done by volunteers. Senior citizens residing in assisted-living facilities have participated in phone contact programs with other senior citizens living alone in their communities. This approach not only creates peer support but also helps to identify individuals who need further intervention. The Internet is emerging as a useful tool for assisting isolated individuals, as it enables them to communicate with peers, other persons of interest, and health care providers. Ease of use, continuous availability, and ability to span geographic boundaries have made the Internet a powerful contributor to efforts to address isolation, as it enables individuals to develop and maintain the levels of social interaction they desire. Some studies have found a decrease in loneliness among isolated individuals after introduction of Internet communication access, but long-term research is needed to determine the economic and health status benefits that may be derived from Internet use. Most of the Internet-related interventions examined to date have involved the use of chat rooms, but continued development and increased availability of audio and video communication over the Internet may further enhance the benefits of this approach. As with the limitations of case management, recognition of individuals who may benefit from this type of intervention is key.

Finding and assisting isolated persons with disabilities is a societal obligation; working against isolation is not solely the responsibility of the isolated individual. Since the deadly heat wave of 1995, the city of Chicago has instituted programs to ensure that elderly and disabled citizens are contacted during times of extreme weather conditions by community volunteers who go door-to-door to check on them. This expensive, time-consuming process is limited to crisis management, but it has been effective in reducing deaths. Communities need to develop similar approaches to case finding and support that are cost-efficient and meet the needs of individuals in a variety of geographic areas and cultures.

—Mary K. Pabst

See also Caregiving; Community Living and Group Homes; Family; Social Support.

Further Readings

Ades, Philip A., Patrick D. Savage, Marc D. Tischler, Eric T. Poehlman, Justine Dee, and Joelyn Niggel. 2002. "Determinants of Disability in Older Coronary Patients." *American Heart Journal* 143: 151–156.

Coyle, C. P. and M. C. Santiago. 2002 "Healthcare Utilization among Women with Physical Disabilities." *Women's Health eJournal* 7(4). Retrieved May 2, 2005 (http://www.medscape.com/viewarticle/433156).

Hawkley, Louise C. Gary G. Berntson, Mary H. Burleson, and John Cacioppo. 2003. "Loneliness in Everyday Life: Cardiovascular Activity, Psychosocial Context, and Health Behaviors." *Journal of Personality and Social Psychology* 85:105–111.

Hopps, S. L., M. Pepin, I. Arseneau, M. Frechette, and G. Begin. 2001. "Disability-Related Variables Associated with Loneliness among People with Disabilities." *Journal of Rehabilitiation* 67(3): 42–48.

McNeil, J. M. and J. Binette. 2001. "Prevalence of Disabilities and Associated Health Conditions among Adults—United States, 1999." *MMWR* 50(7): 120–125.

Moore, Kent R. 2003. "Defining 'Confined to the Home.'" *Family Practice Management* 10(3):20.

White, H., E. McConnell, E. Clipp, L. G. Branch, R. Sloane, C. Pieper, and T. L. Box. 2002. "A Randomized Controlled Trial of the Psychosocial Impact of Providing Internet Training and Access to Older Adults." *Aging and Mental Health* 6:213–222.

World Bank, Office of the Advisor on Disability. 2003. "World Bank International Dialogue on Disability and Development, Helsinki, May 29–30, 2003." *Disability World* 19(June-August). Retrieved May 2, 2005 (http://www.disabilityworld.org/06-08_03/development/dialogue.shtml).

ITARD, JEAN MARC GASPARD (1774–1838)

French physician

Jean Marc Gaspard Itard was born in Oraison near Digne in southern France in 1774. He was charged by Lucien Bonaparte, interior minister during the Consulate, and by Abbé Sicard, director of the Institute for Deaf-Mutes on the Rue Saint-Jacques in Paris, with the care of a boy who had just arrived, in July 1800, and who was already being called "the wild boy of Aveyron." Itard undertook to teach him to speak and to civilize him, rejecting the diagnosis of idiocy made by Philippe Pinel, the famous specialist in mental disorders at the Salpêtrière asylum.

Contrary to Pinel, Itard judged that the wild boy had not acquired the benefits of civilization because he had been isolated in the forest without human contact. Dealing with a natural being, he thought that through education—the fundamental empirical concept—he could "return him to society," as the celebrated Sicard was doing with deaf-mutes. To achieve this, Itard employed methods intended for the deaf. These methods failed, however, since the wild child was very different from them. More different, in fact, than he would have thought, since we now know that early alterations in the brain are not, or are hardly ever, open to modification.

After some years of fruitless efforts, Chaptal, Napoleon's interior minister, suspended the financial support that had until then been given for the education of "Victor," so named because he had learned at least to sound the letter *O*. Itard then turned back to the deaf, for whom he invented a method of physiological education to teach them to speak. Before his death in 1838, he supported Eduoard Séguin's efforts in treating and training the mentally impaired.

In 1970, French filmmaker François Truffaut wrote and directed *The Wild Child,* a film based on Itard's work.

—Jean-René Presneau

See also Feral Children; Philippe Pinel; Eduoard Onesimus Séguin; Victor of Aveyron.

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 multifamily 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.

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

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 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.

Further Readings

Ackermann, Ernest C. and Karen Hartman. 2000. *The Information Specialist's Guide to Searching & Researching on the Internet & the World Wide Web*. Chicago: Fitzroy Dearborn.

Blasiotti, Ellen Liberti, Iwao Kobayashi, and John Westbrook. 2001. "Disability Studies and Electronic Networking." Pp. 327–347 in *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury. Thousand Oaks, CA: Sage.

Bradley, Phil. 2002. *Internet Power Searching: The Advanced Manual*. NewYork: Neal-Schuman.

Conner-Sax, Kiersten and Ed Krol. 1999. *The Whole Internet: The Next Generation—A Completely New Edition of the First and Best User's Guide to the Internet*. Beijing and Cambridge, MA: O'Reilly.

Davoren, J. B. 1998. "Searching the Internet." Pp. 129–144 in *Evidence Based Medicine: A Framework for Clinical Practice*, edited by D. J. Friedland. Stamford, CT: Appleton & Lange.

Harris, Robert H. 2000. *A Guidebook to the Web*. Guilford, CT: Dushkin/McGraw-Hill.

Health Information Technology Institute. 1999. "Criteria for Assessing the Quality of Health Information on the Internet—Policy Paper." Mitretek Systems. Retrieved June 22, 2004 (http://hitiweb.mitretek.org/docs/policy.html).

Johnstone, David. 2001. *An Introduction to Disability Studies*. London: David Fulton.

World Wide Web Consortium (W3C), Education and Outreach Working Group. 2001. "How People with Disabilities Use the Web: W3C Working Draft, 4 January 2001." Retrieved June 29, 2004 (http://www.w3.org/WAI/EO/Drafts/PWD-Use-Web/Overview.html).

Websites

American Medical Association, "Guidelines for Medical and Health Information on the Internet," http://www.ama-assn .org/ama/pub/category/ print/1905.html

Olin & Uris Libraries, Cornell University Library, "Evaluating Web Sites: Criteria and Tools," http://www.library.cornell.edu/ olinuris/ref/research/webeval.html

Schnall, Janet G., HealthLinks, University of Washington, "Navigating the Web: Using Search Tools and Evaluating Resources," http://healthlinks.washington.edu/howto/navigating

Section 508, http://www.508.gov

Sheridan Libraries of the Johns Hopkins University, "Evaluating Information Found on the Internet," http://www.library.jhu .edu/elp/useit/evaluate/

UC Berkeley Library, "Finding Information on the Internet: A Tutorial," http://www.lib.berkeley.edu/TeachingLib/Guides/ Internet/FindInfo.html

University of Illinois at Chicago, Library the Health Sciences Peoria, "Finding Information on the Internet: Evaluating Web Sites," http://www.uic .edu/depts/lib/lhsp/resources/evaluate.shtml