# ENCYCLOPEDIA OF
# DISABILITY

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# S

## SAINT VITUS' DANCE

St. Vitus, the patron saint of dancers and performers, grew up in Sicily and became a matyr during the reign of Emperor Diocletian (ca. 243–316). Sometime during the sixteenth century in Germany, his name began to be invoked to ward off diseases and conditions such as epilepsy, nervous disorders, and, most notably, Sydenham chorea minor and major. Sydenham chorea, referred to as St. Vitus' dance throughout the seventeenth century, caused involuntary movements of the muscles associated with the onset of rheumatic fever. These movements were thought to be stress-induced responses of "wild dancing." Multitudes of people were recorded as experiencing this condition across the continent of Europe, particularly during the fourteenth century. The condition could last from days to weeks and has been traditionally associated with women. The spasticity of movement was often believed to be a sign of insanity. As Burton's *Medical Encyclopedia* explained in 1621, "They that are taken with it can do nothing but dance till they be dead, or cured." The U.S. television show, *Buffy the Vampire Slayer,* spoofed this condition as a demon-induced plague in the musical episode "Once More with Feeling."

*—David T. Mitchell*

***See also*** Disease.

## SANGER, MARGARET (1879–1966)

*Birth control activist*

"Margaret Higgins" was the sixth of 11 children born live to her Irish American working-class parents, Anne and Michael Higgins. When her mother, who suffered from tuberculosis and became progressively weaker with each pregnancy, died at age 49, Margaret attributed her death to her numerous pregnancies. Margaret herself acquired tuberculosis, and during her nursing training at White Plains Hospital in New York state, she was afforded an early example of a disability accommodation when her work/study day was shortened by several hours so that she could take walks and get fresh air, the treatment then for tuberculosis. Her only daughter, Peggy, contracted polio at age three and died of pneumonia two years later. When her second husband, millionaire Noah Slee, suffered a stroke in 1943 and began using a wheelchair, Sanger installed a bell on the wheelchair by which he could summon her. She devoted herself to his care until he died a few months later.

Like early feminists before her, Sanger linked birth control with freedom of sexual expression and reproductive rights. Over time, Sanger's arguments evolved to portray birth control as a women's health issue as well as a method of social control. Sanger explicitly linked birth control to eugenics, and one of the goals of International Planned Parenthood, which Sanger founded, included establishing scientific research into the "elimination of harmful dysgenic births in the nation." She also supported research for hormonal anovulants, and by the time of her death, an oral contraceptive had been developed and was being used by women worldwide.

In addition to tuberculosis, Sanger experienced a number of disabling conditions during her adult years, including a nervous disorder, depression, heart condition, alcohol and drug dependency, and leukemia. She spent her last five years in a nursing home, where she died at age 86.

*—Sharon Lamp*

***See also*** Feminism; Reproductive Rights.

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## SARASWATI, VIRJANANDA

**(1779–1868)**

*Vedic scholar*

Swami Virjananda Saraswati was blinded by smallpox when he was about five years old and orphaned six years later. At 15, he left his brother's unwelcoming home, found refuge among the scholars and saints at Hardwar on the Ganges, and became an assiduous student of Vedic literature, orally taught. Virjananda eventually became a teacher of Sanskrit grammar among religious students at several of northern India's holy cities. He denounced the vast range and shallowness of superstitions bound up in popular Hindu belief and campaigned for a return to the austere fundamentals of Vedic teaching. In later life, Virjananda had a profound influence on Dayananda Saraswati (1824–1883) and thus on the founding and direction of the powerful Hindu reform movement, the Arya Samaj, with effects continuing into the twenty-first century. Dayananda sat at Virjananda's feet in Mathura from 1861 to 1863, showing more perseverance than most, for the blind guru was famously volcanic. Centuries of the downmarket end of Hindu belief and practice received condign punishment from the elderly scholar, whose cane fell on the nearest proxies, the hapless students sitting before him.

*—Kumur B. Selim*

***See also*** Disability in Contemporary India; Experience of Disability: India.

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## SAUNDERSON, NICHOLAS

**(1682–1739)**

*English mathematician, linguist, and teacher*

Nicholas Saunderson, blinded by smallpox in infancy, became a proficient mathematician, linguist, and teacher. In childhood, his education was mostly informal, but the teenage boy's intelligence attracted teachers, and his mathematical ability was assisted by two tactile learning boards that he devised for arithmetic and geometry. The first enabled him to calculate rapidly, using his own code of larger and smaller pins in a grid of holes. On the second board, he made and altered shapes with thread attached to pins. Saunderson continued his education from various tutors, and in 1707, he went to Cambridge, where his talents as a teacher were exercised. In 1711, he received an M.A. and was elected Lucasian Professor, against stiff competition. He was highly regarded as a teacher of mathematics and science, both by his students and colleagues, although some of the former found his standards too exacting and tried his patience, while some of the latter suffered from his frankly aired opinions. A modern mathematician notes that Saunderson hardly contributed to mathematical research but produced useful textbooks and guides to his subjects. He married in 1723 and had children. With some adjustments, Saunderson apparently lived the typical life of an able and gregarious professor of his times.

*—Kumur B. Selim*

***See also*** Blindness and Visual Impairment.

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## SAVELJEV, PAVEL ALEKSEEVICH (1890–1975)

*First chairman of the All-Russian Federation of the Deaf*

Pavel Alekseevich Saveljev lost his hearing at the age of nine. In 1924, he started publishing the newspaper *Life of Deaf-Mutes.* In 1926, he set up the All-Russian Federation of the Deaf and was its chairman from 1926 to 1949. He also organized evening schools, workshops, factories, and vocational training for the deaf. In 1957, he organized a drama school that attracted many amateur deaf actors. In 1960, the school became a part of the Schukin Professional Drama College in Moscow. Seventeen deaf students were trained there and, in four years, received certificates as professional drama actors. Three more groups of deaf actors graduated from the drama school.

*—Anna Komarova and*
*Victor Palenny*

***See also*** Deaf, History of the.

## SCHIZOAFFECTIVE DISORDERS

The term *schizoaffective disorder* was originally coined by Kasanin (1933) to define a subgroup of psychoses in which affective and schizophrenic symptoms are prominent simultaneously, or within a few days of each other, within the same episode of illness. Historically, other concepts, such as *intermediate psychoses* or *mixed psychoses,* have been also used to describe the psychoses between affective and schizophrenic disorders. The current definition in the diagnostic manuals of mental disorders states that this co-occurrence of affective and schizophrenic syndromes is required for diagnosis. Two types of schizoaffective disorders have been established according to the affective symptoms: *manic or bipolar type* if the mood disturbance includes a manic or a mixed episode and *depressive type* if the mood disturbance includes only major depressive episodes. About 1 in every 200 people (0.5 percent of population) develops a schizoaffective disorder at some time during her or his life. Although it is well established that this is a biological disorder, the specific cause or causes are unknown. The studies of sociodemographic, clinical, biological, and outcome characteristics have demonstrated that schizoaffective disorders lie midway between the two major psychoses, schizophrenia and pure affective disorders. Although patients with schizoaffective disorders suffer from recurrent episodes and thus need preventive treatment, they usually make a full recovery, and only a small percentage of cases end in chronicity or a defect state.

*—Benedicto Crespo-Facorro*

***See also*** Mental Illness; Psychosis; Schizophrenia.

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## SCHIZOPHRENIA

Schizophrenia is a serious mental illness that begins early in life and leads to substantial morbidity, increased mortality, and significant disability. Recent World Health Organization (WHO) estimates suggest that schizophrenia is among the top 10 causes of disability worldwide. Characteristic symptoms include hallucinations, delusions, unusual behavior, and disorganized thinking (positive symptoms); decreased motivation, decreased energy, and social withdrawal (negative symptoms); and cognitive impairments leading to functional disability. Basic social skills, including the capacity to read and respond to facial expressions, are often lacking, making social communication difficult. The illness runs a protracted course in many patients and frequently leads to chronic institutionalization or multiple hospitalizations, homelessness, unemployment, and social isolation. There is evidence that in less industrialized countries, individuals with schizophrenia have a more favorable outcome and less disability as they are better able to manage the social skills needed for survival in less complex societies.

While conventional antipsychotic medications effectively control positive symptoms, they have little impact on cognitive impairment and functional disability. Recent research suggests that atypical or "second-generation" antipsychotics compared with conventional antipsychotics may have superiority in rectifying functional impairments in schizophrenia. However, atypical antipsychotics produce only limited improvements in overall disability; a comprehensive approach to overall management, including individual-, group-, and community-based psychosocial treatments, is therefore critical. There have been recent major advances in such treatments.

## MODELS OF COMMUNITY CARE

A good deal of research has been conducted on two approaches to community care: the assertive community treatment (ACT) and intensive case management (ICM) models. ACT provides a continuum of medical, psychiatric, and social services to patients in the community via mobile outreach teams of clinicians providing services needed to keep patients out of the hospitals. Such services include case management, social service entitlements, housing, vocational rehabilitation, crisis intervention, financial support, and advocacy. Specifically, case managers help in discharge planning, establishing linkages with community programs, and networking to confirm that quality community care is provided. These models reduce time in the hospital and improve housing stability, especially among patients who are high service users. ACT and ICM also have moderate effects on improving symptomatology and quality of life. However, most studies suggest relatively less effect of ACT and ICM on disabilities in social functioning, arrests, time spent in jail, or vocational functioning. Some British studies have failed to replicate American observations of improved outcomes in ACT. However, these differences might reflect variable implementation of differences in available resources for ACT in the United Kingdom versus the United States.

## SUPPORTED EMPLOYMENT

Most patients with severe mental illness live in the community, but many are socially isolated and few have jobs. In recent years, supported employment, an approach that uses the "place and train" as opposed to the "train and place" method, has been increasingly gaining acceptance as the preferred method for vocational rehabilitation. Such supportive employment, coordinated with clinical care, increases the rate of competitive employment, lower hospital admission, and better treatment compliance. The addition of social skills training, combined with supported employment, may enhance the individual's ability to meet the interpersonal demands of the workplace.

## SUPPORTED HOUSING

The gradual deinstitutionalization in the past several decades has necessitated the need for developing a variety of housing alternatives, ranging from transitional housing, 24-hour highly staffed residential care or board, and home care through staffed group homes to less supervised and more normalized community settings. Too frequently, states have allowed the "warehousing" of chronic schizophrenic patients in nursing homes, which have little or no treatment or rehabilitation interest. Recent years have witnessed a move from facilities in which to "place" patients toward partnership between the mental health service provider and providers of ordinary housing. A range of mobile case management, crisis intervention, and continuous treatment services allows patients to be managed in the housing of their choice. Patients and treatment providers often prefer this approach; quality of life is usually increased, and length of hospitalizations may also be reduced.

## SOCIAL SKILLS TRAINING

Social skills training is a widely used psychosocial intervention in the management of schizophrenia. Complex social skills are broken down into simpler and smaller steps and then taught using a variety of techniques, including didactic and Socratic instruction, modeling, corrective feedback, and homework exercises. Several randomized controlled trials have shown that social skills training produces improvement on specific behavioral measures, although changes in symptoms and community functioning are less pronounced.

The Schizophrenia Patient Outcomes Research Team (PORT) pointed to the underutilization of these approaches and recommended their inclusion in the treatment package. Social skills training was also included in the practice guidelines for treating patients with schizophrenia published by the American Psychiatric Association.

## FAMILY INTERVENTIONS

It has been known for some decades that patients who return to families with high expressed emotion (EE) (e.g., criticism) have a higher likelihood of relapse than those whose families are low in EE. Family interventions (i.e., family psychoeducation and behavioral family therapy) are highly effective for reducing families' EE and improving patients' relapse rates and outcomes. Furthermore, family interventions are also associated with reduced family burden. Several studies have demonstrated the efficacy of family psychoeducation leading to reduced relapse rates, improved recovery of patients, and improved family well-being among participants. Effective approaches in family psychoeducation programs include empathic engagement, education, ongoing support, and clinical resources during periods of crisis; social network enhancement; and problem-solving and communication skills. Coordination among patient and family advocacy organizations, clinician training, and ongoing technical consultation and supervision can help in implementing psychoeducational approaches in routine clinical settings. Family psychoeducation for a particular patient and family should be tailored to the extent and quality of family and patient interest and involvement.

## COGNITIVE REMEDIATION

In the past few decades, cognitive dysfunction has been recognized as a fundamental disability feature of schizophrenia. Domains of cognition that are impaired in schizophrenia include attention, working memory (e.g., capacity to keep things in mind long enough for immediate use, such as directions or a phone number), and learning and general memory. Other deficits include impairments in forward planning, concept formation, initiation, and self-monitoring. These impairments are noticeable against a background of generalized cognitive deficits and may affect between 40 and 95 percent of individuals with schizophrenia. Specific executive deficits appear to be related to specific symptom clusters and are linked to structural and functional brain abnormalities. Recent research has convincingly demonstrated a relationship between cognitive deficits and functional outcome in schizophrenia.

Cognitive remediation involves repeated practice and acquisition of compensatory strategies on cognitive exercises designed to engage underfunctioning brain systems. Researchers in Pittsburgh have recently developed a novel approach to the cognitive remediation in schizophrenia, called cognitive enhancement therapy (CET). This approach capitalizes on observations that deficits related to social cognition—the ability to act wisely in social interactions—may be of particular importance in impeding social and vocational recovery. Social cognition is acquired during adolescence and early adulthood and may be at least partly independent of formal IQ and neuropsychological problems. CET draws on a contemporary neurodevelopmental model of schizophrenia whereby social cognition deficits are thought to serve as intermediary links between impairments in executive cognitive functions and the emergence of characteristic symptoms of schizophrenia. CET is designed to facilitate the individual's transition from prepubertal to young adult style of social cognition and emphasizes developmental learning experiences during the remediation of social cognitive deficits. The treatment involves helping the individual to develop a "gistful" appraisal of interpersonal behavior and novel social contexts. Cognitive remediation strategies vary widely along dimensions of duration, intensity, method, target of behavioral intervention, and clinical status of participants. Using these approaches, improvements have been observed on measures of working memory, emotion perception, and executive function. Functional magnetic resonance imaging studies have begun to suggest changes in task-evoked brain activation in several functionally relevant neural systems.

## COGNITIVE ADAPTATION

U.S. researchers in Texas have developed cognitive adaptation training. This involves modification of the patients' environment to allow patients to bypass their deficits. Following a detailed behavioral assessment and analysis of the home environment, behaviors are modified by increased structure, signs and labels, and electronic devices—such as tape recorders—for providing cues and instructions. Cognitive adaptation interventions have also been found, in a controlled trial, to produce improvements in symptoms, psychosocial status, and relapse rates.

## CONCLUSIONS

More research is needed to establish cost-effective approaches to psychosocial rehabilitation in schizophrenia. The best evidence suggests that if rehabilitation interventions can begin in early adolescence or young adulthood, schizophrenia can be far less disabling than it has been historically. Characteristics of successful psychiatric rehabilitation programs include interventions that (1) are direct and behavioral; (2) have specific effects on related outcomes, with generalization to other domains; (3) are long-term; (4) are delivered close to patients' natural environments; and (5) combine skills training and environmental support. However, despite improved knowledge about approaches to psychosocial rehabilitation, a wide discrepancy persists between efficacy in trials and effectiveness (what is actually implemented in naturalistic settings). Administrative, financial, and organizational barriers need to be broken down by obtaining evidence-based new information and disseminating such knowledge to the relevant professional groups, advocacy groups, and policy makers.

*—Matcheri Keshavan*

***See also*** Case Management; Mental Illness; Psychiatric Disorders; Schizoaffective Disorders.

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The Schizophrenia Patient Outcomes Research Team (PORT) Treatment Recommendations, http://www.ahcpr.gov/clinic/schzrec.htm#treat

## SCOLIOSIS

A condition of the lateral deviation of the spine, scoliosis has been documented in skeletons dating from at least 26,000 years ago. One of the first medical descriptions of scoliosis occurs in the *Hippocratic Corpus* from the fourth century BCE. Historically, there are many examples of figures, both prominent and less so, who reputedly had scoliosis, ranging from Tutankhamun to Richard III.

As a clinical condition affecting between 3 and 30 percent of the U.S. population, scoliosis can exist at birth or be acquired from trauma, infection (e.g., tuberculosis), or disease of the nerves and muscles; the most common cause is from unknown causes (idiopathic). Scoliosis is categorized as congenital, infantile, juvenile, adolescent, or adult (degenerative) in onset. Either static or progressive, scoliosis can lead to pain, weakness, impaired breathing, or death from a compromise of lung function. "Discosmetic" effects are suggested by the term *hunchback.* Kyphosis, a condition in which there is forward deviation of the spine, is frequently associated with osteoporosis (e.g., "dowager's hump"). Contemporary Western medicine characterizes scoliosis by the anatomical location of the curvature, the severity of the curvature, and progression. Intervention varies from observation (the most common therapy) to bracing and casting (usually until growth of the bones has stopped) to surgical correction, including fusing vertebrae together or the introduction of stainless steel rods to maintain the straight position of the spine.

Scoliosis as an object of focused medical intervention started in the late eighteenth century and had an early peak in the 1830s in France with the rise of a bourgeoisie concerned about their posture and its implications for employment and marriage. Putative correction through exercise, bracing, regimental programs, and proprietary devices was the means through which a variety of kinds of medical practitioners competed for clientele. Orthopedists, early therapists, nonsurgical physicians, and nonprofessional healers all offered therapies. With the advent of anesthesia and antiseptic/aseptic surgery in the mid- to late nineteenth century, orthopedists increasingly "won" this competition. The invention of the X-ray examination of the spine gave investigators a tool to make numerical studies of scolioses and gradually allowed them to gather enough epidemiologic knowledge to create decision rules about when to intervene. By the early twentieth century, pediatricians began to include examination for scoliosis in their emerging "routine" physical examination of schoolchildren. The other significant interventional tool has been pulmonary and cardiovascular evaluation. The first artificial disk was cleared by the Food and Drug Administration in June 2004. While the physical effects of scoliosis can be significant, inspiring the above medical developments, the physically and psychologically damaging effects of medical interventions over the centuries have been equally profound. That history has yet to be written.

In literature and art, scoliosis has often been a trope for indicating the outcast or menacing character, such as Shakespeare's Richard III. This theme has led some to argue that people with severe scolioses were burdened with unfortunate fates in premodern cultures. Nevertheless, figures such as the hunchback, Quasimodo (meaning "partially formed"), in Victor Hugo's *Notre-Dame de Paris* show that individuals with scoliosis were also employable and could evoke respect as well as pity.

*—Walton O. Schalick III*

***See also*** Orthopedics; Pain; Spinal Cord Injury.

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## ▣ *SCOTT AND DISABLED PEOPLES INTERNATIONAL (AUSTRALIA) v. TELSTRA* (1995)

The decision in *Scott and Disabled Peoples International (Australia) v. Telstra,* handed down following a four-day Human Rights and Equal Opportunity Commission (HREOC) inquiry in 1995, represents a watershed in telecommunications policy for people with disabilities. The commission found Australia's national carrier, Telstra, guilty of discrimination against the class of people with severe hearing or speech impairments. In particular, a joint complaint from Geoff Scott and Disabled Peoples International (Australia) (DPI(A)) claimed the carrier exercised indirect discrimination for not providing them with access to teletypewriters (TTYs) on the same basis as others obtained standard telephone handsets (T200s) to access the telecommunications network. The findings of the committee were as follows:

> In my opinion, the services provided by the respondent are the provision of access to a telecommunications service. It is unreal for the respondent to say that the services are the provision of products (that is the network, telephone line and T200 [standard handset]) it supplies, rather than the purpose for which the products are supplied, that is, communication over the network. The emphasis in the objects of the Telecommunications Act (s.3(a)(ii)) on the telephone service being "reasonably accessible to all people in Australia" must be taken to include people with a profound hearing disability. (Human Rights and Equal Opportunity Commission 1995:12)

At the time, Australians requiring TTYs paid approximately $600 for the equipment.

The case tested the application of the Disability Discrimination Act of 1992 and the inclusiveness of the definition of universal service obligation (USO) in the Telecommunications Act of 1991.

The Telstra lawyers claimed that the carrier was not discriminating against anyone because people had a right to use its services or not. Primarily, the counsel acting for the carrier claimed that it was not in the business of supplying specialized equipment but a standard service that gave access to the telecommunications network. Furthermore, Telstra revealed that it had supplied millions of dollars of free and heavily subsidized services to Australians with disabilities.

The complainants argued that the carrier exercised discrimination against hearing- or speech-impaired consumers by placing unreasonable conditions for network access, which are not required of most in the wider community. Furthermore, Scott and DPI(A) argued that Telstra's corporate generosity was irrelevant to the issue before the commission.

The commissioner, Sir Ron Wilson, accepted Telstra's claim that it had no obligation to provide a new service as stated in section 24 of the Disability Discrimination Act. However, Wilson also accepted the complainants' argument that they were not seeking a new service but access to the existing service that formed Telstra's social obligation under the USO.

Wilson's statement at the beginning of this entry identifies the telephone service primarily as a social phenomenon and not a technological system or even a market commodity. Once a social context is used as the defining environment in which the standard telephone service operates, it is difficult to dispute the claim that *all* does not include people with disabilities. Part of the service includes the point of access in the same way that a retail shop front door is a point of access for a customer to a shop. Consequently, the disputed provision is not a new or changed service but another mode of access to the existing service. Furthermore, the commissioner ruled that Telstra exercised illegal discrimination by refusing to accommodate those affected with modified access to the network in the form of affordable access to TTYs, which would not place unjustifiable financial hardship on the national carrier.

The HREOC inquiry represents a tension among discourses of disability. Arguably, the respondent framed disability within charity and market models of policy, which emphasize corporate philanthropy, dependency, and profit maximization. In contrast, the complainants framed disability within a rights model that emphasized the legislated entitlement of citizen-consumers as active political subjects. The success of the action resulted in new provisions for the Deaf community and people with severe speech impairments in the Telecommunications Act of 1997, which provided affordable equitable access to TTYs and associated services.

*—Michael Bourk*

***See also*** Disability in Contemporary Australia; Disability Studies: Australia; Worksite Modification.

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## SEATING AND POSITIONING

The term *seating* refers to all components (seat cushion, back support, external body supports) that assist a person in achieving and maintaining a sitting position. This includes items that individuals use daily such as dining room chairs, desk chairs, couches and seats in automobiles as well as specialized supports designed for individuals with disabilities.

The term *positioning* means placing and maintaining a person in a specific postural alignment such as sitting, side lying, standing, supine, or prone. Some examples of positioning devices include seats, back supports, and standing devices. For all individuals, the primary goals of positioning are to maximize an individual's comfort, support, and function to allow participation in a given task. For individuals with disabilities, additional positioning goals include improving postural alignment and stability, improving motor control, preventing or minimizing contractures and deformities, and improving sensory and bodily functions.

Typically, an individual's seating and positioning needs are assessed with relation to wheelchair mobility (either manual or electric powered). The purpose of the assessment process is to determine the postural needs of an individual and relate those needs to appropriate positioning components and methods of mobility. An individual or a team of individuals with specialized experience and training in the field of seating, positioning, and wheeled mobility devices performs the evaluation. These individuals can be (but are not limited to) physical therapists, occupational therapists, and rehabilitation engineers.

An individual's seated posture is assessed in parts and as a whole. The alignment of the pelvis is typically assessed first because this is the base of support in a seated posture. Once a functional pelvic position is established, the alignment of the lower extremities, the spine, and ultimately the head and neck position is assessed and established. Emphasis is placed on the individual's ability to perform functional tasks from this position.

Typical cushion materials used in manufacturing specialized seating include foams, air, and viscous fluids. The materials can be used alone or in combination with each other to create a support surface that matches an individual's postural and pressure management needs. Material properties such as density, stiffness, and envelopment are critical to the decision-making process when selecting a material for a specific application.

There are three main categories of specialized seating systems for use by individuals with disabilities. They are linear/planar, generically contoured, and custom contoured/custom molded.

*Linear/planar cushions.* These cushions (seat or back) are typically made of foam and covered with fabric upholstery (e.g., Lycra, Cordura, vinyl). They are typically flat and provide a firm base of support.

*Generically contoured.* Nearly all seat cushions and back supports available commercially today fall into the generically contoured category because they have a generic, preestablished shape. The shapes, typically, cannot be easily altered but offer general curves and contours to provide a functional base of support for some individuals. They can be made of foam, air, viscous fluids, or combinations of them.

*Custom contoured/custom molded.* These seat cushions and back supports represent the highest end of options. These supports are custom made for an individual to conform to body parts to provide increased pressure distribution and increased postural control. They are typically made of specialized foams.

*—Brenda A. Sposato*

***See also*** Mobility Aids; Rehabilitation Engineering; Wheelchair; Wheelchair, Electric.

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## SÉGUIN, EDOUARD ONESIMUS (1812–1880)

*French physician*

Styled the "apostle to the idiots" by Pope Pius X, Edouard Séguin studied at the *lycées* of Auxerre and St. Louis in Paris prior to learning medicine with Jean Itard and Jean-Etienne Esquirol. Following Itard's halting methods to help the "Wild Boy of Aveyron," Séguin convinced Esquirol of the possibility of teaching "idiots"; Esquirol obtained a post for him at the Bicêtre. Upon the death of his mentors, Séguin also took a post at the Salpêtrière and continued a long string of publications. His meteoric rise in Parisian medical circles was halted after a shadowy falling out with the Bicêtre medical staff and his dismissal in

1843. Despite relative disgrace, Séguin continued a private practice and his writing, including his most influential book, *Moral Treatment, Hygiene and Education of Idiots* (1846). In 1850, he emigrated to the United States, where he helped found a large number of institutions for children with disabilities, finally obtained a medical degree (University Medical College of New York), and died in New York City.

Séguin's influence came from his staunch belief in the heretofore unthinkable educability of those with significant cognitive disabilities, regarded by contemporaries as "idiots" or "backward." His "physiological method" employed exercise and the senses as a lever to stimulate the will, ideas, and thence education; these techniques were influenced by Philippe Pinel's (1745–1826) "moral treatment" of the insane, Rousseauvian ideas of the senses, and Christian socialism, then popular among Parisian mental health reformers. Séguin also absorbed the contemporary Parisian emphasis on comparison with "the normal," and after his MD, his writings increasingly evoked the medical model. Séguin's influence was particularly strong in the United States, especially among those working in institutions for "idiots" and reforming them, helping to remove "the mark of the beast," as a eulogist noted.

—*Walton O. Schalick III*

***See also*** Medicine; Mental Health.

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## SELF-SUFFICIENCY

Self-sufficiency is a goal that the disability rights movement has promoted, challenged, and redefined in its quest to increase options available to people with disabilities. Some advocates view self-sufficiency as an impossible standard that should be rejected in favor of recognition of universal interdependency. Others claim self-sufficiency as a right to which all are entitled, including those who may need support to exercise it.

Historically, Western culture has put a high value on self-sufficiency, defined as the ability to provide for one's own needs with minimal assistance or support from other people. In this light, the goal of self-sufficiency assumes and requires that all individuals are equally capable of functioning within the existing environment. By this definition, which many disabled people were unable to fulfill, disability was seen as inadequacy and as a reason to exclude people with disabilities from social roles and benefits. Without the capacity to be completely self-sufficient—for instance, because of a need for physical assistance, extra learning support, or other help—people with disabilities were judged unfit to compete and thus undeserving of equal resources, rights, and responsibilities. Dependency, neediness, and failure were therefore deemed to be the inevitable consequences of disability.

Because of this bias, disabled people who could not be entirely self-sufficient (i.e., those who need assistance or support) have often had to forfeit some of the basic choices and opportunities that other citizens take for granted. For example, people needing help with dressing, eating, and other activities of daily living are often forced by public policy to enter a facility, the only setting in which an adequate level of support is available. People who need publicly subsidized health care coverage and/or in-home support services may have to forego employment because poverty is a precondition for eligibility. These forfeited choices and opportunities, mandated by social conditions and political decisions, tend to undermine disabled people's self-sufficiency much more than the disabilities themselves.

Beginning in the 1970s, the U.S. independent living movement has put forward a new view of disabled people as being capable of independent choice and responsibility, even if not capable of fully independent functioning. Independence, these advocates insisted, is not a matter of doing everything unassisted but of making one's own decisions without penalty or coercion. Some explicitly rejected the concept of self-sufficiency, arguing instead for self-determination. Others have used the terms *self-sufficiency, self-determination,* and *independence* more or less interchangeably.

Currently, the term *self-sufficiency* is most often used in the context of employment and the ability to support oneself financially. For example, in the preamble to the 1990 Americans with Disabilities Act (ADA), Congress found that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency" (ADA 1990, sec. 2(a)8).

*—Laura Hershey*

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

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## SEQUOYAH (1770?–1843)

*Cherokee warrior who devised the Cherokee alphabet*

Disabled due to a swelling on his knee, Sequoyah (1770?–1843) was made lame by the shortening of his diseased leg. While his lameness prevented him from becoming a foot warrior, he participated as a horse-mounted combatant, serving in the Cherokee regiment under Colonel Gideon Morgan against the 1813 Alabama Red Stick Creeks in the Battle of Horseshoe in General Andrew Jackson's campaign. Though lame, Sequoyah led his people, the Cherokees, to heights untenable to other Native American Indians: the path to literacy. He analyzed and reduced a complex inflected multidialect language to 85 (originally 86) minimal sound units, to each of which he attached a particular symbol. A daughter assisted him during the arduous process. Completed by 1819 and spread by 1821, this writing system allowed Cherokees to become literate almost overnight and culturally revitalized. Sequoyah's discovery of the concept of the phonemic structure predated academic linguists one hundred years. Fascinated with European American writing styles that he named "talking leaves," he worked tirelessly to bring all Cherokees together through his unique writing convention. Correspondence between east and west Cherokees could easily be facilitated because the efficiency of the syllabary permitted Cherokees to become proficient writers with a few days' study.

Born in the prehistoric capital, Echota, on the Little Tennessee River in what is now Monroe County (Tennessee) between 1760 and 1770, Sequoyah left his ancient village among the Overhill Cherokees and migrated south as far as his territory would take him, then to Willstown, in what is now DeKalb County (Alabama). He followed other Cherokees who had been moving south for decades to escape border ruffianism.

After introducing his writing style to Cherokees in the East in 1821, he migrated to the Arkansas Territory in 1822 to join fellow Cherokees, who had left the East for the West. There he continued to teach his syllabary. After the infamous Trail of Tears (1838–1839), whereby eastern and western Cherokees reunified their nation in Indian Territory, Sequoyah's syllabary was the nucleus of unification for both traditional and acculturated Cherokees. Cherokee shamans recorded sacred formulas for ceremonial purposes in the syllabary. The power of his writing convention facilitated his teaching of the syllabary to Cherokees in the Indian Territory and those living beyond its borders.

Seeking to usher in literacy among as many Cherokees as possible, in 1842, Sequoyah left the Cherokee capital Tahlequah (Oklahoma) in an oxcart for Mexico, where he hoped to create literacy among Mexican Cherokees. In 1843, Sequoyah died in northern Mexico before his companions, once alerted to his grave condition, were able to get him assistance.

*—Rowena McClinton*

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## SERBIA

*See* Experience of Disability: Serbia

## SEX INDUSTRY, INTERNATIONAL

The term *international sex industry* includes prostitution and prostitution-related activities; the pornography industry; the sex-related entertainment industry, including phone sex and Internet sex services; syndicates involved in the trafficking business in persons and drugs; travel agencies that promote sex tourism; and other related activities. Commercial sexual services also include paramedical areas such as sexual surrogate therapy. The relationship between disability and the sex industry has become increasingly visible globally as the sexuality of people with disabilities has emerged as an important issue.

Due to the heavily gendered aspect of sex commerce—typically involving men as buyers and women as sellers—any discussion of the sex industry requires attention to the issue of gender as well as disability and other categories of inequality. The gender dynamic involved in the operation of the sex industry complicates the position of disabled women and men but also highlights the limitations of considering "disabled people" as a unified category. Another important factor is the global dynamic associated with commercialized sex, which exploits disabled and nondisabled women from the non-Western world for the benefit of men from wealthier countries.

### DEFINITIONS AND SCOPE OF THE INTERNATIONAL SEX INDUSTRY

The international sex industry is a multi-billion-dollar concern operating all around the world. Income from the sex industry supports a massive underground economy of pimps, procurers, and organized criminals, as well as multinational conglomerates operating hotels, airlines, and tourist industries. Definitions of the sex industry from feminist perspectives have emphasized its financial aspects and its power differentials. Brock and Thistlethwaite (1996) define sex industries as the institutionalized sexual use by more powerful members of male-dominant societies of the less powerful. One of the most important elements of the international sex industry is trafficking in human beings, which usually targets vulnerable sections of the population, including disabled people. Human trafficking has been defined in the "UN Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children" in the following manner:

> Trafficking in persons' shall mean the recruitment, transportation, transfer, harboring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include, at a minimum, the exploitation of the prostitution of others or other forms of sexual exploitation, forced labour or services, slavery or practices similar to slavery, servitude or the removal of organs. (see http://www.state.gov/g/tip/rls/fs/2005/43630.htm)

The United Nations reports estimate that 4 million women have been trafficked, both within countries and from one country to another. U.S. reports estimate that between 700,000 and 2 million women and children are internationally trafficked each year for the sex industry and for labor (Richard 1999). Most of the victims of human trafficking are women and children, and they are often moved to other countries where they are isolated and essentially enslaved. The sale of mail-order brides and sex tours are important dimensions of human trafficking. Mail-order brides are typically from Asia and Eastern Europe and are often promoted as conforming to more traditional, "feminine" notions of womanhood than their Euro-American counterparts. In 1998, the International

Labour Organization (ILO) estimates of the number of prostitutes in Indonesia ranged from 140,000 to 230,000; in Malaysia, from 43,000 to more than 142,000; in the Philippines, from 100,000 to 600,000 (and the ILO suggests that 500,000 is a more reliable figure); and in Thailand, the estimated number of prostitutes in 1997 was between 200,000 and 300,000. Such figures are not unique to Asian countries—an article in the *New York Times* by Michael Specter in 1998 estimated that approximately half a million women are also trafficked into Western Europe every year. The European Conference on Trafficking in Women in June 1996 claimed that women from Africa (Ghana, Nigeria, Morocco), Latin America (Brazil, Colombia, the Dominican Republic), South East Asia (the Philippines, Thailand), and Central and Eastern Europe (Czech Republic, Hungary, Poland, Romania, Russia, Ukraine) were being trafficked into the European Union in large numbers.

The key issues regarding disability and the sex industry can be identified as follows: (1) disabled people's entrance to the sex industry in various forms as workers, (2) disabled men's access rights to prostitution or pornographic material as consumers, (3) seeking destigmatized or legalized prostitution by relying on a rationale that it is necessary for disabled men, and (4) advocating for medically prescribed sexual services (not involving prostitution) such as sexual surrogacy for disabled people, with an emphasis on the psychological benefits of sex for self-esteem.

## DISABLED PEOPLE'S ENTRANCE TO THE SEX INDUSTRY

Disabled people are employed as sex workers in a number of fields. Some customers specifically look for certain attributes in prostitutes—such as disability—as a form of sexual fetish. It is becoming increasingly common for a "disability fetish" to be advertised on commercial Internet sex sites. There are niche markets for videos of disabled women having sex, pictures of naked amputees, and pictures of naked little people. For instance, recent videos include *Gimp Lovin, Roped Gimp, Gimp Pain,* and *The Gimp Sees a Doctor.* Websites such as "criptease.com" or "disabilitypayperview.com" sell photos and videos of fantasies involving disabled people who use wheelchairs and braces, who are amputees, who use strong glasses and other ocular devices, or who have leg casts. Often, these sites involve disabled women from Asia or Eastern Europe—such as Romania and the former Soviet Union. Similarly, there are devotees whose fetish involves other impairments, such as blood clotting. Calendars showing naked disabled people are also available and are advertised under such titles as "Gimps Gone Wild." A related fetish is the "medical fetish," which is also served by the commercial sex industry, through the production of videos of people receiving medical examinations, enemas, and so on. This industry also sells medical equipment such as neck braces, straitjackets, electrostimulators, catheters, mouth spreaders, and speculum (http:// www.medicaltoys.com/enemas.htm).

It has also been noted that the technological involvement in the sex industry, including Internet and phone connections, has resulted in an increase in both the number and the nature of sexual workers. In particular, there has been an increase in sex work outside of the sphere of genital contact. Many disabled women have been recruited into the industry in this way. For instance, increasing numbers of women with physical disabilities have been employed in the phone sex industry. In South Korea, it is reported that women with cognitive or physical disabilities have been procured and forced to prostitution. Disabled women often enter into traditional prostitution as the lowest and cheapest commodity due to their extremely marginalized status (commonly lacking resources and education and having a history of sexual abuse). *The Women's News* reported in 2003 that the Coalition for Eradicating Sex Trade of Women with Disabilities and the Rescue Hotline have been recently installed to deal with this problem in South Korea. In Zimbabwe, forced marriages and prostitution put women and girls, including the disabled, in danger of contracting sexually transmitted diseases or HIV/AIDS. This seems to be more serious for women and girls with disabilities as they are being sexually abused and raped by people who believe that HIV/AIDS can be cured by having sex with someone with a disability.

While Indian women and girls are trafficked into Kuwait and other Middle Eastern countries for purposes of prostitution, disabled Muslim children, primarily girls, are trafficked to Saudi Arabia for the purposes of begging or being sold into brothels. Hwang and Bedford (2003) reported that mentally disabled girls and other aboriginal girls were forced into indentured prostitution and kept in control with violence, deception, indebtedness, and affection in Taiwan. In China, the most common traditional image of the blind woman is a prostitute. Traditionally, blindness became an advantage in a prostitute, presumably because the client's own identity and defects were thereby spared any scrutiny.

## DISABLED MEN'S RIGHT TO COMMERCIAL SEX AS AN ACCESS ISSUE

Some Western disability rights movements have made a connection between disabled people's sexual rights and the need to use commercialized sex. Sexual liberalism arose among disability activists to challenge discriminatory attitudes prohibiting and controlling disabled people's sexuality. Sexual liberalism suggests that disabled people should have equal access to prostitution and to other kinds of paid sexual services that are available to able-bodied citizens. This argument sometimes asserts that the cost of such commercial sexual services should be covered by a state welfare fund. It is proposed that prostitution is often the only way disabled people can have sex or even close physical contact with another person. This approach emphasizes the private and personal nature of purchasing a sex service. It is based on an individual's personal choice, and the fact that disabled customers can enjoy themselves away from their families and personal assistants is a sign of independence, which is thought to be a key element in their pleasure as sex industry consumers.

In addition to being positioned as an access issue, within sexual liberalism, disabled people's right to hire prostitutes often falls within a discourse of consumerism. There was a disabled Dutch man who fought a seven-year battle to win a 1997 court ruling giving him a monthly allowance for using the sex industry, paid by his council (Ananova 2005). Following the lead of a Dutch town that implemented a similar program, Ivo Konings, a city councilor with a disability in Hasselt, Belgium, proposed to give disabled men money to visit prostitutes. Konings, a former adviser to the Belgian government, consulted an organization of prostitutes in Hasselt about providing discounted rates for disabled customers and education for prostitutes. However, conservative arguments promote the abstinence of disabled people by emphasizing the potential danger of sexual activities to physical and mental health. Religious ethics forbid disabled men from seeking an "alternative" way of having sexual lives as well. Responding to such conservatism, the liberal approach is often paralleled by moves for the legalization of prostitution, with the prostitutes' rights movement asserting the necessity of their work in terms of disabled people's needs. In this way, disabled people's campaigns for practical solutions that will enable them to have access to sexual relationships converge with the efforts of the sex industry to promote access for "special" customers. For example, the Netherlands Prostitution Information Center provides tips for disabled customers on its website.

The Pink Palace in Melbourne also gained favorable media attention by carrying out building modifications that made their premises more accessible. Its new features included enlarged doors to accommodate wheelchairs and the installation of a sit-down shower. George Taleporos (2001), a researcher in the area of sexuality and disability, said in a BBC interview that many disabled people used prostitutes and brothels because it is difficult to date in the "usual" way. In Australia, the Accsex Network aims to provide disabled people with "therapeutic help" and access to sex services. The name *Accsex* stems from a combination of the words *access* and *sexuality.* Two of the major achievements of Accsex were establishing a fund by the Eros Foundation (Australia's sex industry trade union) to financially assist people with physical disabilities on low incomes to access the sex industry and raising awareness with attendant care providers about the need for "sex attendants" or attendant carers who are prepared and trained to assist their clients in sexually related activities. These activities, according to Taleporos, may include, among other things, "visiting a brothel, having sex with a partner, being assisted to purchase or use erotica or sex toys or providing assistance with masturbation."

The issue of access to pornography in alternative formats and assistance to purchase pornography has been controversial. A Braille copy of *Playboy* was provided by the National Library Service for the Blind and Handicapped in the United States, but Congress banned later funds for its production. Many people in the disability rights movement saw this as the violation of the First Amendment of the U.S. Constitution. Of course, disabled people are not only consumers of pornography but also may be its objects. For instance, the June 1987 *Playboy* employed disabled female Ellen Stohl. Ellen Stohl sought to express her sexuality by being included in the sex industry. The position of nondisabled caregiving women complicates the arguments regarding the right of disabled people to access the sex industry. A number of specialty brothels are provided for disabled men, and state-employed caretakers, who are mostly women, must take these men to the brothels if they wish to go. The competing rights of these women to be free from an environment that they may find objectionable and objectifying complicates the argument that disabled men, as their employers, have an unfettered right to access the sex industry.

## USING DISABILITY TO DESTIGMATIZE PROSTITUTION

In contrast to the movement to end prostitution entirely, sex workers and some feminist movements have advocated decriminalization of all prostitution between consenting adults and have promoted the destigmatization of prostitutes. The need to sexually serve disabled people is often employed as a rationale for justifying prostitution in this context. Some sex workers find pride and identity in their roles, particularly when they define themselves as sex experts helping people with disabilities. In this paradigm, sexual exchange between a disabled man and a prostitute is perceived as friendly, mutual, supportive, and therapeutic. The asexual or emasculated image of disabled men can position disabled men as naive and in need of care, and prostitutes become seemingly authoritative in terms of sexual experience and knowledge. The power domination and violence prevalent in some feminist criticisms of prostitution are often assumed to be absent in prostitution relationships involving someone with a disability. In 2003, when New Zealand passed the Prostitution Reform Bill that decriminalized prostitution, it was argued that access to prostitution improves the lives of disabled people. The Green Party argued that prostitution was often the only way people with disabilities could have sex or even close physical contact with another person.

The call for respect for prostitutes, improvements in their conditions of work, and acknowledgment of prostitution as a profession has been addressed in a number of concrete schemes. For instance, as Shrage (1994) points out, as a result of the growing AIDS risk in the international sex industry, there have been some attempts to promote the medicalization of sex services and the licensing of prostitutes as “sex providers” with college-level education to assign social authority. The 1997 International Conference on Prostitution included the workshop on “Sex Work, Sex, and the Disabled.” Sex surrogates working with a variety of disabled people called on fellow sex workers to deal with disabled clients with particular care and sensitivity. In this context, the label *sex surrogates* refers to prostitutes who specialize in dealing with disabled clients.

Tuppy Owen, organizer of Britain’s annual Sex Maniac’s Balls, which raise funds to “help handicapped people find love,” has gone so far as to describe neighbors, friends, and hospital staff who masturbate people who are unable to masturbate themselves as “sex angels” (Steinberg 1997). Another argument that is used to justify prostitution is that it provides sex for persons who would otherwise be deprived of sex, for example, male migrant workers without their wives, disabled or old men, or men in the military. However, in responding to these arguments, feminists who are against prostitution argue that this argument is underpinned by an assumption that men, in any and every circumstance, must be able to have sex. Feminist organizations have made a strong stance against the exploitation of women, including disabled women, by the commercial sex industry.

In the words of Australian activists Mary Sullivan and Sheila Jeffreys (2001), from the Coalition Against Trafficking in Women,

> So normalized has brothel become that the sex industry markets itself as promoting the “rights” of people with disabilities by specifically catering to men and disability charities. Disabled men are seen as a good

> market opportunity by the legalized sex industry, and carers are expected to help these men engage in the abuse of women in brothels, or at least deliver them and wait in the lounge. It is the "rights" of men that are being catered to here. Disabled women are not mentioned.

## MEDICALLY PRESCRIBED SEX SERVICES FOR DISABLED PEOPLE

Medicalized practices around disabled sexuality are another axis in the discussion of disabled men's participation in the sex industry. The sexological invention of sex therapy (more specifically, sexual surrogate partner therapy) has been employed for disabled men from the early 1980s in the United States. In this approach, sexuality is considered as a psychological and biological necessity for life and has to be promoted in a certain way. Disabled people's access to such sexual experiences and commercial sexual service first emerged in clinical settings. Promoters of sexual surrogacy for disabled people tend to distinguish sexual surrogacy from prostitution by arguing that sexual surrogates provide more than sexual service to the clients with whom they work. They attempt to meet the special psychological needs of clients and emphasize the therapeutic effects of their work. The term *partner surrogate,* suggested by Masters and Johnson (1970), refers to the partner provided for an unmarried man referred for treatment, who has no one to provide psychological and physiological support during the acute phase of his therapy. In the 2002 volume of *Disability Studies Quarterly,* it was suggested that disabled people should have the cost of hiring sexual surrogates incorporated into Ontario's government-sponsored personalized funding program presumably because sexual surrogacy functions as a real and meaningful form of erotic communication and self-realization and is practiced widely in the United States.

However, as Noonan (2000) points out, sexual surrogate therapy tends not to address heterosexual disabled women since heterosexual male surrogates remain the most rare of sex surrogates. Despite the fact that the concept of sexual surrogacy came from medical sex therapy discourse and was associated with professional discourse through the involvement of the team therapist, a licensed and/or certified professional with an advanced degree, sex surrogacy is actually more likely to exist within a continuum of sex industry practices. European advocates of sexual surrogacy are closely related to prostitute/sex worker organizations. The employment of sex therapy for disabled people's sexual experience or "fulfillment" in the rehabilitation paradigm is a relatively recent combination. Sex therapy has been mostly dedicated to the problems of able-bodied males who experience general anxiety over fulfilling cultural standards of masculine sexuality. Many sex therapists are not members of the medical profession. However, as researchers such as E. J. Haeberle (1983) suggest, there are tendencies on the part of many therapists and promoters to borrow respectability and authority from the medical establishment.

Even though sexual surrogates are supposed to be paid to aid people to express and develop their sexuality and not to give sexual gratification, there have been criticisms that sexual surrogates are simply providing medicalized and institutionalized sex. There have also been suggestions that surrogacy places disabled people's sexuality in the medical area alongside many other therapies; Shakespeare, Gillespie-Sells, and Davis (1996) and O'Brien (1990) both argue that suggesting sex workers require "special" training to engage in sexual activity with a disabled person can be seen as reinforcing the medical model of disability and ignoring institutional oppression and societal barriers, which are some of the causes of imposed celibacy.

A Swiss organization, Pro Infirmis, launched the "touchers project" in Zurich in June 2003 and publicized this project internationally. The pilot scheme involved training 12 professional "touchers" under the guidance of Dutch disabled sex pioneer Nina de Vries. Service would range from massage, body contact, stroking, holding, and bringing people to organism. "The successful applicants were then expected to offer sexual and emotional relief to the Zurich disabled community." However, after this project was announced, the organization suffered a significant reduction in donations. Pro Infirmis decided to end its direct involvement in the project and announced that it was looking for an independent association to take over. Similar programs were known to be running for years in Germany, Denmark, and the Netherlands, where it was called *Stichting Alternatieve Relatiebemiddeling*. The expansion of "therapeutic sexual services" for disabled people has therefore opened up new occupations for sex workers, sexual counselors, and surrogates.

The concept of sexual surrogacy came from a medical sex therapy discourse and seems to evoke a sense of professionalism because it involves a team therapist who is a licensed and/or certified professional with an advanced degree. However, sex surrogacy should still be understood in the context of a massive worldwide effort to make profits out of the sex industry. Often, sexual surrogates simply refer disabled people to sex workers who are prepared to have sex with them. In effect, *sex surrogacy* is interchangeable with *prostitution* in its implementation.

## CONCLUSION

The international sex industry is a large-scale industry that includes prostitution, pornography, sex-related entertainment such as phone sex and Internet sex services, sex tourism, and other related activities. Representatives of the international sex industry often use disability to justify their existence by suggesting that commercial sex is the only way of helping disabled people meet their sexual needs. Commercial sex activities are also commonly discussed in a medicalized discourse, such as when they are euphemistically referred to as "therapy." At the same time, sex therapy in medical settings provides programs for disabled people who presumably have problems in sexual relationships. Sexual surrogate therapy emphasizes its psychological benefit to disabled people. However, the fact that the sex industry largely involves women from the non-Western world and many disabled women performing sexual activities for the benefit of men from wealthier countries makes it difficult to sustain the arguments that access to the commercial sex industry is an issue of "equal rights for all." Instead, this argument seems to involve an extension of male privilege to include disabled men, with little regard for the women who work in the industry, including the disabled women who work in prostitution, phone sex, pornography, and other related fields. It has been noted that the expansion of sexual services, facilitated by technological developments, has increased the number and nature of sexual workers, especially outside the sphere of genital contact. Expansion of the therapeutic sexual service area has also opened up new occupations for sexual counselors and surrogates. Such specialized sexual services are often used to justify the existence of sexual labor in general.

*—Eunjung Kim and Mark Sherry*

***See also*** Accessible Internet; Gender; Sexual Access; Sexuality.

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## SEX THERAPY

Sex therapy offers treatment for problems of sexual function and expression. A professional therapist will use specialized clinical skills to help individuals and couples to overcome sexual problems. The types of issues that clients present with include loss of desire, erectile dysfunction, premature ejaculation, pain on intercourse, and communication or other relationship problems. Many individuals are uninformed or unconfident about sexual issues. Many people experience sexual problems at some point in their lives.

Sex therapy is of particular relevance to disabled people. Some impairments may lead to loss of feeling or to difficulty in achieving sexual positions or performing sexual acts. Others may affect body image and lead to the individual feeling abnormal or unattractive. Those who are born with impairment may have been treated as asexual. They may not have received sex education or support in developing their sexuality. Some individuals may also not have been able to express feelings of same-sex attraction due to dependence on family and carers. Those who become impaired may believe that their sexual lives are over. They may experience this reaction from family, friends, and medical professionals. These attitudes may undermine self-esteem, self-confidence, and sexual expression. Disabled people's sexual problems are social and cultural as well as medical and physical: experience of social exclusion and disempowerment may be as important as particular functional issues.

Sex therapists should be trained in sexual anatomy and physiology, have counseling or therapeutic training, have the experience of relationship counseling, and adhere to a professional code of ethics. A series of sex therapy sessions will start by identifying problems and then finding solutions. A program of exercises and activities may be devised for the client(s) to do at home.

Sexual surrogacy is a separate and more controversial form of sex therapy in which an individual with sexual problems is referred by a sex therapist to a sexual surrogate, who will engage in sexual activity with that individual. Whereas sex therapy may work on emotional problems and may offer advice and exercises, sexual surrogacy works with bodies and offers practical sexual activity to resolve difficulties. The dividing line between sexual surrogacy, facilitated sex, and sex work or prostitution may be blurred and may not be recognized by law in some jurisdictions. Disabled people, who may have had difficulties forming relationships and may have issues with sexual activities or with body image and confidence, are commonly cited as potential beneficiaries of sexual surrogacy services.

Sexuality is an important part of self-identity; therefore, sexual problems may be experienced as undermining and distressing in general. Sexual rights have been neglected within both traditional rehabilitation services and the disability movement's campaigning and advocacy work. Disabled people have the same needs as nondisabled people, and sex therapy and sex education should be regarded as priorities alongside more obvious goals such as independent living, employment, and education.

***See also*** Identity; Sexuality.

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British Association for Sexual and Relationship Therapy, http://www.basrt.org.uk

Relate (U.K. agency offering relationship counseling), http://www.relate.org.uk/sexproblems/sextherapy

Sexual Health (advice and support website founded by a disabled man, with a particular attention to disabled sexuality), http://www.sexualhealth.com

## SEXUAL ACCESS

Despite an increase in critical approaches to disability, gender, and sexuality (Shuttleworth 2000b, 2003; Shuttleworth and Mona 2002), researchers need to develop conceptual frames that can be applied to a wide range of relevant issues and also assist in politicizing these issues. The concept of sexual access has recently been proposed to fit the bill for elucidating both the impediments and avenues to sexual well-being for disabled people (Shuttleworth and Mona 2002; Shuttleworth 2003, forthcoming; Grossman, Shuttleworth, and Prinz 2004). Application of the cornerstone disability studies concept of access has traditionally been limited to easily demarcated contexts such as schools, workplaces, and the built environment. A legalistic and technical understanding of the term has held sway that does not appreciably alter even when programmatic access becomes the analytical target (see, e.g., Burgstahler 1994). Embodied feelings, communicative processes, and the symbolic aspects of disability are usually not taken into account. Yet in terms of disabled people's sexual issues, these aspects are often the most crucial to interrogate.

Conceptualization of sexual access as it is developing in disability studies must be clearly differentiated from a similar term used by bioevolutionary scholars to refer to the degree to which males of a species have access to sex with females (e.g., Buss 1994). Instead, sexual access as theorized by the above disability studies researchers encompasses several related meanings. First and foremost, interpersonal sexual negotiations are viewed as situated within a cultural and sociostructural framework of inclusion-exclusion. It is important to interrogate not only sexual negotiations themselves but also multiple aspects of this framework to discern the degree to which these aspects work toward access to sexual expression and sexual relationships for disabled people. Depending on a disabled person's particular situation, relevant aspects of this framework may include physical access to environments and social contexts in which sexually relevant interpersonal encounters may occur, monetary access, programmatic access to personal assistance services, access to transportation, communication access, and many others. Perhaps the most powerful impingement on disabled people's interpersonal sexual negotiations, which presents formidable difficulties for systematic investigation, is the adverse context of cultural images and meanings of disability and sexual desirability.

Sexual well-being is reliant on psychological, social, and cultural supports that sustain a positive sense of one's sexual self. The availability of these supports for disabled people is another sense by which sexual access or exclusion may be gauged. Disabled people, whether it is in their families of origin, institutional contexts, or in the society at large, often experience a lack of support for their sexuality. For instance, people with early onset impairments often report that family members do not expect them to experience a sex life and marriage (Shuttleworth 2000a, 2000b; Mona and Gardos 2000; Shakespeare, Gillespie-Sells, and Davies 1996; Rousso 1993). One example of the way psychological, social, and cultural supports might reinforce each other to promote disabled people's sexual access and sexual well-being is if disabled people were represented in more sexually positive ways in the media. For some disabled people, this more positive sexual representation might result in a more positive sexual self-identification and heightened sexual self-esteem, which might also result in many nondisabled people perceiving them in a more sexual light.

A final sense in which the concept of sexual access might be fruitfully used is in interrogating the formation of gender and sexual identities for disabled people. For significantly disabled people, especially those who live in more structured living environments such as nursing homes and group homes, access to opportunities for sexual and gender expression may be limited given the multiple social restrictions operating and minimal sociocultural support within these institutions (Shuttleworth and Mona 2002; Hamilton 2002; Wade 2002). The question that needs to be asked is to what degree can one form a sexual or gender identity (normative or not) and a sense of one's self as a sexual agent in these kind of living environments.

The concept of sexual access can thus be used to critically frame many of disabled people's sexual issues. Use of an access frame importantly situates disabled people's sexuality squarely within a political context on par with other issues on the disability rights agenda (Shuttleworth 2003, forthcoming).

*—Russell P. Shuttleworth*

***See also*** Sex Therapy; Sexuality.

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## SEXUALITY

Historically, people with disabilities have either been regarded as asexual or sometimes as sexually deviant and threatening. The sexuality of people with disabilities has often been ignored by health and social services. If the sexuality of people with disabilities were considered, it was mostly in relation to physiological functioning. The psychosocial influences on the sexual lives of people with disabilities were generally overlooked in favor of purely medically focused models. After the Vietnam War, there was a significant increase in U.S. attention toward physical impairment and sexual functioning in men but sparse recognition of the wider issues.

Today, there is widespread awareness that sexuality is equally important to men and women with disabilities and that sexuality is an integral part of the development and experience of all people. Disability activists have played a strong role in this, campaigning for the sexual rights of people with disabilities to be recognized, including the right to have sexual relationships, the right to be parents, and the right to access sexual services.

Recognizing the physiological, psychological, and social aspects of sexuality is essential to obtaining an understanding of the issues related to the sexuality of people with disabilities. While hormones, the nervous system, and the human body in general play a significant role in regulating sexuality, sexuality is also influenced by psychological characteristics, culture, and society.

### PHYSIOLOGICAL ISSUES AND SEXUAL FUNCTION

Different impairments affect sexual response in different ways, and most disabilities do not affect sexual functioning. However, impairments that affect the sensory pathways, such as spinal cord injuries and multiple sclerosis, are often associated with challenges for people in sexual function. Men can find it difficult to achieve and maintain an erection and ejaculation, and vaginal sensation and lubrication and orgasm can be problematic for women. Some developmental disabilities are also associated with impaired sexual functioning.

### PHYSICAL DISABILITY AND SEXUAL FUNCTIONING

For men with spinal cord injury (SCI), sexual response is likely to be permanently affected in some way. This will vary according to the level and completeness of the lesion and whether a sphincterectomy, which commonly abolishes erectile function, has been performed. Many men with SCI are capable of erections. Erections have been reported to occur in most men within one year following their injury. Those with incomplete upper motor neuron lesions are more likely to have erectile capabilities. The type of erection experienced may be either psychogenic, caused by a psychological stimulus, or reflexogenic, caused by a physical stimulus. Psychogenic erections are more likely in men with incomplete lower motor neuron lesions, and reflexogenic erections are more likely in men with complete upper motor neuron lesions. Ejaculation is less likely than erection because of the common experience of retrograde ejaculation, where the semen is ejected into the bladder rather than the urethral meatus. The frequency of self-reported orgasm is approximately 45 percent.

Vaginal lubrication may remain in women with incomplete injuries at all spinal levels. For women with complete injuries between the T10 and T12 level, there is typically an absence of either psychogenic or reflexogenic lubrication. The act of sexual intercourse may be made difficult as a result of spasticity of the adductor muscles and pelvic floor. It has been reported that 53 percent of women experience orgasm after SCI.

Difficulties with erections may eventually be experienced by nearly half of men with multiple sclerosis (MS), and this is likely to be caused by lesions of the thoracic spine and autonomic nerves. Sexual difficulties, ranging from premature ejaculation to lack of sexual interest and reduced frequency of masturbation, are also common. Women also experience sexual difficulties as a result of MS, including loss of libido and lack of vaginal lubrication. Women with MS also report difficulty achieving orgasm and a decrease in their frequency of having intercourse since diagnosis. Women with MS also commonly report numbness, spasms, fatigue, and painful intercourse.

An inability for people with disabilities to perform sexual acts may be associated with depression and low sexual esteem for the person with the impaired sexual response, particularly when social and cultural values are considered. For example, some may feel like they are not suitable as sexual partners because of their impaired sexual functioning, particularly in Western society, where there is a strong emphasis on sexual performance.

## INTELLECTUAL DISABILITY AND SEXUAL FUNCTIONING

People with intellectual disabilities generally do not experience difficulties in sexual function as a direct result of their impairment. There are a few exceptions of note where the genetic etiology affects sexual development and function of the individual's reproductive capacity. Men with Down syndrome have been observed to have a very low fertility rate and may require reproductive assistance to become a parent. Men with Down syndrome can also experience cryptorchidism (undescended testes). Almost all men with fragile X syndrome experience macrorchidism (enlarged testes), and this is frequently not observed until puberty. Men who have Prader-Willi syndrome can experience cryptorchidism and hypogonadism (smaller testes and penis) and may not develop secondary sexual characteristics (voice breaking, body hair, etc.) due to lower testosterone production.

People who have psychiatric disabilities and are prescribed psychotropic medications sometimes report the medications having an impact on sexual function and libido. This impact may be caused by the impairment itself, a result of side effects from their prescribed medication, or a combined effect.

Women with intellectual disabilities have commonly experienced sterilization, often without their knowledge and consent. Women who have had a hysterectomy at a young age have reported difficulties sexually. Some of these women have experienced menopause at a young age and have difficulties with vaginal lubrication and report sex to be painful.

Many women with intellectual disabilities have described sex as painful. When discussing sex, very few talk about it as a source of pleasure or mention that they have orgasms when they have intercourse. Sex is something that they describe being done to them rather than them having an active role. Much of their experience of sex is from sexual assault. When women with intellectual disabilities describe the consenting sex they have, it is frequently void of foreplay and can often be very hurried, resulting in a painful experience due to poor vaginal lubrication.

Men with intellectual disabilities can also be subject to medical control of their sexuality. The negative perceptions of others toward these men's sexual expression (including masturbation) can result in chemical intervention through the prescription of antiandrogenic drugs that reduce testosterone levels or various forms of confinement or control.

## SOCIAL AND PRACTICAL BARRIERS TO SEXUAL EXPRESSION

While sexual dysfunction relates to specific impairments, other barriers to sexual expression are likely to exist across the range of impairments. These barriers are associated with societal attitudes as well as the physical impediments that are associated with decreased mobility, speech impairment, and a dependence on others for care.

### *Societal Attitudes*

It is widely accepted that the problems people with disabilities face in sexuality more often reflect attitudinal barriers set up by our culture and accepted by both disabled and nondisabled persons rather than actual physical limitations. Furthermore, it is claimed that sexual problems experienced by people with disabilities are more often related to culturally established attitudinal barriers rather than physical limitations.

A common social attitude is that people with physical disabilities are dependent and helpless. This attitude may lead to other assumptions that prevent an able-bodied person from accepting a person with a disability as a sexual partner. For example, the person with the disability may be perceived as very "needy," and a relationship with this person could be viewed as extremely demanding and never equal. This attitude may be internalized by people with disabilities as they come to believe that they will always rely on their families and that their dependency makes them undesirable life partners.

Dominant beliefs held about the sexualities of people with disabilities come from mythologies. People with intellectual disabilities, in particular, are either believed to be oversexed and dangerous because of an innate inability to know what they want and control themselves in a socially acceptable way or they are perceived to be asexual, eternally childlike, and not in possession of adult sexual desires. Other pervasive myths about people with disabilities are that they are unable to parent, conceive, or adequately raise children.

The myth that people with disabilities are asexual or that sex is not relevant to them is also commonly blamed for the exclusion of people with disabilities from sexual activities. This has been highlighted by an increasingly vocal constituency of people with disabilities who have expressed frustration at the social barriers to full participation in life, particularly in the taboo area of sexuality.

According to Tom Shakespeare (2000), a prolific author in this field, where disabled people are seen as sexual, it is in terms of deviant sexuality, for example, inappropriate sexual display or masturbation. Therefore, the sexuality of people with disabilities is more likely to be considered when it is a problem. Shakespeare also argues that there is an unspoken taboo about sexuality and disability, pointing out that disabled people's sexual and emotional needs are rarely included in any discussion or representation in popular culture such as movies, music, and magazines. This reinforces the public's attitudes and expectations toward disabled people as seeing them as "sick and sexless" rather than participating in full sexual and family relationships.

Much of what we know about the social barriers that people with disabilities face in relation to their sexuality comes from the reports of people with disabilities themselves. Robert Murphy (1995) drew on his personal experience living with quadriplegia to reflect on the position of physical disability in American society. He argued that the disabled, individually and as a group, contravene all the values of youth, virility, activity, and physical beauty that Americans cherish. He believed that disabled people are resented by the able-bodied and are seen by them as ugly and repulsive—they are perceived as subverters of social values and ideals. According to Murphy, these values and ideals include strength, independence, virility, and health, and they are promoted and affirmed constantly in the media, while the disabled body is hidden or presented as something to be avoided, corrected, and pitied.

The sexualities of people with disabilities have been and continue to be affected by the ideology of eugenics. Historically, there has been a fear that people with disabilities will produce offspring with disabilities, as well as a belief that this is something that should be avoided. This stems from a fear of disability and a belief that people with disabilities are of less value and a threat to the genetic good or survival of the human species. Sometimes the message is implicit and at other times explicit. Explicitly, the continuing practice of sterilization as a reproductive control of people with disabilities (particularly women with intellectual disabilities) and the institutionalization of people with disabilities (particularly people with intellectual, cognitive, or psychiatric disabilities) show the continuing influence of the eugenic ideology and have a serious impact on sexuality.

There is also evidence that people with disabilities (particularly women) experience sexual abuse at a higher rate than in the general population. This may be because people with disabilities are more likely to live in institutions or to have contact with a wide range of caregivers; it may be because communication barriers mean that people with disabilities are less likely to be heard or believed if they report abuse; it may also be because of physical vulnerability or availability. Awareness of the dangers of abuse may be lacking and protection absent. Conversely, focus on abuse may lead to overprotectiveness of people with disabilities and an unwillingness to provide information about their bodies and sexual behavior. It may be thought that raising awareness of sexuality increases vulnerability, whereas appropriate education may instead reduce the likelihood of an assault and increase the possibility of individuals reporting inappropriate attention or actions.

People with disabilities are vulnerable to sexually transmitted infections like any other member of society. People are placed at increased risk of exposure if they do not receive education on the risks and protective measures that people can take. Particular groups of people may be more vulnerable due to their sexual practice and where they live (e.g., men who have sex with other men where there is a high prevalence of HIV among homosexual men). Sex education and HIV/AIDS education need to take into account information barriers: for example, making health information available in simple text, via sign language and in different formats for people with visual impairments.

General societal attitudes toward sexuality are also likely to affect people with disabilities. Society places a great deal of emphasis on sexual intercourse, and other kinds of sexual behavior, such as kissing, cuddling, and mutual masturbation, are viewed as less significant and labeled “foreplay.” The achievement of orgasm is also emphasized, and sensation and movement are equated with sexual eligibility. For some people with physical disabilities, these attitudes could hinder their sexual esteem, as they may be physically unable to engage in the sex acts that are socially valued. Likewise, they are discouraged from participating in the acts that they are capable of because they are socially devalued. A more open approach to sexuality may value nonheterosexual forms of sexuality, may foster a more imaginative and experimental approach to sexual expression and activity, and may enable people with disabilities to achieve pleasure and intimacy in diverse and individual ways.

### *Practical Barriers*

Reduced mobility may interfere with sexual expression in all physical impairments, but the exact nature of the practical difficulty is likely to be disability specific. For example, people with an impaired urinary system, such as those with MS and SCI, may need to contend with removing an indwelling or external catheter or bending and taping the catheter when preparing for sexual intercourse. They also risk spontaneous bladder and bowel emptying. People with impairments that cause physical weakness, such as neuromuscular conditions, may not have sufficient motor strength to masturbate to orgasm or to sufficiently pleasure a sexual partner. Mobility problems involving inaccessible public transport, clubs, and housing are also likely to affect opportunities to socialize and meet potential sexual partners.

Speech impairment can also be a significant barrier to establishing sexual relationships. The use of augmentative communication devices requires skill and patience, and consequently, the speech-impaired person’s opportunities to express his or her personality and attract a partner through two-way communication are affected.

Dependence on others for care can also seriously restrict an individual’s opportunities to freely express his or her sexuality because of a lack of privacy and overprotective parents or caregivers. For people who live with their parents, the establishment of sexual relationships is likely to relate to the degree of independence from parental figures. However, the person with a disability often remains dependent on parents much longer than the able-bodied individual. The parents of a person with a disability may have difficulty acknowledging the sexuality of their child and struggle accepting that their son or daughter could have a life independent of them. These overprotective parents may be especially concerned about their child being “hurt” or “exploited,” and they may communicate, either directly or indirectly to their child, that a sexual relationship and marriage are not a realistic possibility. Overprotective parents and a dependence on others for care can be a contributing factor to social isolation, which limits the social and sexual opportunities of a person with a disability.

For people with disabilities who reside in supported accommodation, social isolation and barriers to sexual relationships can be even more serious as a result of cramped conditions, a lack of privacy, and the intrusion of support staff. These people are often more segregated from able-bodied people, and in some institutions, sexual contact between residents is prohibited. In cases where sexual contact is allowed, it is still unlikely to be possible if both residents have mobility problems, and often the only able-bodied people they associate with are professionals who are forbidden to engage in sexual relationships with a resident or to provide the assistance needed for two residents to have sex.

People with disabilities may experience enormous external pressures that impinge on their sexualities. This control can come from family members, carers, service providers, and support agencies that provide accommodation, recreation, or medical services. To self-advocate and assert their choices and express sexual desires in such a negative climate takes huge courage and determination. The places where people with disabilities live (institutions, nursing homes, boarding houses, hospitals, prisons, group homes, and, particularly for people with cognitive and psychiatric disabilities, on the street) all have an impact of the sexuality of people with disabilities and affects the way they see themselves and their opportunities for forming a positive sexual identity. People with intellectual disabilities who have experienced living in institutions and group homes in the community have sadly reported fewer opportunities in group homes to have sexual relationships due to the increased level of supervision (those staff see it as their job to prevent sexual contact rather than enable people's relationships) than when people resided in institutions. Many aspects of people's lives have seen conscious planning and support for people to gain independent skills or have their needs met by services in the areas of managing finances, learning housekeeping skills, and having educational and vocational opportunities, but the area of sexuality has largely been ignored, reinforcing the belief that people with disabilities are not whole and that emotional and sexual connections with others should not be encouraged.

Wider discrimination against people with disabilities also affects the capacity to achieve intimacy and express sexuality. For example, people with disabilities may be isolated and lonely. Many people make friends or meet partners at college or in the workplace: if people with disabilities are excluded from both those domains, their social life may suffer. To participate in leisure activities, they need money to buy clothes, pay for admission to venues, and buy drinks and meals, but because many people with disabilities are poor, this may be impossible for them. Above all, meeting people and making friends and becoming lovers all depends on individual self-esteem and confidence: if people with disabilities are socialized into dependency, feel bad about their bodies, or lack self-worth, then they may find it difficult to overcome barriers to interaction and may be seen as unattractive or undesirable.

## SEXUAL MINORITIES WITH DISABILITIES

While most are probably heterosexual, some people with disabilities are gay, lesbian, bisexual, intersex, and transgender. These sexual minorities face unique challenges when they are coupled with disability. For example, a dependence on others for care makes the exploration of a person's sexuality and the gay, lesbian, bisexual, and transgender community more difficult. This early exploration is usually achieved privately and independently, at a time when the person feels a sense of apprehension and cautiousness. The nondisabled person can do this with minimal risk and with little fear of his or her family and friends knowing. However, a person with a disability may need support to attend a gay or lesbian venue, such as assistance with transport, communication, or personal care. This often requires negotiation and disclosure and the need to "come out" at a time when the person may not feel prepared or confident. Furthermore, physical access to the venue also needs to be considered. For transgendered people who require assistance to dress, there may be a fear of asking to wear clothing of their choice. If they do ask, their requests may be refused, and they may be subjected to abuse and ridicule.

The sexualities of people with disabilities are also affected by common assumptions that people should only have monogamous relationships and that the sex they have cannot involve experimentation, sexual role-play, cross-dressing, or an expression of fetishism. Engaging in any of these activities is often perceived as being sexually deviant if one or more partners have a disability, whereas it is seen to be within the spectrum of sexual behavior for those without disability.

## SEXUAL RIGHTS OF PEOPLE WITH DISABILITIES

In the face of the many barriers, it is important to consider the sexual rights of people with disabilities. Ann Craft (1994) identified the following rights. First, they have the right to be treated as adults and not perceived by others as eternally childlike and sexless and to be treated with the dignity and respect accorded to adults. Second, they have the right to be provided with accurate knowledge about sex and sexuality in ways that they can understand. Third, they have the right to be sexual and to make and break relationships. People with disabilities need to be able to exercise risk taking in order to learn and should not be overprotected for fear they may suffer some emotional or physical harm. A lack of experience will place the person at greater risk. Fourth, they have the right not to be at the mercy of the individual sexual attitudes of different caregivers. Those supporting people with disabilities need to promote self-realization in the individuals, not compliance, enabling them to make their own choices and be able to express their own sexual identity without a prescribed notion of what constitutes a norm. Finally, they have the right to live in humane and dignified environments, free from sexual abuse. To foster a positive and healthy sexuality, people require a safe space that affords privacy, personal control, and choice.

While traditional service providers have neglected the sexual rights of people with disabilities, for reasons discussed above, it is perhaps more surprising that the disability movements have been slow to take up the campaign for sexual rights. American disabled feminist Ann Finger (1992) argues that the disability rights movement has not put sexual rights at the forefront of its agenda:

> Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction. (p. 9)

Perhaps because other disability rights have been prioritized, perhaps because acknowledging the exclusion from intimacy is painful, or perhaps because of wider taboos about sexuality, effective work to achieve the sexual rights of disabled people has been neglected in many countries. However, promising developments include better campaigns around HIV/AIDS and sexual health, often based on peer education; better training for professionals, carers, and personal assistants; provision of nightclubs and other social activities for people with learning difficulties; respect for privacy and the right to have control over your own body; and new positive images of disabled people's bodies, sexuality, and relationships, such as the Australian Intimate Encounters project.

Despite the history of exclusion and the reality of isolation and abuse for many people with disabilities, it is important to note that for other people with disabilities, their sexual rights are being achieved, and they are leading satisfying sexual lives. People with disabilities are having relationships of all kinds, heterosexual, homosexual, monogamous, and polyamorous. People with disabilities are having children. Many are marrying other disabled people and people who do not have disabilities. People with disabilities are dating, loving, touching, kissing, hugging, sucking, fingering, and fucking. Some are accessing the sex industry, visiting sex workers, working as sex workers, consuming pornography, and, in some instances, making pornography. People with disabilities are learning and teaching about sex, as sex educators, counselors, and researchers. They are finding and sharing useful ways to enjoy sexuality and increase sexual pleasure and sexual esteem. Prioritizing the sexual rights of people with disabilities, as well as breaking down taboos and silences, will ensure that these successful stories become the norm for most people with disabilities in years to come.

*—George Taleporos and Matthew Bowden*

***See also*** Children of Disabled Parents; Gender; Identity; Sexual Access.

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Disabled Sex, http://www.disabledsex.org
Intimate Encounters, http://www.intimate-encounters.com.au
Sexual Health Network, http://www.sexualhealth.com

# SHELTERED EMPLOYMENT

Sheltered employment provides paid work opportunities for people with disabilities for whom a job in the community-based labor force is believed to be unlikely. These work activities are typically offered in protected environments or sheltered workshops, where the demands of competitive employment are minimized. For example, the sheltered working environment can be constructed to reduce levels of responsibility, hours of employment, pace of work, and the number of work demands placed on an employee. It is organized to provide assistance from human services support personnel so that individuals engaged in sheltered employment can reach their maximum level of performance and productivity.

In recent years, sheltered employment has been the focus of much critical debate because the underlying beliefs about work and disability, as well as the structure and practices of this employment model, have serious implications for the community inclusion and citizenship of people with disabilities.

## THE STRUCTURE AND FUNCTIONS OF SHELTERED EMPLOYMENT

Sheltered employment is offered in small- to medium-sized organizations, typically employing fewer then 100 persons. It is administered by private, nonprofit, or voluntary organizations. The jobs offered by sheltered employment are varied, but they may include commercial ventures (e.g., a car wash, catering, or woodworking business serving the public), subcontracts negotiated through other industries (such as packaging or assembly), activities to serve the administrative organization (such as mailing and filing), or simulated work activities. In most cases, sheltered employment receives government funding or subsidy for costs such as human resources, equipment, space, and employee payment. Control of the income realized through the sales of goods and services depends on the relationship to the funding source. The extent to which organizations offering sheltered employment retain control of their income will have significant implications on their ability to purchase equipment, offer compensation to workers, upgrade facilities, and other activities that are common in workplaces in the regular community labor market.

Sheltered employment has been developed to fulfill several functions. The first is to provide people with disabilities the opportunity to participate in work for pay. From this perspective, the person is considered an employee, and sheltered work can be conceptualized as the person's job or occupational status.

A second function of sheltered employment is to create a context for improvements in health and well-being. Through participation in work activities, individuals with disabilities have the opportunity to experience psychosocial benefits, including the development of self-esteem and worker identity, promoting a sense of personal competence, which contributes to the community and establishes social relationships. Work is thought to have therapeutic functions, and sheltered work improves physical, mental, and emotional impairments. From this perspective, individuals working in sheltered employment are clients of a health service that is an integral part of their treatment.

Finally, sheltered employment provides training to develop skills essential in the regular, community-based labor force. These include skills needed to successfully perform work activities (such as concentrating on the task, consistently producing high-quality products, working at speeds that are considered standard in regular employment settings), work-related skills (such as good grooming and personal hygiene, traveling to work, punctuality and attendance), and social skills at work (including getting along with coworkers, following instructions, and respecting authority). Sometimes, sheltered employment is organized to include work enclaves, direct job placement, and follow-up support to assist in the move to regular employment settings. From this perspective, the individual involved in sheltered employment is a trainee, learning skills that can lead to employment in the regular community labor market.

## HISTORICAL PERSPECTIVES

Contemporary applications of sheltered employment for persons with disabilities can trace their origins back to the sixteenth and seventeenth centuries. The development of workhouses for the poor, as well as asylums for the indigent and people with disabilities, established work settings segregated from the public, which provided relief from poverty and the spiritual deterioration associated with idleness and loss of employment. In the nineteenth century, sheltered employment was developed on the grounds of institutions that provided long-term care with a view to promoting the therapeutic benefits of work participation and a daily routine, including a balance of work and rest. The rehabilitation functions of sheltered employment likely originated from efforts by schools for the blind in the late nineteenth century to facilitate the vocational training of students. Sheltered employment was actively promoted as a viable option in vocational rehabilitation until the late 1970s, when the model was criticized by activists promoting the civil rights of persons with disabilities. The model also came in conflict with legislation designed to combat worker exploitation. It was also shown that sheltered employment did not lead to full and integrated employment. New models of employment in the 1970s and 1980s demonstrated how individuals with disabilities could be supported directly in regular employment settings, encouraging a trend toward vocational rehabilitation efforts that supported, rather than sheltered, people in their employment.

## PROBLEMS WITH SHELTERED EMPLOYMENT

Sheltered employment has been criticized because its tenets and assumptions are inconsistent with contemporary perspectives on disability that highlight the basic rights of all persons to participation in the life of the community, including full integration in regular occupational settings, and on the social and economic costs incurred when the potential of all citizens is underused. Sheltered employment designs the work situation with the aim of promoting workers' health and well-being, as well as their potential for regular employment. Traditionally, though, sheltered employment has not incorporated practices consistent with the social perspective of disability, such as working directly with employers to secure an integrated employment situation, one that incorporates accommodations and other supports that help workers function in integrated work settings.

The sheltered employment model has been criticized precisely because it "shelters" workers from the demands of regular work and segregates them from larger society. While workers in sheltered employment may contribute to society through the goods and services they produce, the model is structured to regulate the extent to which workers have direct contact with people in their communities, with nondisabled workers, or even with other community businesses to acquire needed supplies or services.

Sheltered employment has generally been unable to prepare people for employment in the open labor market. The nature of the work that can be done in segregated settings is limited, and generally it has not been able to provide jobs that are consistent with the knowledge, innovation, and technological demands of the current economy. It has been argued that the model cannot adequately prepare people if they are not exposed to the actual production and social context of mainstream employment. Similarly, individuals with disabilities are deprived of experiencing all of the personal benefits of work, including elements of work that might contribute to their own motivation to seek and maintain employment. For example, holding a job in the regular labor force may provide an individual with a social status that is personally valued and encourages staying at the job.

Critics also point out that the many functions of sheltered employment are incompatible, which hinders efforts to achieve mainstream employment. For example, the therapeutic functions of the model mean that it is likely to depend heavily on government funding, while the employment functions of the model support a more heavily production-oriented organization that is oriented to decreasing government assistance. This has significant implications for people with disabilities who may be held back in the sheltered setting because of their capacity to contribute to production demands. It can also affect those who are denied access to sheltered employment because they are perceived as less able to meet production standards.

The working conditions of sheltered employment have also been the object of some concern. The physical plant, work tasks, and the social segregation of sheltered work environments give the impression of an asylum and contribute to negative social attitudes. In addition, the nature of the work offered tends to be repetitive, requiring a low skill level, and without opportunities for advancement. This undermines efforts to present sheltered work as a credible place to acquire work skills and possibly contributes to discrimination toward persons with disabilities in the regular workforce. Furthermore, workers in sheltered employment may not have access to basic rights of employment enjoyed in the open labor market, such as compensation for unemployment and vacations, the protection of minimum wage standards, or the ability to organize themselves as a collective to negotiate their conditions of employment.

## INTERNATIONAL PERSPECTIVES

Sheltered employment is an international phenomenon, and it is on the increase, despite efforts to develop alternate models that favor mainstream employment through the provision of supports and accommodations directly in regular community work settings.

There is considerable variation in the way sheltered employment is organized and structured around the world, so it is difficult to generalize about sheltered work. For example, sheltered employment will be affected by the employment rates of a country. Where the unemployment rate is rising, the numbers of individuals in sheltered employment can be expected to rise. There is also considerable variation between countries with respect to the nature of the disabilities experienced by workers in sheltered employment. Countries take different approaches to sheltered employment. European countries, for example, tend to focus on production functions and so are more likely to have people without disabilities working alongside disabled people, which is less common in North America.

Legislation will influence the prevalence of sheltered work. In countries with strong legislation to promote inclusion in the workforce, sheltered employment is likely to be a less prominent employment model. Where standard labor laws are applied to sheltered employment, employees can benefit from the standards and rights enjoyed by all workers. National policies may categorize some workers in sheltered employment as trainees or as employees, each with distinct policies governing their employment. Some countries recognize workers in sheltered employment only as clients of a service, and no formal employee relationship is established. While most countries provide some form of income support for persons with disabilities who are not economically self-sufficient, national policies will differ on the status granted sheltered employment with respect to minimum wage provisions and the remuneration for labor.

## THE FUTURE OF SHELTERED EMPLOYMENT

The future of sheltered employment is uncertain. There are powerful arguments for the termination of sheltered employment as a vocational support program. Yet, the model persists internationally, probably because it is so difficult to change established social structures. The pressure to close sheltered work will be resisted by the support staff. Workers with disabilities may also resist, especially if they are long-time employees in sheltered settings. There are also concerns that, although more consistent with the ideals of mainstream employment, new employment models will not secure work opportunities for all people with disabilities, both because of constraints within the open labor markets (e.g., variable employment rates) and because it will be hard to support those with the most severe disabilities. Some worry that supported models may lead to bad working conditions and segregation within the workplace, without the benefits of the camaraderie available in the sheltered employment setting.

In response to criticisms directed at the model, modification can be expected. For example, sheltered employment may be modified to incorporate supported employment services or to develop a broader variety of work options and opportunities for advancement. Attempts may be made to enhance worker ownership and control, as well as develop training measures that are more likely to lead to the development of skills associated with success in mainstream employment. Whether true "sheltered" employment remains after these changes is not entirely clear.

*—Terry Krupa*

***See also*** Employability; Employment; Job Analysis and Placement; Job Training; Supported Services; Vocational Rehabilitation.

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# SIBLINGS OF PEOPLE WITH DISABILITIES

Unlike their parents, who remember a time "before," the nondisabled siblings of people with disabilities often possess an intimate familiarity with disability from their first memories. Psychological literature identifies many common themes in the lives of such siblings: gradual awareness of the disabled sibling's difference, competition for the parents' resources, fear that the sibling's disability will reflect on their own competence or health, increased sensitivity and acceptance of diverse abilities, and rebellion against, or acquiescence to, the expectation that they will take on advocate or guardian roles for their disabled sibling into adulthood. These assumptions are generalized mainly from recent, Western, family studies; whether they apply across cultures and eras remains to be seen. While past decades saw an emphasis on warning about the problems siblings would experience, current thinking holds that most siblings in otherwise "functional" families gain useful adaptive skills through their relationships to disabled brothers or sisters.

Many historical figures have been the siblings of people with disabilities. In the American context, at least two U.S. presidents (Thomas Jefferson and John F. Kennedy) had sisters with mental retardation. Ralph Waldo Emerson was responsible for the supervision of more than one institutionalized brother; his friend Margaret Fuller held a similar role in her family.

As siblings are seen as potential lifelong supports to individuals with disabilities, public programs have begun to concentrate some effort on addressing their concerns and educating them for this role. For example, "Sibshops" are offered by many community agencies serving people with disabilities; usually, but not always, developmental disabilities are the focus. Directed at school-age brothers and sisters of children with disabilities, they enable peer interaction through discussion, recreation, and activities designed to increase disability awareness in age-appropriate ways.

Beyond juvenile literature, support group curricula, and advice books for parents, reflective memoirs (and other literary nonfiction) by adult siblings have been published in increasing numbers in recent years. Rachel Simon's (2002) *Riding the Bus with My Sister* is perhaps the most lauded of these. This genre is still far less developed than the parental narrative but shows promise as a useful alternative glimpse at family life and disability.

*—Penny L. Richards*

***See also*** Family; Family, International.

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## SICK ROLE

Sick roles are the culturally established expectations for how a person should act when he or she is ill or is perceived as ill/abnormal in a particular group. Each person learns these sick roles through a process known as socialization, in which people are subtly educated in the norms of a particular group.

While the term *socialization* can be used to refer to modest processes such as introducing a new employee to the norms of a business or institution, here we are interested in the broader and more fundamental socialization that teaches a person how to become a member of society. This process starts neonatally and occurs at each moment of interaction with others. Over time, by living and interacting with others within a given society, each person internalizes the norms and expectations of others, sometimes to such an extent that they seem essential and natural—the only way the world could possibly be and the only way people could possibly behave within it. When this occurs, those "essential" norms and expectations become tinged with morality so that people refer to them with "shoulds" and "ought tos" and look disapprovingly at any ideas, behaviors, or realities that flaunt them. This process embeds within each person more or less a similar sense of appropriate behavior, for example, that murder and theft are bad and following traffic rules is good. Socialization makes society possible in a very fundamental way. And yet, the socialization of the sick role, the assumption that people with any illness or disability are morally obligated to behave in a particular way, has become deeply problematic in American society. But before exploring this, let us review the scholarly history of the notion of the sick role so that we might understand the recent backlash against it.

The first scholarly work on the subject of sick roles was published in 1929 in German by the medical historian Henry E. Sigerist. Sigerist, examining Western civilization but also drawing on cross-cultural information, defined illness as whatever disturbed the rhythm of a person's life so that the physiological symptoms isolated him or her, making that person suffer in helplessness, pain, and fear. For Sigerist, this sick role of isolation, dependency, and fear was the universal outcome of physiological suffering.

Talcott Parsons, the mid-twentieth-century American sociologist who made the notion of sick roles famous, did not take such a universalistic approach and instead grounded sick roles in the cultural and social dynamics of American medicine in the 1940s and 1950s.

Parsons recognized that for Americans of that era, illness and disability were both a deviation from an idealized norm of health and a deviation from the normal expectations of society. Parsons outlined basic features of the American sick role. First, the person who showed signs of deviating from health is exempted from his or her normal social activities and obligations and is exonerated from normal expectations of self-responsibility; in essence, the person takes on a dependent, childlike social status. Second, and largely because of the first feature, the person is socially isolated. Third, the person must accept that he or she is in this undesirable state, in need of help, and morally obligated to cooperate with others' therapeutic efforts at restoring the person to society's ideal of normal health so that the person can resume or take on normal social activities and obligations. The most appropriate source of therapy was seen as Western biomedicine.

This American model of the sick role developed out of an idealized notion of the body as normatively healthy and in conjunction with a model of biomedicine as a hierarchically structured, active, authoritative, parental institution that was responsible for making grateful, passive, childlike, and cooperative patients into healthy persons who could fulfill society's normal expectations and responsibilities.

There have been numerous scholarly criticisms of Parsons's sketch of the sick role, particularly the problems of applying it to specific physical conditions. Parsons based his sick role on the patterns of behavior that arise in response to those maladies that are temporarily incapacitating. Many conditions do not fit comfortably within his typology, including pregnancy, alcoholism, mental illness, chronic illness, congenital abnormalities, and many physical and mental disabilities. In such cases, the classification of sickness and its corresponding expectations for sick role behavior simply do not fit.

Indeed, the central problem of Parsons's sick role is the idea that perfect health and a perfect body are normal, and any deviation from these idealized norms constitutes sickness and the need for a sick role.

Norms of health vary tremendously cross-culturally, as do the expectations of what a person does when identified as sick. Sick roles, as the expectation for behavior when identified as ill or disabled, also vary significantly cross-culturally based on two variables: (1) who has access to medical information and technology and (2) how health is defined.

In societies where all people consider themselves more or less well, however far from perfect health, as long as they can fulfill some modest responsibilities in a society, illness itself becomes narrowly circumscribed to those instances of acute suffering. In such societies, long-term or chronic conditions are unlikely to be socially labeled as ill, but simply as a personal characteristic of the particular person. Among the Sasak of Indonesia, a place where the people describe themselves as "less than healthy," disabilities stemming from conditions such as skeletal deformities, chronic heart failure, and severe arthritis may physically limit tasks and are evaluated on a case-by-case basis, but they do not carry automatic expectations of changed behavior or responsibilities. The anthropological record, in fact, is full of examples in which people with chronic or debilitating conditions are not isolated or even viewed as sick until contact with the Western biomedical gaze medicalizes conditions, isolating their victims in the process.

The theoretical idea of a sick role has come under fire in the social sciences since the 1980s for various reasons. First, sick roles are an ideal type that may describe patterns of behavior across patients in a given culturally constituted social group but cannot predict or thoroughly describe the behavior of any particular patient. Second, the sick *role* has theatrical implications, suggesting that a person can perform or take on a role without being intricately bound to it; the notion of a sick role does not reflect the ontological reality and suffering of people who are ill or disabled. As a result of these criticisms, social science research has been more person centered, focused on patient narrative, patient experience, and sociolinguistic detailing of physician-patient interactions. The results of this work show a tremendous amount of diversity in the behaviors, attitudes, experiences, and interpretations of people who are ill or disabled.

In addition to this scholarly reaction, significant portions of Western society itself have reacted against the social expectations of patient passivity and isolation that Sigerist and Parsons described. Beginning in the 1970s but taking off in the 1980s, particularly with the AIDS movement, for some members of the population, ideals of passivity have changed gradually into expectations for activity and engagement. For people in America today, there are at least two widely distributed cultural ideas of what someone should do when he or she is sick. First, the passive, isolated behavioral expectation as described by Parsons and Sigerist remains a salient model for behavior. Second, there is an active and engaged model in which patients remain engaged in their lives, keep their social responsibilities, are considered responsible for their own recovery, and are educated and empowered consumers of health care. Recent scholarship suggests that people may choose either role or blend the two as best suits their particular needs and circumstances at the time.

Sick roles, as the cultural expectations of how someone who is ill or otherwise disabled should behave, can and do shift over time within a single society and vary significantly across societies.

*—M. Cameron Hay-Rollins*

***See also*** Patient-Professional Relations; Patients' Rights; Stigma.

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## SIGN LANGUAGE

Sign language is a means of communication through the use of body movements, gestures, and facial expressions. It could be described as plainly as pointing, shrugging, and grimacing or could be as complex as a combination of coded manual signals or signs.

Beyond simply a means of communication, American Sign Language (ASL) is the primary language used by Deaf and hard-of-hearing people in the United States and in parts of Canada. It is the native language of many Deaf men and women, as well as some hearing children born into Deaf families.

ASL is a visual-spatial language based on concepts rather than words. It is a linguistically complete language, gaining recognition and acceptance as a genuine, formal language due in large part to the research done by an English professor named William Stokoe. Stokoe worked to legitimize ASL, proving scientifically and unequivocally that ASL meets the full criteria of linguistics phonology, morphology, syntax, and semantics to be classified as a fully developed language. ASL shares no grammatical similarities to English and should not be considered in any way to be a broken, mimed, or gestural form of English. For example, ASL has a topic-comment syntax, while English uses subject-object-verb.

The history of ASL begins in the mid-eighteenth century in France. In 1755, Abbé Charles Michel de L'Épée (1712–1789) of Paris founded the first free school for deaf people, where the first sign language was developed. In 1815, Thomas Hopkins Gallaudet (1787–1851), an American Episcopal priest, traveled to Europe to study methods of communicating with the Deaf. After several months, Gallaudet returned to the United States with Laurent Clerc, a Deaf instructor from the Paris school for the Deaf. In 1817, Gallaudet established the first American school for the Deaf in Hartford, Connecticut, and Clerc played a primary role instructing Deaf children using sign language. The opening of subsequent residential schools for the Deaf throughout the United States promoted the standardization of ASL. Today, America has one of the most complete and expressive sign language systems of any country in the world, owing much to the French sign system, from which many present-day ASL signs, though modified, have been derived.

ASL is the primary language of Deaf people in the United States. This number of people represents those who view themselves as members of a cultural-linguistic minority group (Deaf), as opposed to those who audiologically are unable to hear (deaf). Estimates for the number of ASL users in the United States range from 300,000 to as high as 900,000. The most recent estimate given by the Gallaudet Research Institute puts that number at 360,000. Precise numbers are hard to come by due to the difficulty of discerning in the population those who are audiologically deaf and those who are culturally Deaf. In addition, it is also difficult to discern and measure the actual sign language used. A spectrum exists between ASL and other manually coded English (MCE) signs. Beginning signers, mainstreamed Deaf children, and late-deafened adults generally comprise the MCE side of the spectrum, while expert signers and Deaf families fall on the ASL side of the spectrum. In between there exist signers with a wide variety of skill.

The Deaf share a common history, language, value system, beliefs, characteristics, and behaviors, with American Sign Language as the common thread that binds them together. ASL is the fourth most commonly used language in the United States.

Deaf communities around the world use native sign languages that are indigenous to Deaf communities within specific countries and geographic locations. Within each signed language, there are regional dialects and variations that represent geographical differences; sign language is not universal. Signers in Great Britain use British Sign Language (BSL), while those in France use French Sign Language (LSF), and those in Switzerland have five distinct sign language dialects. There are international communication systems such as Gestuno and International Signs, which are similar to spoken Esperanto and commonly used in international conferences. These systems are more or less agreements on a vocabulary of signs among the international Deaf community.

*—William Ennis*

***See also*** Deaf, History of the; Deaf Culture.

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## SIGN LANGUAGE INTERPRETATION

Sign language interpreting has been a practice since signers came into contact with speakers. Facilitating communication between these two groups of people constitutes what Stewart, Schein, and Cartwright (1998) call "the art and science" of sign language interpreting, a profession now centered on enabling communication between deaf, signing persons and nondeaf, speaking persons. The interpreting process involves more than just these two (groups of) people, however. Indeed, interpreting is always a triangular act, calling on three—and sometimes even four—groups of people: those who know and use sign or sign languages, those who do not, those who interpret between those two, and sometimes also those who administer and finance interpreting programs.

While the practice of sign language interpreting is nothing new, the development of a profession around it is. The unlicensed predecessors of this profession were (more often than not) anonymous individuals—most likely friends or family—who have interpreted for deaf people in oral/aural-centered communication situations throughout undocumented periods of history. In this preprofessional period, interpreting was usually performed as a favor. The interpreting profession in the United States marks its inception in June 1964, when Ball State Teachers College in Muncie, Indiana, hosted the Workshop on Interpreting for the Deaf, sponsored by the Vocational Rehabilitation Agency, and members of this workshop voted to establish a national body of professional interpreters. This body was originally known as the National Registry of Professional Interpreters and Translators for the Deaf and is now known, more simply, as the Registry of Interpreters for the Deaf (RID). Fifteen years later, in 1979, Canadian interpreters formed the Association of Visual Language Interpreters of Canada (AVLIC); similar associations have also been formed in Great Britain, Australia, and a few other countries. Interpreting, as a recognized and organized profession, still rarely exists throughout the rest of the world.

Immediately after the RID was formed, two institutions developed interpreter training programs (ITPs): California State at Northridge in 1965 and the National Technical Institute for the Deaf (NTID) at Rochester Institute of Technology (RIT) in 1966. In 2003, the RID listed 159 interpreter training programs offering the following degrees: Certificate in Interpreting (43), associate's degree (75), bachelor's degree (30), graduate degree (3), and distance learning programs (8).

## KEY LEGISLATION IN THE UNITED STATES

Several important pieces of legislation have helped instigate, effect, and even reinforce the professionalization of sign language in the United States. The Vocational Rehabilitation Act amendments in 1965 (P.L. 89–333) gave state rehabilitation agencies the authorization to employ interpreters for deaf clients, and in 1973, interpreting for deaf people in additional settings was mandated with the Rehabilitation Act amendments. This 1973 act contained Section 504, guaranteeing rights for "the handicapped." Included in those rights, the provision of interpreters—especially trained and qualified ones—in schools and "under any program or activity receiving Federal financial assistance" was no longer seen as a favor or a fairly rare occurrence. The power of this 1973 law was carried forward and even expanded with the passage of the Americans with Disabilities Act (ADA) in 1990. Between those two key pieces of legislation, the Bilingual, Hearing and Speech Impaired Court Interpreter Act was also passed by the U.S. Congress in 1977, stating that a federal court must appoint and pay for interpreting for a deaf person who is the subject of any criminal or civic action initiated by the federal government.

## THE REGISTRY OF INTERPRETERS OF THE DEAF (RID)

In July 2002, full RID membership stood at 10,007, with 3,779 of those (about 37 percent) currently fully certified and practicing. These numbers are also supplemented by interpreters who are certified by the National Association of the Deaf (NAD). The RID now follows the definition of the ADA (see above) as its standard for recognizing a "qualified interpreter" as "an interpreter who is able to interpret effectively, accurately and impartially both receptively and expressively, using any necessary specialized vocabulary." As an indicator of the increasing demand for qualified interpreters and the specialization of this evolving profession, the RID currently offers 20 different certificates, including, for example, the following: Certified Deaf Interpreter (CDI), interpreters who are themselves deaf or hard of hearing; the Reverse Skills Certificate (RSC), for interpreting between American Sign Language and other English-based sign language forms; four different certificates for oral transliteration or interpreting; and specialist certificates for legal interpreting or performance arts interpretation (see www.rid.org).

## THE INTERPRETING PROCESS

There are three key steps in the interpreting process: the interpreter must first understand the meaning of the message being received, the message must then be encoded into the target language, and the message must then be effectively expressed in that target language. In these steps, the ability to use both short- and long-term memory simultaneously is necessary as the interpreter moves between reception, encoding, and expression across not only two languages but also two modalities (spoken to visual/manual or vice versa). Interpreters must be able to walk (in one language) and chew gum (in another) at the same time.

Several sets of factors can greatly influence the interpreting process: physical, psychological, forms of interpreting, and the settings/scenes for the interpretation. Physical factors are often related to the auditory field, the visual field, personal factors, and the environment itself. In the auditory field, for example, the positioning of the three members of the triangulated situation, the acoustics of the setting, and the ambient noise all matter. The visual field also influences the interpreting process in such dimensions as the positioning of three members (again), the available lighting, the background "visual noise," and even the appearance of the participants. Interpreters tend to dress in dark, single colors and to avoid patterns in their professional clothing to present an uncomplicated and visually effective background for their hands. Personal factors also come into play in the interpreting process: interpreters should have good eyesight and hearing, the ability to focus in potentially distractive settings, and mechanisms for managing the cumulative stress that recent research shows often—carpal tunnel syndrome and repetitive stress tendonitis in their arms and shoulders, for example. Finally, management and manipulation of the communication environment itself must often take place to facilitate the process. For example, while a seating/standing rearrangement of not only the speaker, interpreter, and receiver (or vice versa) often occurs in interpretation, even nonparticipants in the interpreting process must also often resituate themselves—moving out of the line of sight, giving up the front-row seats, and so on.

Psychological factors play as great a role, if not sometimes even greater, as do physical ones. The interpreter's success at becoming either anonymous and seemingly absent in the process—and yet also, if needed, the center of attention—is one dimension of the psychological arena that interpreting often occurs in. Interpreters often find that they must also walk multiple fine lines: moving between their needs and their client's needs, practicing advocacy without oppression or paternalism, negotiating the stress of communication speed and time, dealing with overlapping speech and/or signs, balancing their own ethics (over the discourse they receive) with the accuracy of what they express back, and simultaneously maintaining distance—yet some camaraderie—with their clients. Gender variations in receiving, encoding, and processing language are also likely to influence the interpreting process, although little research has been conducted in this area (the profession is dominated by approximately 75 percent women).

In addition to these psychological factors, as the availability and even quality of interpreters seem to increase, so do the standards of the people who use them. Thus, the interpreting process can be affected by these standards when interpreters are almost always caught in the center of blame for failed communication between the other two stakeholders and when interpreters are sometimes viewed as merely communication conduits (not humans with inherently fallible communication capabilities) or as prostheses (akin, for example, to a hearing aid). Psychological causes and effects have also come to surround the tension created by legislating deaf citizens' "rights" for interpreters and the institution of their existence as a paid professional act. A vacillation between (too much or too little) trust of them and a concern over too much dependency on them commonly defines their contemporary relationship with deaf clients, who have also come to understand that interpreters make a living (and a good one, at that) off of their socially constructed "disability." Interpreters in the post-ADA era are often cursed if they do and cursed if they don't do their jobs.

Beyond physical and psychological factors are variations in discourse/language forms and in the settings that interpretation takes place in. Examples of forms might include interpreting for deaf-blind clients, oral interpretation, transliterations of cued speech, relay interpreting (often used with clients who have minimal language competency) when two or more kinds of interpreters are involved, and the now common use of tag-team interpreting—when paired interpreters alternate turns in timed periods over the course of a longer period. Each of these interpreting formats can change the interpreting process substantially. In addition, the form of the signed language itself matters: whether, for example, American Sign Language (ASL) or a pidgin/contact version that moves toward English is used, such as Signed Exact English (SEE) or Pidgin Signed English (PSE). Code switching and lexical borrowing between these three, as well as across regional "dialects" of signs and levels of formality, are also likely to enter into the interpreting process.

Interpreting now takes place in an endless variety of settings. Even the most common of these settings illustrates the breadth of skills any one interpreter might need to successfully insert specialized discourses into the interpreting process: legal, health/medical, mental health, rehabilitation and workplace, performance or "platform," religious, educational (across all levels and subjects), and emergency situations.

## EDUCATIONAL INTERPRETING

Since the Education for All Handicapped Law (P.L. 94–142) and the Individuals with Disabilities Education Act (IDEA) in 1973, educational interpreting has comprised the largest arena of certified interpreting. The "mainstreaming" or "inclusion" of deaf and hard-of-hearing students into "regular" classrooms and public school settings has probably created more questions and issues (and demands) for the interpreting profession than any other dimension. The stakes are so high and the ethical, legislative, and policy implications for placing (typically adult) interpreters alongside (typically children) clients throughout the course of a school day are so varied and immense that research around and general attention to educational interpreting have come to the forefront of the interpreting profession. As one study published in the *American Annals for the Deaf* has shown (Antia and Kreimeyer 2001), interpreters often come to occupy an interesting variety of additional roles in the course of those school days—clarifying teacher directions, facilitating peer interactions, tutoring deaf children, and even informing teachers of the deaf child's progress or difficulties.

## ETHICS

As might be expected, the ethical issues around interpreting are thick and thorny. When one group of people (sign language interpreters) represents the communication of another group of people (deaf, signing) and literally even "voices" their expressions and ideas, difficulties are likely to arise. The development of an official code of ethics was one of the first acts the RID undertook at its inception. The first code set forth in 1964, however, was heavily flavored with religious undertones since interpreting in the United States and Canada was grounded in volunteers who interpreted for church services. But by 1965, only a year later, the first official RID Code of Ethics had been substantially revised to include eight major points that interpreters were expected to strive for and maintain: (1) confidentiality about client, assignment, and so forth; (2) accuracy and completeness of message; (3) impartiality; (4) discretion, especially in not working beyond their own competence; (5) compensation commensurate with professional standards and situation; (6) professional standards; (7) professional obligations such as continuing their education and updating skills; and (8) application of sound judgment in all interpreting situations.

*—Brenda Jo Brueggemann*

***See also*** Ethics; Sign Language.

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## SIGN POETRY

Sign poetry, like its written and spoken counterparts, is a literary art form recognized for its heightened use of language. Yet, rather than featuring the acoustic patterns of spoken language, sign poetry manipulates the visual, spatial, and kinetic properties of its embodied medium.

As manual languages have had no written form, the Deaf community has been practicing what could ironically be referred to as an "oral" literary tradition. They have handed down their traditions from generation to generation in Deaf schools, clubs, and social gatherings. As a part of this "oral tradition," the American Deaf community has generated several unique genres that derive from technical and literary play on the "manual constraints" of the language. The most prominent of these are known as "ABC poems," "number poems," and "handshape poems," where the poetic narratives are told with predetermined pattern of handshapes, either those of the manual alphabet or the number system, or other specific handshapes. These predetermined structural forms may be similar to other literary traditions that feature formal constraints such as sonnets, haiku, and acrostic poems. The literary merit of a poem is often determined by the poet's ability to work within the constraints to produce a poem that ultimately transcends them.

While this oral tradition has been a lively part of the Deaf community since the nineteenth century, two events in the last half of the twentieth century have had an impact on sign poetry. First, the validation that American Sign Language (ASL) is a full human language, which began in the 1960s, instigated a desire to exploit this language for its poetic potential in ways analogous to spoken and written poetic language. Several Deaf poets originally composed poems in written English until it became apparent that ASL could just as easily be the primary language of a new body of Deaf literature. Many of these poets emerged as their work was supported through the National Theatre for the Deaf, including Bernard Bragg, Dorothy Miles, Gil Eastman, Ella Mae Lentz, Joseph Castronovo, and Pat Graybill. The National Theatre of the Deaf's landmark performance of *My Third Eye* in 1971 represented a break with previous traditions of sign performance, which still placed the written text as the "script." Instead, *My Third Eye* began to feature sign language for its strong ability to create visual imagery, thereby placing the written text in a secondary role.

This newfound awareness of sign language and a growing sense of a Deaf culture were accompanied by the advent of video technology, which allowed poets to "write" their poems on video. Deaf poets began to create and revise their works according to rough video drafts of a poem. This technology transformed an "oral" tradition into a body of poetry that became published and distributed much like written poetry, only in video format. The first ASL poetry videotapes appeared in 1988, in the *Poetry in Motion* series produced by Sign Media Inc. These featured the works of Patrick Graybill, Debbie Rennie, and Clayton Valli. These tapes still sell widely within the Deaf community, yet as they are not voice interpreted, they are not accessible to nonsigners. In 1995, Ella Mae Lentz produced *The Treasure,* which broke new ground it its use of cinematic effects, including stage sets, costumes, and camera movements. Clayton Valli's *ASL Poetry: Selected Works of Clayton Valli,* which appeared in 1995, features a collection of Valli's poems. The author, however, does not recite the poems; instead, they are performed by a host of different signers, ranging from children younger than age 10 to older members of the Deaf community. After all of the poems have been performed, the text replays each in slow motion, explaining the various poetic techniques employed in the poems. Valli's *Selected Poetry* demonstrates the ways in which the linguistic validation of signed languages, accompanied by the use of video technology, has influenced the ways that critics discuss sign poetry and poetics.

Clayton Valli has identified a wide range of poetic techniques as they appear in signed languages. Rhymes, for example, are based not on sound patterns but on visual patterns of linguistic units. These units, which are equivalent to phonemic elements, consist of

- particular handshapes,
- movement paths of the hands,
- signing location,
- palm orientation, and
- nonmanual signals on the face and body.

A single poem may be threaded together with one or more of these rhyme types. A single handshape may run throughout a poem, a movement path (i.e., circular, diagonal, etc.) may lend a particular symbolic and aesthetic structure to a poem, or a repeated pattern signing location may accentuate contrasts between stanzas and topics.

In Clayton Valli's "Hands," for example, the principle handshape is the open "five" handshape, which Valli then uses to weave images that correspond to the seasons, each of which is placed along a larger circle, representing the full-year cycle. Valli ends the poem with breaking the plane of the circle, foregrounding his hands. In this poem, which takes less than a minute to perform, there is a complex structure of handshape, signing location, and nonmanual signals (facial expressions) that work simultaneously to create a distinct visual and spatial poetic effect.

Clayton Valli's work is highly structured and often lyrical. In fact, he often likens his work to the poetry of Robert Frost, who represents a lyrical, highly symbolic poetic tradition in American poetry. Yet, just as with broader traditions in American poetry, sign poetry also features emerging traditions. On one hand, poets such as Ella Mae Lentz, Clayton Valli, and Patrick Graybill create poems that are densely structured, highly lyrical, and often related to Deaf themes; other poets have created a more experimental, avant-garde tradition that might be likened to the imagist poetry of Ezra Pound and the beat poetry of Allen Ginsberg. These poets emerged from Rochester, New York, the hotbed of ASL poetry in the 1980s, including Debbie Rennie and Flying Words Project—Deaf poet Peter Cook and hearing collaborator, Kenny Lerner. This poetic community, inspired in part by hearing poet Jim Cohn, promoted sign poetry to both Deaf and hearing communities by sponsoring the first national ASL poetry conference and meetings with hearing poets such as Allen Ginsberg. Flying Words Project has now produced two videotapes, titled *The Year of Walking Dog: The Early Poems* and *The Can't Touch Tour: Current Works.*

This poetic tradition emphasizes the cinematic nature of the signed languages, often making deliberate use of the poetic technique named by Bernard Bragg as "visual vernacular." This technique enables the poet to embody characters and images within the poem, giving a distinctly cinematic impression, replete with such signed versions of cinematic techniques as closeup, medium and distant, and cut-away shots. In Debbie Rennie's "Missing Children," for example, Rennie deftly assumes the character of a small Nicaraguan boy and then a member of a government death squad, back and forth, until we witness the murder of the boy, which is told using another cinematic technique, slow motion. In addition, Flying Words Project often features cinematic techniques as a means of producing hard, clear images.

The work of Flying Words Project is unique in its use of spoken English as a part of the text. Most sign poetry has not been translated for hearing audiences. Poets are often very aware of the difficulties in translating a text from the visual, spatial, and kinetic domain of sign to the static written page, or the invisible voice. This is not to suggest, however, that sign poetry is not relevant to the wider practice of poetry. Indeed, poets have been experimenting with the visual and performative aspects of poetry. Sign poetry seems to realize some of the creative experimentations in poetic form, while also contributing to the aesthetic and literary aspects of Deaf culture.

Sign poetry, therefore, is an emerging domain of creative practice that promises to produce works that give a voice to Deaf resistance and affirmation, in addition to furthering the boundaries of conventional poetic practices that have been mostly confined to speech and writing.

*—H-Dirksen L. Bauman*

***See also*** Deaf Culture; National Theatre of the Deaf; Poetry; Sign Language.

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## SLOVAK REPUBLIC

*See* Experience of Disability: Slovak Republic

## SOCIAL CAPITAL

Social capital is becoming an increasingly important and more generally accepted concept within the broad area of inquiry commonly referred to as social determinants of health. Social determinants of health include factors that influence health at multiple levels, including the individual, group, organization, community, system, and global levels. Factors such as risky behavior, social support, organizational culture, environmental stress, and the political system work simultaneously to determine the health of individuals and populations. More recently, the concept of social capital has been demonstrated to be an additional determinant of health and health outcomes (e.g., physical and mental morbidity) at both the person and group levels.

There are numerous definitions of *social capital,* but in general, the term is understood to refer to "resources" available to a population that bind it together as a system of social relations. The World Bank defines social capital as the norms and social relations embedded in the social structures of societies that enable people to coordinate action to achieve desired goals (www.worldbank.org/poverty/scapital/). Some research suggests that the resources that comprise social capital can be broken down into two parts: structural (i.e., how people interact with each other) and cognitive (i.e., how people perceive their interactions with others). Structural aspects of social capital could include the number and strength of social relationships, and cognitive aspects of social capital could include issues such as trust, sharing, and support. A second way to understand social capital is to view the "resources" according to their function. In this view, social capital is understood to have both a "bonding" and a "bridging" function. The bonding perspective suggests that social capital functions to bond similar and like groups to one another (social cohesion) at a horizontal or "within the same context" level. The bridging perspective suggests that social capital functions across contextual levels or vertically and aims to bridge relationships between different societal levels (social integration). An important distinction to keep in mind when defining social capital is that it is essentially an ecologic characteristic that is related to social structure. It is not a characteristic that is related to individual attributes as are the concepts of social support and social network.

The empirical relationship between social capital and health has just recently been demonstrated. In the United States, social capital has been shown to be associated with self-ratings of health, violent crime, heart disease, infant mortality, and life expectancy. In developing countries, social capital has been related to general household status. Several instruments to measure social capital have been developed, and most of them include variables that measure the structural and cognitive aspects of the construct. For example, factors related to connectedness and participation with family, friends, local communities, work, and neighborhoods are used to measure structure while, factors such as feelings of safety, trust, and tolerance of diversity can be used to measure the cognitive aspects of social capital.

The inclusion of social capital concepts, particularly as might be related to disability, provides numerous opportunities for new empirical research. For example, the notions of bonding and bridging functions suggest that the disability community might gain both local and national political power as it builds local community and national-level constituencies. Likewise, increased access to organizations that promote the working status of disabled individuals may increase feelings of self-esteem, thus demonstrating the positive impacts of both the structural and cognitive social capital.

More research is needed on how to incorporate the bonding and bridging concepts into social capital measurement, and there is also a need for combining these quantitative measures with more qualitative measures that might better capture the social capital of communities with diverse cultures, history, and health status.

*—Karen E. Peters*

***See also*** Models; Social Networks; Social Support.

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## SOCIAL MODELS

*See* Models

## SOCIAL MODEL: SWEDEN

Before "social model" became an established way of thinking in disability research, a similar but not identical way of conceptualizing disability was developed in Swedish politics and research.

Since the 1970s, Swedish disability policy and disability research have been guided by what has become known in Sweden as "the relative concept of handicap." The basic meaning of such a concept is that handicap is something that arises in the meeting between an individual and his or her environment.

Handicap/disability was defined as a specific area of politics in the mid-1960s. A parliamentary investigation made clear that some groups were lagging behind in the development standard of living. Many of them suffered from chronic illness or different kinds of impairments. To capture their vulnerable situation, these different groups were collectively labeled "handicapped." Of course, several measures had been taken for groups with different impairments before that, but they were usually dealt with and thought of as separate groups—one type of measures for the intellectually disabled, another type for the visually disabled, and so on. What was new was the explicit formulation of a broader group as "handicapped."

Introducing such a general concept created a need to know what groups with different impairments had in common. In official documents, they were described in terms of the substantial difficulties they experienced in their daily living. From that definition, it was but a small step to realize that those difficulties were not in themselves a necessary outcome of having impairment. They were also dependent on the kind of environment in which individuals lived their daily lives. The relative way of defining handicap/disability grew out of that insight. It was especially promoted by the organizations of the disabled. In response to the general definition of handicap, organizations for groups with different impairments/disabilities came together during the 1970s and formed an "umbrella organization" that most energetically argued for a relative definition. If the environment is adjusted to the capabilities of disabled people, there will be no handicap. So, this organization argued, general reforms to change the environment are the most effective way of reducing the problems for people with impairments. The creation of "a society for all" should help eliminate or at least diminish problems of handicap in society. A clear expression of those ambitions was the internationally well-known formulation of the principle of normalization by Bengt Nirje, who was the ombudsman at the organization for persons with intellectual disabilities, which argued for the right of such persons to life patterns and living conditions that were as close to the normal patterns as possible.

In response to those demands, several reforms (such as a law demanding that new buildings be made accessible, the implementation of transport services in the municipalities supported by state grants, and laws that obliged the employer to adapt work environments and only to fire people on "objective grounds") were introduced.

During "the golden age of the welfare state," the social democratic hegemony in politics was well established. The beginning of the postwar period was driven by an ambition to create a material safety net for all citizens, but in the 1960s, those ambitions were raised. This was a decade of fast economic growth and bright forecasts for the future. But the structural changes that created the economic growth also created new social problems. This was pointed out by different interest groups (e.g., organizations of the disabled), and claims for further social reforms were often supported by public opinion.

The shift in ambitions was articulated in the vision of "the strong society": a society that had the means and resources to help "weak" persons and disadvantaged groups should not have social reforms that just aim at caring for or curing manifest problems. The ambition of prevention, of getting to the cause of the problems to solve them, became apparent in many areas. Education is a case in point. Earlier reforms strove to abandon a parallel school system in favor of a comprehensive school that gave equal opportunity to everyone. The school reforms of the 1970s had much broader ambitions. In a comprehensive school, children with such problems should not be segregated, but resources should be allocated to support managing problems within the ordinary school context.

The relative definition of handicap and the ideological arguments as formulated by the organizations of the disabled were thus in accordance with the general welfare ideology of the time.

The relative concept of handicap also influenced research. When the first initiatives to promote social research in the field (which had up until then been dominated by medical/clinical research) were taken in 1980s, it was explicitly stated that disability research should occupy itself with the process by which impairments were transformed into handicap—that is, the interplay between individual and environment that created disadvantages for persons with impairments. The initiative contributed to a wave of research that focused on evaluating reforms, often with the emphasis on how they affected the everyday lives of persons with disabilities, their social relations, and the possibilities to influence that situation.

The extent to which there is a "Swedish social model" grew out of these ambitions to create a "strong society," which were directed toward general environmental reforms, and the perspective on disabilities was a relative one.

But since the "golden era of the welfare state" and the introduction of the relative notion of handicap, Swedish society has changed. The centralized social engineering that characterized the "golden age" has been succeeded by a more decentralized and individualistic system. In the field of disability, this manifests itself in several ways. One is the introduction of "right laws," where a person with a severe disability can apply for specific services to which she or he is entitled to by law. The social engineers and the state are no longer responsible for centrally intervening and producing the services but are, through legislation, trying to strengthen the position of the individual in his or her dealing with local authorities. The general trend of individualization is also mirrored in the way different actors in the field conceptualize influence for persons with disabilities. In the earlier period, influence meant influence for the disability organizations, something that mirrors the collective and cooperative ideas of the time. The "strong society" needed a strong collective counterpart to legitimate the reforms. Nowadays, *influence* always refers to the possibilities that the individual has to influence her or his everyday life. Also, a concept such as "empowerment" is nowadays usually interpreted as empowering individuals, not collectives, with common interests.

This means a substantial change in what might be called "the Swedish social model." Redistribution of resources by collective labels is substituted by legally strengthening the individual's possibilities to steer her or his own life. Material welfare is substituted by identity politics. Formal rights of individuals are emphasized rather than obligations of the state to correct unjust distribution of resources.

This change can also be noticed in social research, although it is not as obvious. Most researchers still try to apply a relative perspective on disability. But the emphasis in research mirrors the political changes by focusing on the political catchwords of today: participation, influence, and empowerment for individuals rather than collectives and organizations, as well as individual identities more than political ideologies.

The basis of the "Swedish model," the relative definition of handicap, is still adhered to in politics as well as research. But the application of that framework is now more individualistic than before.

In international literature, "the social model" referred to is usually the one developed by English disability researchers. That model has a strong materialistic base and emphasizes the oppression that different groups of the disabled share. In that sense, it can be said to be a collective model that also underlines the liberation from oppression to be a collective task.

In that perspective, the "Swedish model" developed in the 1970s and 1980s shares some characteristics of the British model, at least more so than the present individualistic one. But there are also differences, the major one perhaps being that the "Swedish model" was developed in a close interplay between central politicians ("social engineers") and organizations of the disabled and consequently was more reformist than the comparatively militant British one. One way of expressing the difference is to say that both the Swedish model (in both its earlier and its present manifestations) and the British model share a relative notion of disability, emphasizing the role of environment. But the Swedish model is more focused on the interplay between individual and environment at different levels, while the British model focuses on the environmental side of that interplay. Or, to put it another way, the Swedish model is a "weak" example of a social model, while the British model, at least in its earliest formulation, is a "strong" social model.

*—Mårten Söder*

***See also*** Disability Law: Sweden; Models; Politics of Disability: International.

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## SOCIAL NETWORKS

Social networks are basic building blocks of human experience. They map the connections that individuals have to one another. They also map relationships among organizations, for example, examining "cracks" in social service systems. Networks hold the potential to be rich sources of support, care, and information as well as monitoring, control, and hassle.

The idea that "others" are important has become a major focus in epidemiological and health services literatures. Much existing research has focused on the role of social ties, particularly social isolation, on mortality and morbidity. Networks have been demonstrated to be vectors of the incidence and prevalence of infectious disease, from common colds to HIV infection, as well as chronic problems such as heart disease. Networks have also been implicated in the consequence of health and disability, including the recognition of problems as physical or mental health issues, help seeking (e.g., knowledge, advice, access, system barriers), involuntary treatment (e.g., coercion), caregiving, adherence, and outcomes.

### THE NATURE OF NETWORKS

The central focus is on relationships between a social actor ("ego" or the "focal" person, organization) and the social actors ("alters") with whom they have a certain kind of relationship. Three overall characteristics are central to mapping social networks: structure, content, and function. Structure targets the overall size of the network, the different types of relationships that people can have (e.g., kin, coworker), the basis of connection (i.e., multiplexity), how tightly knit the social network is (i.e., density), and strength (strong/weak, frequent/infrequent, close/distant). Content taps the kinds of things that flow from or to each individual or organizational actor (e.g., social support, contact-based resources, positive/negative valence, belief structure). Network ties can be helpful or harmful; they can integrate individuals into a community or isolate them from others. Finally, networks serve a variety of functions—emotional support (e.g., care and concern), instrumental aid (e.g., lending money, providing transportation), appraisal (e.g., evaluating a problem or a source of aid), and monitoring (e.g., making sure a person takes his or her medications).

For health- and disability-related concerns, another simple distinction is important—external and internal social networks. *External social networks* are composed of family and friends, which Freidson (1970) referred to as the "lay referral system" and Wellman (1982) called "personal communities of meaning." They map individuals' community-based relationships and represent the more usual notion of "community ties." *Internal social networks* are ties within treatment and rehabilitation organizations and systems. They open up the "black box" of treatment by seeing it, at least in part, as the human provision of care. Internal networks are not "treatment," but any diagnostic, treatment or rehabilitation instrument, or medication or manipulation delivered by human providers in human service organizations. Interventions determine "what" is offered; internal networks shape "how" it is implemented.

Three types of external tie relationships are important: between individuals and providers (client-provider), among providers within organizations (provider-provider), and among providers across organizations (agency-agency). The nature of these provider- and organization-level networks influences client participation and outcomes. Finally, inside and outside networks meet at the interface of community and treatment networks. They can work together or in opposition.

## NETWORK THEORY

Social network perspectives aim to understand behavior through social relationships that shape everyday lives and experiences through exposure, consultation, resource sharing, suggestion, support, and nagging. While many epidemiological studies incorporate networks into their analysis of risk and protective factors, the most detailed theoretical frameworks address issues related to service use. For example, the health belief model, which focuses on whether individuals seek out preventive or curative medical services, incorporates social networks into its concept of normative influence. "Others" shape individuals' views of the efficacy and applicability of services.

The only existing network-based theory synthesizes work from a number of relevant traditions. The network episode model (NEM) starts with the idea that dealing with any health problem or disability is a social process managed through the contacts that individuals have in the community, the treatment system, and social service agencies. Interaction in social networks is the underlying mechanism at work, thereby contextualizing the response to disabilities in everyday life. Individuals are seen as pragmatic, having commonsense knowledge and cultural routines that they draw from past experience. People face disabilities by interacting with other people who may recognize (or deny) a problem, send them to (or provide) treatment, and support, cajole, or nag them about appointments, medications, or lifestyle. These day-to-day encounters provide meaning to issues surrounding health or physical impairment.

The "illness or disability career" marks all of an individual's attempts to cope with the onset of an episode of a health or physical impairment or associated acute illness episode, charting what individuals do and when they do it. Careers are embedded in personal lives and changing communities. At any time, network advisers may or may not be consulted, they may or may not be a stable set, or they may or may not be consistent in their advice. Strong ties may provide the greatest support, but weak ties act as a bridge to other resources. Too much oversight, whether positive or negative, can be stifling and repressive.

## MEASUREMENT ISSUES

Deciding which kinds of social networks are of interest and how to elicit the ties are critical issues. There is no standard way to chart network relationships—they may be derived from a list on a survey form where individuals are asked to name persons they trust, consult, or dislike. The information may come from observing the behavior of individuals (e.g., who they talk to in their work group) or the behavior of organizations, checking which organizations in the health care system have referral agreements. They may also be different from the perspective of the interacting parties.

In surveys, the selection of the "stem question" or "network generator" can determine, for example, whether a researcher taps into a personal support network, a trail of contacts in a search for information, or a set of formal treatment arrangements. The network generator can elicit ties sent (e.g., On whom do you depend for advice?) or ties received (e.g., Who depends on you for advice?).

Sociodemographic characteristics, such as age, sex, race/ethnicity, and social class, cannot be used as indicators of existing social networks because their role in placing limits around interaction partners is decreasing historically. Sociodemographic characteristics may interact with social networks, for example, making the influence of social networks different for men and women.

## FUTURE DIRECTIONS

Network theory contrasts with approaches focusing on individuals' cognitive maps. However, symptoms, identity, cognition, and even biology may shape and be shaped by social bonds. This view requires bringing together the expertise of different, traditional disciplines. Furthermore, networks are dynamic, not static, structures and processes. A consideration of the degree of change inherent in social networks requires that we consider the ebb and flow across time and over the illness career. This also raises the issue of the causal relationship between social networks and health status. The ability to form and maintain social ties may be the result of changes in health status (social consequence), not simply factors implicated in their cause (social causation).

Finally, a social network approach presents challenges in capturing social networks. Can they be measured with reasonable scientific precision and ethical sensitivity? Can we improve the measurement of networks while reducing their current cumbersome approaches? In 1986, Berkman suggested that adequate social network measures had not been developed and that this issue remains. We have only recently begun to discuss the inevitable ethical questions that surround asking people about intimate connections or using them clinically.

In sum, at this point in time, empirical findings mostly document that social networks matter rather than how or why they operate; how and why they change; how they are meshed with psychological, biological, or clinical factors; or how to efficiently and ethically map them.

*—Bernice A. Pescosolido*

***See also*** Caregiving; Community-Based Rehabilitation; Family; Peer Support; Social Support.

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## ▣ SOCIAL SUPPORT

Social support has been diversely defined in the human services fields, often as perceived social support in the context of relief of stress (Sarason, Sarason, and Pierce 1990). In its purer sense, social support is a positive aspect of exchange between or among parties, offering benefits for the persons involved, families, neighbors and coworkers, organizations, associations, and even the broader community and society (human ecological roots; Brofenbrenner 1979).

The research contributions in this field concentrate on negative support (Riley and Eckenrode 1986) and the costs of social support (Schumaker and Brownell 1984), in addition to an understanding of its benefits to the well-being of the person. Social support is viewed as buffering critical life events (e.g., Lin, Woelfel, and Light 1985) and provides protection against the difficulties encountered in life (e.g., unemployment, death of spouse, divorce).

Social support has been defined in family support as mediating outcomes for the child, person, and family. In the research sense, it is a "multi-dimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support" (Dunst and Trivette 1986:403). Social support is also a personality characteristic (attachment theory), a sense of acceptance, and highly related to concepts such as intimacy (Sarason et al. 1990).

Social support is viewed as enhancing child rearing in families and as "encompassing a multitude of activities, relationships and subjective appraisals" (Vaux 1988). One of the goals of social support theory and practice is to improve the skills of community resources. Social support has more than 20 years of research and is one of the largest literatures in community and social intervention (Barrera 1999) contributing to the growth in community support.

Social networks is a related concept and research area that introduces the complexity of social ties and their contradictory nature (Cochran 1990). Social network research involves the acquisition of friends, the neighborhoods, the family status, social class and structures, and cultures of the world (e.g., Sweden). Social support intervention is also one of the purposes of social support research and has been the subject of studies on children and families, in work and welfare, in the community and neighborhoods, and in caregiving and service systems.

Today, social support has been described as consisting of formal and informal supports (Bulmer 1987), improving the understanding of the service systems that have proliferated in nations such as the United States and in countries in Europe, Asia, and Africa. In this context, social support has been studied by contrasting the perspectives of service users and workers on support (Racino and O'Connor 1994). Social support theory remains as leaders in many fields worldwide both conceptually and practically merge it with the newer consumer empowerment theories, including in service systems (see Racino 2000).

*—Julie Ann Racino*

***See also*** Family; Peer Support; Social Networks.

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## SOCIAL WORK

Social work is a profession that includes practice with individuals, families, groups, organizations, and communities toward the goal of enhancing human functioning. A key concept in social work practice is simultaneous emphasis on change for both individuals and the environment. According to the Code of Ethics of the National Association of Social Workers (NASW) in the United States, the mission of the social work profession includes helping to meet the basic human needs of all people, with a primary focus on the needs and empowerment of people who are poor, vulnerable, and/or oppressed. People with disabilities have historically been an important group to social workers as part of their professional mission. Core social work values relevant to working with people with disabilities include self-determination, social justice, and dignity and worth of the person.

The NASW issued a policy statement in 2003 that discusses these core values with respect to working with people with disabilities. Self-determination is a key value that emphasizes the importance of working *with* consumers rather than providing services *for* them. The NASW policy statement mandates the promotion of full participation of people with disabilities in decisions regarding housing, community accessibility, education, employment, income, and health care. Consistent with another key value, that of social justice, the NASW statement emphasizes that social workers are responsible to take action with people who have disabilities toward advocating for their rights to fully participate in society. The value of dignity and worth of the person implies that social workers should recognize people with disabilities from a strengths perspective, which requires a focus on abilities rather than limitations. Although these ideals are consistent with the current emphasis in the field of disabilities on choice and empowerment, actual social work practice with people who have disabilities has room for improvement in meeting these ideals.

Throughout the history of services for people with disabilities, social workers have fulfilled many roles. These roles have included a micro focus on working with individuals and families, a midlevel focus on developing and managing programs for people with disabilities, and a macro focus on advocating for changes in policies and attitudes on behalf of and with people with disabilities and their families.

Over the past several decades, the specific roles of social workers working with people with disabilities and their families (micro-level practice) have varied and evolved depending on shifting paradigms and service delivery models. During the 1960s and before, a medical model of service delivery was prevalent, and persons with disabilities were typically characterized as patients who had disorders, illnesses, and impediments. Service delivery settings included large institutions and custodial care. Within this context, social workers were often part of an interdisciplinary team of health professionals. They frequently served as counselors who helped individuals and primarily their families adjust to the diagnosis and disability. During the 1970s and 1980s, a developmental approach was used in service delivery. Deinstutionalization was taking place, and community placement was the focus of intervention. Persons with disabilities were typically considered to be clients. Social workers served as case managers who coordinated individual program plans. These plans were focused along a developmental continuum that assessed skills needed by persons with disabilities to move them into less restrictive vocational and living environments. More recently, a support model of care is being implemented that considers persons with disabilities to be consumers and works to provide a number of individualized supports. The goal in this model is for consumers and their circles of support to direct their own service planning. In this context, social workers are collaborators with persons with disabilities and serve in roles as consultants and brokers.

Some examples of the support model are family support programs and cash and counseling programs. Family support programs are a way of providing flexible services to families who have children with disabilities through the provision of vouchers or cash allotments. Self-determination and empowering families are key components of these programs. Within family support programs, social workers serve as service coordinators, advocates, and brokers. Cash and counseling programs are a relatively new joint initiative of the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services. These programs allocate a monthly allowance to people with disabilities to use for long-term supports. A personal broker, who is often a social worker, is made available to help consumers make decisions about services, locate resources, and monitor the quality of supports and services. Consumers also have the option of managing an individualized budget instead of choosing a broker.

Although the support model of care is most consistent with the ideals and values of the social work profession, its implementation is in varying stages across the United States. Barriers to the expansion of home and community-based services include budgetary constraints and waiting lists. Furthermore, remnants of the medical and developmental models persist in many settings, and social workers continue to fulfill roles within these models.

In addition to support models of care, other domains that social workers are involved in include supportive living, vocational and employment services, health and mental health, transportation and accessibility, leisure and recreation, and social and sexuality issues. Social workers also fulfill roles in programs across the lifespan related to disabilities (e.g., birth to age three programs, school age, transition planning for older teens, adult services, and programs for the growing aging population). In their varying roles on the micro level of practice, social workers are trained to work across systems and on interdisciplinary teams as well. While health professionals address specific medical and treatment needs for people with disabilities, social workers complement these areas by working with people who have disabilities on social and environmental issues in their lives and on helping with the overall coordination of services. This may include advocating with and on behalf of consumers to eliminate barriers to receiving services or other necessities. Social workers are also involved in building bridges and supporting persons with disabilities to use the "generic" human service systems.

Within the field of disabilities, social workers are also involved in midlevel practice such as designing agency programs that serve people with disabilities and serving as managers and administrators of those programs. Social work education provides social workers with skills for community and administrative work, including the ability to see the larger picture of individuals and their interactions in the environment.

At the macro level, social workers are involved in advocating for and developing state and national disability policies. An important part of social work education is the development of skills relating to policy analysis and development as well as specialized skills in advocacy. Social work researchers are frequently involved in analyzing disability policy and programs and investigating the effectiveness of new programs and models of care. An example of social work professionals' involvement in advocacy is the active participation in the self-advocacy movement by the late Gunner Dybwad. Professor Dybwad was a social worker and lawyer by training as well as a professor at the Heller School of Social Welfare Policy at Brandeis University in Waltham, Massachusetts. Professor Dybwad, other social workers, and professionals in other fields have worked side by side with people with disabilities to build national organizations and a national movement to push for empowerment of people with disabilities on a political level.

In summary, the movement in the disability field toward self-determination and empowerment is consistent with the mission and ideals of the social work profession. While social workers are involved in the provision and coordination of services to people with disabilities, their role as collaborators and advocates is essential to their own professional values and to the disability movement. Social workers play valuable roles in service provision and ensuring quality of life for people who have disabilities, and these roles encompass micro, midlevel, and macro levels of practice.

*—Sandra Magaña*

***See also*** Empowerment and Emancipation; Health Care and Disability; Models.

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## SOCIOECONOMIC CLASS

*Disability* and *social class* are both contested terms, so this entry begins by noting the different ways in which both of these terms have been used by different actors and for diverse purposes. Subsequently, the interaction of disability and social class is examined in a range of key policy arenas (health, employment, income, and benefits and education). Because of difficulties in accessing international statistics in this area, selected Scottish and U.K. statistics are used. A different picture might emerge in different international contexts (e.g., the United States, Nordic countries, developing countries). Overall, it is argued that the relationship between disability and social class has not been widely explored in part because both these terms are conceptually complex. However, in his classic study of poverty in the United Kingdom, undertaken in the 1970s, Peter Townsend (1979) noted, "More of the working, than the middle class, particularly unskilled manual workers and their families, are disabled. Increasing incapacity is correlated with falling cash incomes. . . . At successive ages, greater incapacity was associated with greater risk of being poor." Today, the evidence continues to indicate that poorer people are more likely to be disabled, and disabled people become poorer as a direct result of their impairment and of the discriminatory attitudes and barriers that surround them. There is very little research and writing, however, on the subjective experience of social class and disability and the way these two elements interrelate in the formation of individual identities. Before discussing the available evidence, it is necessary to review briefly current thinking in relation to the conceptualization of both disability and social class.

### DISABILITY AND SOCIOECONOMIC CLASS: DEFINING THE CONCEPTS

In the welfare states of industrialized countries, disability has often been defined in terms of administrative categories devised by social security or social services to determine access to benefits and services. For example, Deborah Stone (1984) noted that disability originated as an "administrative category out of a collection of separate conditions understood to be legitimate reasons for not working." Major surveys conducted within the United Kingdom and Scotland have sought to determine how many people are disabled by asking whether individuals have a long-term illness or disability that has an impact on their normal daily activities or ability to work. Surveys conducted in Scotland for a range of purposes have produced similar findings with regard to the proportion of disabled people. For example:

- The Scottish Executive Health Department, based on its own data, estimated that there were 800,000 disabled adults in Scotland in 1999. This is about 20 percent of the adult population.
- The Scottish Household Survey of 2001 found that 20 percent of respondents reported a disability or long-standing illness.
- Labour Force Survey data estimate that there are 636,000 disabled people of working age in Scotland (20 percent of the working-age population).
- The Scottish Household Survey of 2001 found increasing incidence of disability with age. Forty percent of people age 65 or older reported a disability or long-term illness, in contrast to 5 percent of people ages 16 to 24.

The surveys referred to above adopt a categorical approach, assuming a dichotomy between disabled and nondisabled people. The Disability Discrimination Act of 1995 also operates on the assumption that a distinction may be drawn between disabled and nondisabled people. Under the terms of the act, a person is disabled if he or she has a physical or mental impairment that has a significant and long-term adverse effect on that person's ability to perform normal day-to-day activities.

This categorical view of disability has been challenged by the social model of disability, which drew a distinction between disability and impairment and emphasized the social relational nature of disability (see, e.g., the work of Michael Oliver [1990] and Colin Barnes [1991], key players in the development of social model thinking in the United Kingdom). Within the social model, disability is seen as independent of impairment in that it is a product of the social context in which impairment is experienced. Recently, postmodern and poststructuralist writers have taken these arguments further, critiquing the taken-for-granted distinction between disabled and nondisabled people. Writers such as Mairian Corker and Tom Shakespeare (2002) have argued that such dichotomies perpetuate Enlightenment fallacies that social categories and constructions are "real." Recent writing on disability, culture, and identity has draw attention to the diversity of disabled people's cultural experiences, which may be shaped by their age, gender, or ethnic identity as well as the nature of their impairment. There is, therefore, an unresolved tension between those who work on the assumption that the categories of disabled and nondisabled are meaningful, having their basis in material reality, and those who see these categories as social constructs.

Very similar tensions exist in the field of social class, and commentators have noted the problematic nature of social class categories. Many different definitions of social class exist, but they are generally based on the idea that an individual's social class position is determined by his or her access to economic, social, and cultural resources or capital. Social class is often defined in relation to occupation, and a number of classificatory models and scales are still used extensively. The Registrar General's Classification of Occupation, until recently the most commonly used system in the United Kingdom, grouped the population into six classes on the basis of occupation (1, professional; 2, managerial; 3-NM, skilled nonmanual; 3-M, skilled manual; 4, partly skilled; 5, unskilled). A similar social grade system is used by the Market Research Society (A, B, C1, C2, D, E). Such scales are frequently revised. For example, in November 1998, the Office for National Statistics (ONS) announced the U.K. government's new social classification system, the National Statistics Socio-Economic Classification (NS-SEC), which uses seven occupational categories.

There are a number of problems with occupational classification systems. For example, people who are economically inactive are classified as "other," and in certain parts of the United Kingdom, numbers thus classified may be as high as 50 percent of the population. Members of the category may be very diverse since it includes people on long-term incapacity benefits and those who have been out of work for a short period of time but are likely to find work, possibly at a professional level. The categories were defined with men rather than women in mind and do not accommodate easily families in which the mother and father have different occupations. In addition, as the service sector expands, more jobs are likely to be classified as 3-NM, but in terms of substance, pay, and degree of autonomy, these may differ little from jobs in the old manufacturing sectors. Furthermore, the categories do not readily reflect the position of young people such as university students. It is assumed that young people retain the social class of their families until they have independent jobs. However, with the collapse of the youth labor market in the late 1970s, there has increasingly been a delay in young people having occupational locations independent of their parents. Critics of the occupational classificatory system also point out that the category assigned to individuals may bear little relationship to their internal sense of social class. So, for example, those with professional occupations would be defined as middle class, irrespective of their social origins and identity. Even if individuals have professional occupations, their parents may have had unskilled occupations, and their working-class origins may be more significant in their identity than their more recently acquired occupational status. An assigned social class status may therefore have little subjective validity.

As a result of dissatisfaction with defining social class in relation to an individual's occupation, alternative ways of measuring deprivation have focused on assessing multiple indicators of deprivation. Classificatory systems, such as the Carstairs Deprivation Index, characterize geographical areas on the basis of the characteristics of individuals and households in those areas. The Carstairs Deprivation Index is based on measures of overcrowding, male unemployment, low social class (as measured by occupation), and car ownership. In Scotland, the population is normally distributed from 1 (least deprived) to 7 (most deprived), but some areas have far greater concentrations of people in the most or least deprived categories. For example, in the area covered by the Greater Glasgow Health Board, more than half (51 percent) of the population lives in deprivation categories 6 or 7.

Given the spatial distribution of deprivation, there are arguments over whether regeneration strategies should focus on individuals or on areas where there are clusters of deprivation. There are also debates between those who argue that poverty should be the focus of analysis and those who maintain that there should be a wider focus on social exclusion. The concept of social exclusion, which is highly influential within European and U.K. social policy, emphasizes the multidimensionality of marginalization, which may relate to, for example, people's ethnic as well as their social class location. Social exclusion theorists also stress the complex ramifications of exclusionary processes, which go beyond material deprivation to inadequate social participation, lack of social integration, and lack of power.

To summarize, in relation to both disability and social class, the use of categorical data has been criticized for imposing an oversimplified dichotomous worldview (see, e.g., Paul Abberley's [1987] critique of the OPCS [Office of Population, Censuses and Surveys, United Kingdom] categorization of disability, on the grounds that it is based on a medical reductionist view of the world). Alternative approaches have been suggested by cultural theorists such as Raymond Williams, who argues that social class goes much deeper than occupation and should be understood in terms of the structuring of emotions and consciousness. The sociologist Bourdieu (1984) developed the idea of social class habitus, reflecting the idea of social class as a fundamental framework structuring experiences and shaping the lens through which the individual views the world.

While categorical data on social characteristics have been criticized as tools of an increasingly managerialist society, it is important to remember that such information may also be used in pursuit of social justice goals. Monitoring of institutional performance against equality indicators is promoted by the British Equality Commissions and U.K. Government Social Inclusion Units. Some researchers have explicitly tried to work with both categorical and interpretative approaches. For example, Louise Archer's study of widening access to higher education adopted multiple strategies, using fixed categories to analyze statistical patterns of participation while also exploring the way in which particular groups of students negotiate their identities within specific institutional contexts (Archer, Hutchings, and Ross 2003).

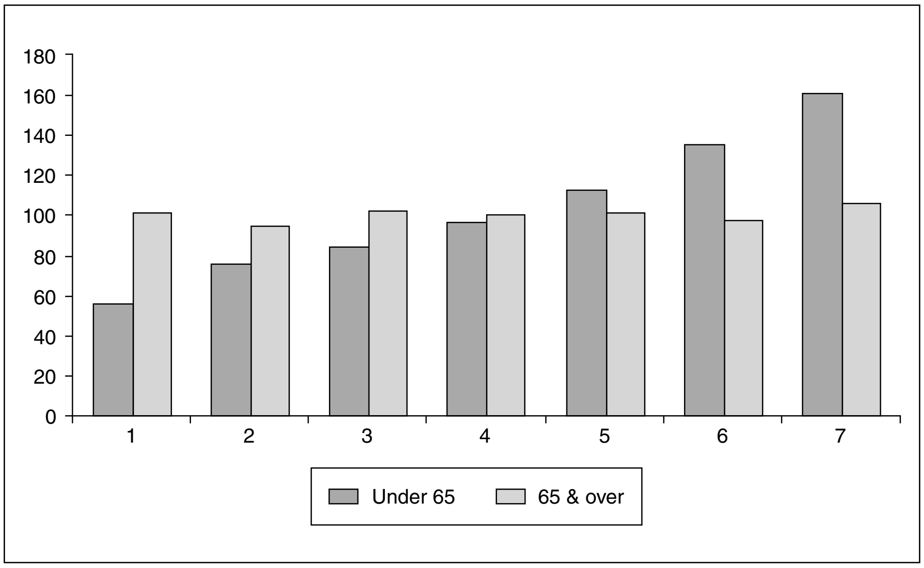

**Figure 1** Stroke: Standardized Mortality Ratios (SMR) by Deprivation Category and Age Group (1994–1998)

Source: Scottish Executive Information and Statistics Division, 2001.

Note: Deprivation categories 1–7 are based on the Carstairs Deprivation Index. See text for an explanation.

In the following sections, official statistics are used to explore some of the emerging relationships between social class and disability before considering the types of research that will be needed in the future to investigate the ways in which subjective identities and experiences are shaped simultaneously by a range of factors, including social class and disability.

## DISABILITY, SOCIAL CLASS, AND HEALTH

*Sickness* and *disability* are not synonymous, and many disabled people are perfectly healthy. However, it is important to recognize that people who are seriously ill are likely to be disabled; indeed, stroke is the biggest cause of long-term impairment in Scotland. Within a number of European countries, including Scotland, there are marked and growing inequalities between the health of richer and poorer communities. Abberley (1987) drew attention to the importance of investigating the social creation, as well as the social construction, of disability, pointing out that, particularly in the developing world, much illness and disability arise as a result of war, pollution, and the lack of access to clean drinking water and basic medication. In the developed world, the growing gap between rich and poor has led to greater diversity in life chances and life expectancy. It is extremely important, therefore, to examine the links between major illnesses and social class.

Figure 1 illustrates the relationship between stroke, deprivation category, and age. The incidence of stroke increases with age (in 1997–1998, more than 80 percent of people admitted to the hospital with stroke were age 60+). For people who are age 65 and older, there is no significant relationship between deprivation category and death from stroke. However, for people younger than 65, there is a very strong relationship. In essence, younger people from the most deprived backgrounds in Scotland are about three times as likely to die from stroke as people from the least deprived backgrounds. Among stroke survivors, about half are left with a permanent impairment. A recent study of young stroke survivors in Scotland, led by Pauline Banks of the Strathclyde Centre for Disability Research at the University of Glasgow, found that two thirds of these people did not return to work after experiencing a stroke.

There are also very strong associations between mental health problems and social deprivation. In contrast with the erroneous perception that high-flying business executives experience the greatest levels of stress, Figure 2 demonstrates that people with the highest levels of deprivation are about three times as likely to visit their general practitioner (GP) as a result of a mental health problem compared with those with the lowest levels of deprivation. Figure 2 also reveals an important story in relation to gender, with women in all social groups significantly more likely than men to visit their GPs as a result of a mental health problem.

Poorer people in Scotland are also more likely to be diagnosed with lung and cervical cancer, and among the four most common forms of cancer (lung, cervical, breast, and bowel), there is decreased survival with increasing deprivation. Scottish Executive data reviewed by Riddell and Banks (2001) demonstrates that children living in deprived areas are also more likely to be killed or injured in road traffic accidents. These findings all reinforce the arguments made by Carol Thomas that there is a need for a greater rapprochement between disability studies and medical sociology, recognizing that the latter may be one of the "engines for the formulation of an ever more sophisticated sociology of disability." The development of a social model of health in tandem with the social model of disability may help to develop a "materialist theorisation of disability, but one that encompasses questions of culture, difference and impairment."

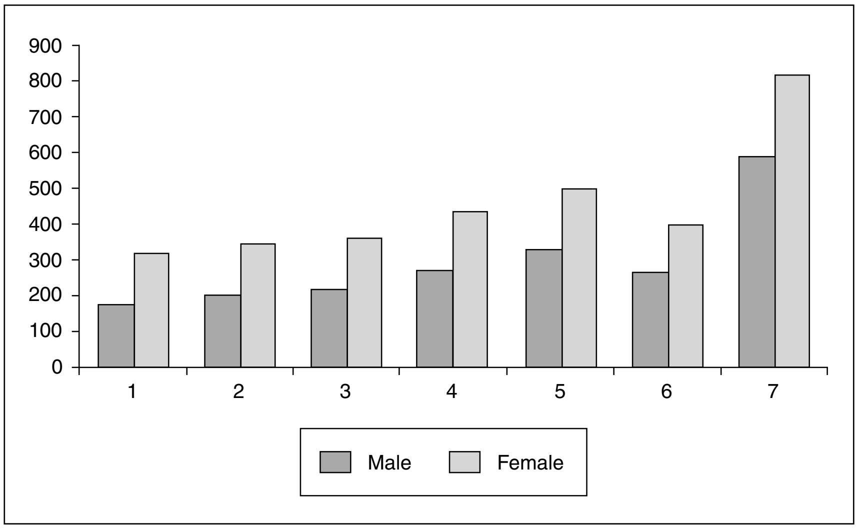

**Figure 2** Mental Health: GP Contacts (Rate Per 1,000 Population) by Deprivation Category in Scotland, Year Ending March 2000

Source: Scottish Executive Information and Statistics Division, 2001.

Note: Deprivation categories 1–7 are based on the Carstairs Deprivation Index. See text for an explanation.

## DISABILITY, SOCIAL CLASS, AND EMPLOYMENT

As noted above in relation to young stroke survivors, there are strong associations between disability, health, and employment, with significant consequences for income, quality of life, and life chances. Using Labour Force Survey data, Figure 3 illustrates the marginalization of disabled people in Scotland in relation to employment. In Scotland, in winter 2001, the Labour Force Survey found the following:

- Disabled people in Scotland account for 20 percent of the working-age population and 11 percent of the workforce.
- Of disabled people, 39 percent had work, in contrast to 81 percent of nondisabled people.
- Fifty percent of disabled people were not working and were on state benefits compared with 6 percent of nondisabled people.
- Of the disabled people of working age in Scotland, 22 percent were not working and were on state benefits but would like to work, compared with 5 percent of nondisabled people.
- Of the disabled people on benefits, 41 percent would like to work. This represents about 136,000 people.

The U.K. New Labour government emphasizes employment as the key to social inclusion, and in a green paper published in 1998, it promised "work for those who can; security for those who cannot." The government's strategy to improve the position of disabled people in employment is three-pronged. First, the Disability Discrimination Act (DDA) of 1995 (as amended) made it unlawful for employers to discriminate against disabled people in relation to employment, access to goods and services, and, since 2001, education. Second, a range of government-funded programs is intended to help disabled people enter and retain employment. Finally, as spelled out in a green paper published in 2003, access to long-term incapacity benefits is to be made more difficult, so that fewer people are certified as permanently incapable of working. Evidence of the success of these measures suggests that employers may not be aware of their new duties under the DDA and that government programs may offer insufficient support to disabled people, particularly those with higher support needs. The extent

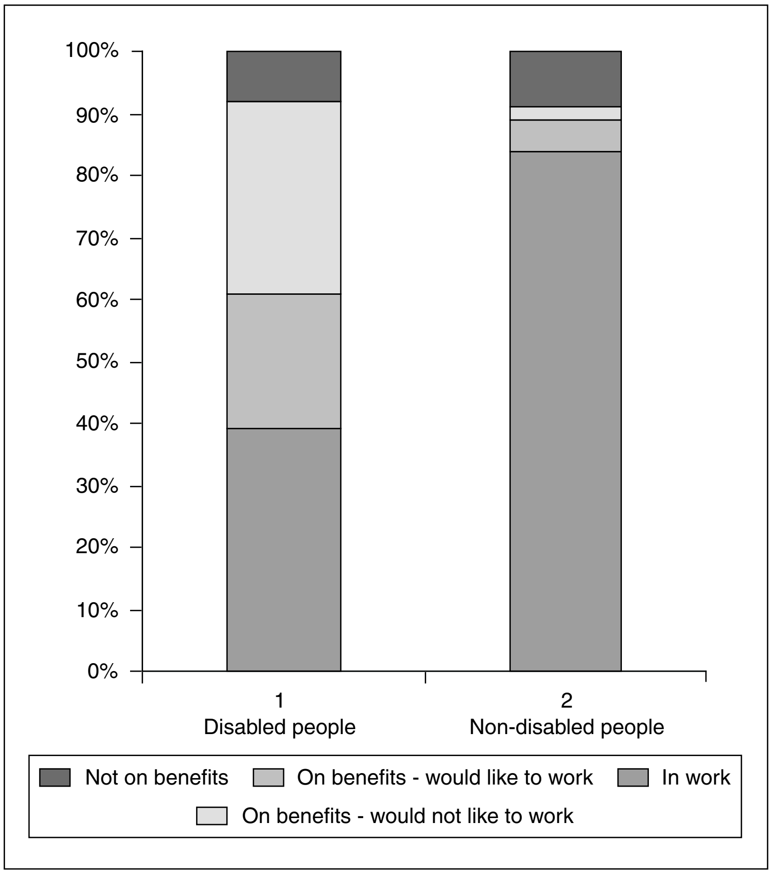

**Figure 3** Disabled People in the Labor Market in Scotland

Source: Labour Force Survey, winter 2001.

to which the government will be successful in its goal of reducing the number of people on long-term incapacity benefits remains to be seen.

The complexity of this area is illustrated by analysis of economic inactivity in Glasgow, based on data from the Department for Work and Pensions for 2002. In Glasgow, 111,000 (40 percent of the working-age population) claimed some sort of state unemployment benefit. Claimants fell into the following categories:

18,700 unemployed claiming Job Seekers Allowance

16,800 lone parents

70,800 sick and disabled

4,700 other category

There are thus almost four times as many people on long-term incapacity benefits as there are on unemployment benefits, and the percentage of people who are claiming long-term incapacity benefits accounts for 25 percent of the working-age population (1 in 4). Clearly, these numbers need careful interpretation; during the 1980s, there was a deliberate policy to move people onto incapacity benefits to massage the unemployment figures. For claimants themselves, there are advantages to claiming incapacity benefits because these are slightly higher than unemployment benefits, and at least until recently, there has been no pressure on claimants with incapacity benefits to seek work. However, as we noted in the previous section, Glasgow has very poor health compared with Scotland, the rest of the United Kingdom, and Europe. This results in extremely high levels of impairment, with serious consequences in terms of poverty and social marginalization.

The focus of research in relation to disabled people and employment has tended to be on those who are economically inactive because the level of long-term incapacity benefits claims is construed as a "social problem." Much less is known about the employment experiences of professional or skilled disabled workers, although Alan Roulstone (1998) studied disabled people's experience of new technology in employment and included a wide range of people, including those attempting to break into the labor market, who had little control over the technology, and those working in higher-level occupations, who had much more say over the way in which new technology was used to enhance their working lives.

## DISABILITY, SOCIAL CLASS, AND HOUSEHOLD INCOME

As noted above, disabled people are much less likely to be employed than are nondisabled people, and this has major implications for quality of life, power, and autonomy. Overall, 11 percent of the working-age population in Scotland receives incapacity benefits (although the proportion in certain areas, such as Glasgow, is much higher). Scottish Household Survey data in Figure 4 show that 33 percent of households with a disabled person have an income of less than £6,000, compared with 26 percent of households of persons without a disabled person. Only 6 percent of households with a disabled person have an income of more than £20,000, in contrast to 24 percent of households without a disabled person. As we noted earlier, disabled people are more likely to be poor than the rest of the population, and occupational-based measures of social class may fail to capture this concentration of poverty, classifying those who are economically inactive as "other," particularly if they have been out of work for many years or have never worked.

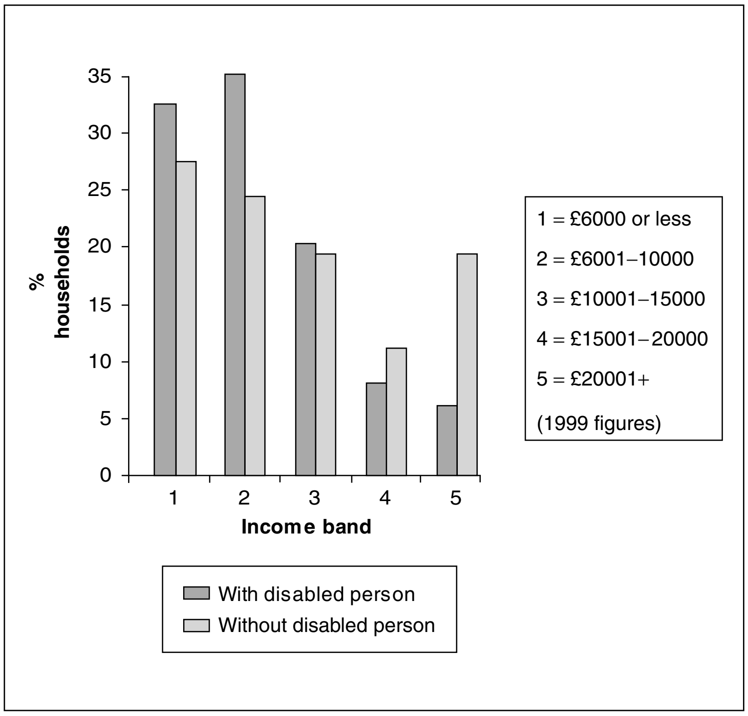

**Figure 4** Income for Households with and without a Resident Disabled Person, Scotland 1999

Source: Scottish Household Survey, 1999 (http://www.dataarchive.ac.uk/findingsData/snDescription.asp?sn=435).

## DISABILITY AND DECLINING SOCIAL CLASS

For many people, disability is linked to declining access to economic, social, and cultural capital. Research has demonstrated, for example, that the onset of illness or the worsening of a long-term condition is associated with a drop in living standards and the loss of employment. Figure 5, for example, draws on data from a study of people with neuromuscular dystrophies, led by Pauline Banks of the Strathclyde Centre for Disability Research, University of Glasgow. People with neuromuscular dystrophies were asked if they had a job, including self-employment, but were no longer working; how long they worked after first noticing symptoms of their illness; and at what age they had stopped working. Analysis revealed the following:

- More than half of all people with neuromuscular dystrophies (51.4 percent) stopped working prior to age 60. Of these, 33 (26.2 percent) stopped working in their 50s, 31 (24.6 percent) in their 40s, 28 (22.2 percent) in their 30s, 24 (19 percent) in their 20s, and 10 (7.9 percent) during their teens.
- Of people with neuromuscular dystrophies who retired before they were age 60 (n = 126), 54 (42.9 percent) did not work at all following the onset of symptoms, 39 (31 percent) worked for between 1 and 5 years, six (4.8 percent) worked for 6 to 10 years, and 27 (21.4 percent) worked for 11+ years.

Qualitative data from the Strathclyde Centre for Disability Research studies of people with neuromuscular dystrophies and Parkinson's disease indicated that the loss of work was accompanied by a deepening sense of financial anxiety and social marginalization. These findings echo Townsend's (1979) work, which documented the cumulative detrimental effects of lacking the financial resources necessary to participate in normal social events such as having holidays, visiting friends, and giving birthday presents.

It should be noted that there are negative consequences associated with having any member of the household with a disability. For example, living with an older disabled relative or having a disabled child affects the ability of working-age adults, particularly women, to hold down a job and advance in their career. This finding is reinforced by Kirsten Stalker's review of services supporting disabled children and their families in Scotland, funded by the Joseph Rowntree Foundation. A number of studies have also

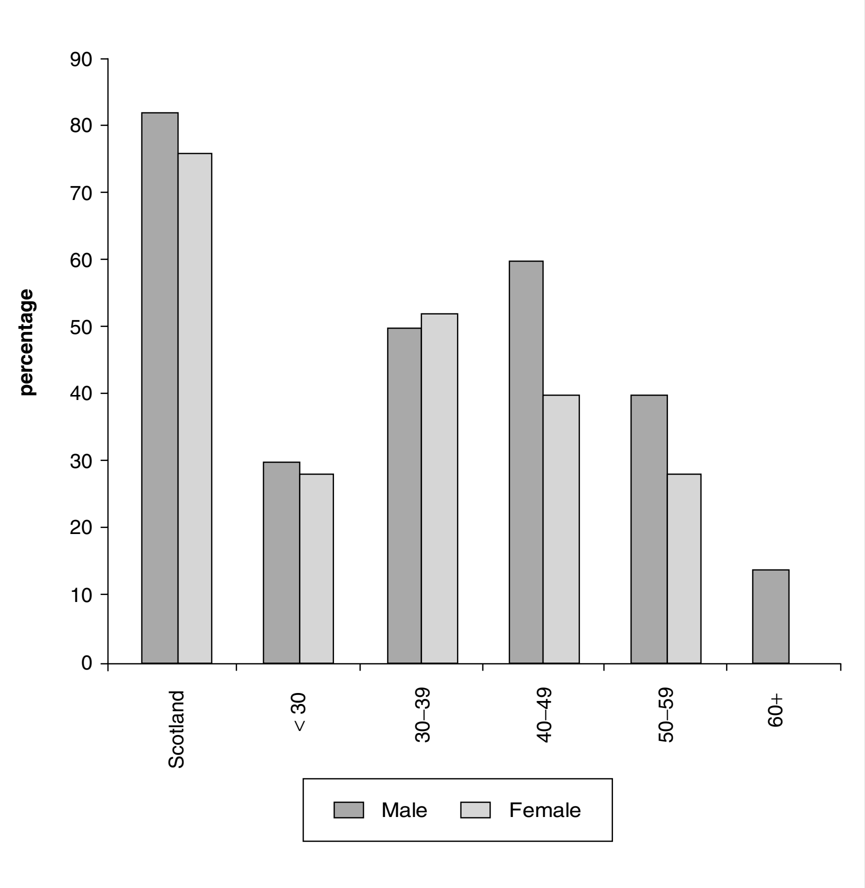

**Figure 5** People with Neuromuscular Disorders and Scottish Employment Rate by Gender and Age Group

Source: Edson et al. (2003).

pointed to the inadequacy of benefits that are intended to assist disabled people and parents of disabled children. In the United Kingdom, the Disability Living Allowance (DLA) is intended to help people with the added expense of having a disability. A recent study funded by Disability Agenda Scotland found that 97 percent of respondents had extreme difficulties in claiming the funds available, partly as a result of overcomplicated forms and difficulty communicating with the Benefits Agency.

A number of Scottish studies mentioned above indicate that many of those at risk of experiencing illness or having a disabled child are already leading a marginalized and stressful social existence and often living in poor housing conditions on rundown estates (see the data presented earlier on mental health problems, stroke, and deprivation). Local education, health, and social services may have become residualized, as market-based policies ensure that the more entrepreneurial are able to use services in more advantaged neighborhoods. The onset of illness or the birth of a disabled child may intensify an existing experience of social exclusion. At the same time, it is important to remember that illness or the birth of a disabled child may affect people across the social spectrum, including the relatively comfortable middle class. There is therefore a need for longitudinal research to track the interaction of illness and social class over time.

## DISABILITY, SOCIAL CLASS, AND EDUCATION

Within educational sociology, there is a considerable body of research in the "political arithmetic" tradition that has charted working-class pupils' poorer educational attainment on entry to school and their slower rates of progress compared with middle-class pupils during their time in school. More recent work has begun to explore the strategies used by middle-class parents to secure their family's positional advantage within education. While it is known that children of poorer parents, particularly boys, are more likely to be assessed as having moderate learning difficulties and/or social, emotional, and behavioral difficulties, studies of educational outcomes in relation to social class have generally not considered disability as a key variable. There is a body of work, however, that has explored the construction of deficit categories in school over time. It has been noted, for example, that dyslexia is much more likely to be diagnosed among middle-class than working-class pupils.

Within the higher education sector, greater attention has been focused on access to higher education

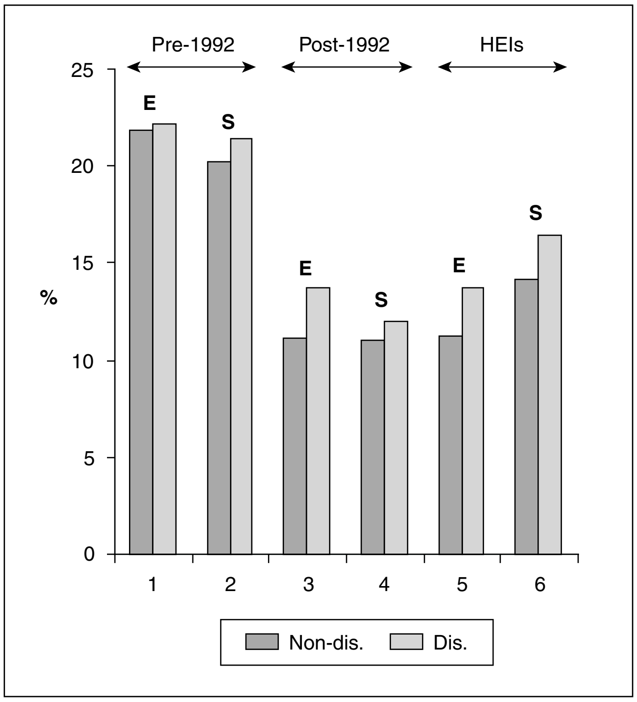

**Figure 6** Percentage of Undergraduates from Social Class 1* by Sector, Country, and Disability Status

Source: Higher Education Statistics Agency, 2002.

*As defined by the Office of Population Censuses and Surveys.
E = England; S = Scotland.
*HELs*: Higher education institutions without university status.

over recent years, given the growing importance of higher-level qualifications in accessing professional and managerial employment. Studies have traditionally compared the relative chances of children from working-class and middle-class families of winning a place in higher education. Government reports on widening access to higher education have picked up on these studies and have often interpreted access to higher education in terms of enhancing the access of children whose parents (usually fathers) have working-class occupations or are from low participating neighborhoods and schools.

Until 2002, data on the disability status of higher education students were not published by the U.K. Higher Education Statistics Agency. Disabled students are now included officially as an "underrepresented group," and the disability indicator is based on the number of students receiving the Disabled Students Allowance on the basis of a needs assessment. The Funding Councils make additional premium payments to institutions based on social class and disability indicators. The benchmarks published in relation to each indicator are based on the performance of other comparable institutions in the sector and are intended to signal to institutions whether they are performing better or worse than expected.

Recent work by Riddell, Wilson, and Tinklin (2002) on access to higher education in the United Kingdom has looked at the interrelationships of a range of variables, including social class, gender, disability, and ethnicity. Higher education institutions fall into three categories: traditional pre-1992 universities, new post-1992 universities, and higher education institutions, which have degree-awarding powers but not university status. The findings, shown in Figure 6, indicate that disabled students in the elite universities share the privileged social class background of the majority of other students in those institutions. This again underlies the point that it is quite wrong to regard disabled people as a homogeneous group. The divisions among disabled people in relation to social class, ethnicity, gender, and nature of impairment need to be investigated to develop a more sophisticated sociology of disability.

## DISABLED PEOPLE AND REGENERATION

It was noted earlier that there have been ongoing debates about whether deprivation should be measured on the basis of an individual's social class or in relation to the cumulative measures of deprivation within an area. Traditionally, urban regeneration programs have focused their energies on areas rather than individuals. However, recent reviews of regeneration strategies have indicated a tendency to base their interventions on the assumption of a homogeneous population. Little attention has been paid to the particular situation of disabled people, those from minority ethnic groups, travelers, lone parents, and so on. Regeneration programs have frequently sought to involve community groups, but disabled people have rarely formed pan-impairment groups and, as a result, have not been easily identifiable in consultation processes. Where disabled people have been involved in regeneration strategies, it is often as a result of a particularly targeted initiative, and they have rarely been included in consultations as ordinary members of communities. Given the overrepresentation of disabled people in areas of deprivation, it is important that more effective ways are found of consulting and involving them in local economic development.

## CONCLUSION

We began by noting the conceptual problems in trying to work with disability and social class as social variables. Nonetheless, the categories do still have some utility as organizing frameworks connected to the material realities of people's lives. Statistical data were used to demonstrate that people experiencing high levels of deprivation, another way of measuring social class, were much more likely to experience serious health problems than people living in more socially advantaged circumstances. Attention was drawn to the concentration of disabled people among those classified as economically inactive, highlighting the problem with traditional measures of social class, which would assign all those not working to the category of "other." Data on household income revealed the financial consequences of exclusion from the labor market, with many households including a disabled person experiencing a significant degree of poverty. Despite the evidence of the links between social deprivation and disability, as well as the tendency of the onset of illness to trigger further social and economic hardship, urban regeneration programs have tended to bypass disabled people because of their invisibility.

Overall, there appear to be strong arguments for the development of more research that systematically investigates the links between different equality and social justice concerns, so that people are not conceived of as unidimensional subjects. Such studies would also need to track changes in social identity and social status over time. This is in line with the U.K. government's attempts to "mainstream" equality issues, possibly establishing a single commission to deal with all six equality strands covered by Article 13 of the European Union's Employment Directive. However, it should be noted that social class does not feature as an equality issue, being dealt with as a social justice concern under a separate policy stream. Much research on disabled people, including work informed by the social model, has tended to assume that all disabled people have similar social class backgrounds and therefore encounter the same barriers. Research such as the higher education study, referred to above, notes that disabled people from socially advantaged backgrounds may share some of the positional goods of their social class, such as access to elite higher education institutions. Recognizing the diverse social class interests of disabled people may be seen as undermining the unity of the disability movement, but in the long run, a more nuanced analysis is likely to lead to a stronger sociology of disability that is able to feed into the future development of the political movement.

*—Sheila Riddell*

***See also*** Economic and Social Development; Economic and Social Development, International; Employment; Employment, International; Poverty.

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Strathclyde Center for Disability Research, http://www.gla.ac.uk/centres/disabilityresearch/publications.htm

## SOCIOLOGY

The identification and experience of disability takes place on a daily basis within the social context, whether in the home or workplace, a rehabilitation center or a shopping center, a neighborhood or a foreign country. Because of this, sociology, which is a discipline that examines the social structure as well as social relationships and interactions, provides a key perspective to understanding that identification process and the experience of living with a disability. Disability is most commonly examined within the specialization of medical sociology, which is an area that focuses on the structure of the health care system as well as the delivery and receipt of health care within the health care institutions that have been developed in a particular society. These institutions can be hospitals, rehabilitation facilities, and health maintenance organizations in the broader U.S. society or the system of barefoot doctors within the Chinese culture. However, many of the other specialty areas of sociology can also provide insights into how we come to define disability and the ways that disability affects personal experience and relationships.

As a discipline, sociology provides ideas about how things work, at either a macro level or a micro level. Those ideas help to explain outcomes associated with a particular organizational structure or relationships in a particular social setting. For example, at the macro level, understanding how the factors within an organizational structure that are part of the accepted way to do things can either facilitate or inhibit the access of people with disabilities to employment within that organization. Sociologists try to understand these underlying assumptions that guide organizational behavior and thus create the outcomes that are observed. At a more micro level, sociologists try to understand how people interact with each other and what aspects of the cultural norms influence interaction in a variety of settings, both formal, such as a court of law, and informal, such as the family setting.

More than ever before, populations in most societies are experiencing circumstances that lead to disability, and these can also be addressed by sociological perspectives. It makes no difference whether the population varies ethnically, racially, or by age or gender; the increased presence of chronic illness, effects of pollution from environmental toxins, industrial or automobile accidents, and the increase in armed conflicts throughout the world create disabling problems for people everywhere. How, when, or why a society intervenes will influence the number and types of disabilities developed among the population. Medicine has taken on primary responsibility for those who experience disease or injury, but medical institutions, medical knowledge, and medical technology are inadequate to address all the issues that take place in the social context of the person who is born with or acquires a disability during his or her lifetime. Sociology as a discipline has developed a group of theories about how the social structure works or how people interact in social relationships. Any number of these can be applied to the study of disability.

One of the first and most important contributions of sociology to our knowledge about disability is the understanding that what constitutes "disability" itself is socially defined. Saad Nagi, a sociologist, was among the first to observe and write about the importance of the social context in defining and understanding disability. In 1965, he noted that disability can be understood as a pattern of behavior that evolves in a situation where there is long-term impairment associated with functional limitations. He described how these patterns of behavior are influenced, not only by the characteristics of the impairment and subsequent functional limitation but also by very socially defined aspects of life. These social aspects include the individual's definition of the situation and his and her reaction, *as well as* the reactions and expectations of those around the individual with the limitations. In more recent years, theoretical models of the relationship among impairments and functional limitations and social contextual factors have proliferated, with the Institute of Medicine model and the World Health Organization model being widely regarded as the most important. While there are some disagreements between the two models, both rely heavily on sociological concepts about social structure and social role.

## SOCIAL DEFINITION

Paul Higgins (1992) has helped to explain how society defines disability by elaborating on the processes that are involved in that construction. Higgins and others have pointed out that we make disability through our beliefs and behaviors, through our interpersonal interaction, and through our organizational and social activities, and it is an active process that is ongoing daily. The beliefs and actions of a particular culture about disability are built through government policy, the media, programs that serve the disabled population, work or school situations, and the family. An important point to recognize in this process is that we produce the variation we recognize in others, whether it is associated with physical or mental capacity or skin color or age or gender. While this approach helps us understand how disability comes to be defined, it also documents how having a disability or being labeled as having a disability is experienced.

Most conceptualizing of disability individualizes the phenomenon; that is, the problem or condition is seen to reside within the individual. This is particularly reinforced in the medical setting, where the disease or impairment is diagnosed, labeled, and, if possible, treated. This is not necessarily inappropriate in that particular setting. However, when that label is attached to the individual, it not only provides a protocol for treatment but, when taken up by other branches of the social structure, also provides a validation for attributing the problem to the individual, thereby reinforcing the differentiation. Other elements of the "defining" process are associated with the socialization process, which is a common concept in sociology. We are all socialized into a variety of roles as we grow and mature. Our family socializes us to the role of son or daughter, sister or brother, while our schools socialize us to be students and to take on roles of independence such as work roles, citizenship roles, and others. Thus, the expectation that a person with an impairment or functional limitation is somehow less independent or less able to do certain tasks or take on certain roles (such as working) becomes a part of the social interactions surrounding and molding the person.

Other useful approaches to understanding the social construction of disability have also been developed. The minority group perspective that was developed by Hahn (1988), Gliedman and Roth (1980), and others does help to develop the conceptualization beyond the individual and forces the recognition of prejudice and discrimination toward the group of individuals with disabilities. A precursor to this approach was the study of attitudes toward persons with disabilities, which demonstrated that some impairments, such as mental retardation, are viewed more negatively than others. While the focus on attitudes was still based on the individualized approach to disability, it documented the widespread and relative uniform prejudice and discrimination toward specific groups. The minority group perspective was a step toward considering individuals as part of a group, regardless of their individual impairments, and subject to experiences because of their group membership rather than their individual characteristics.

## SOCIAL MOVEMENTS

Sociological social movement theory has also contributed to understanding the changes in the opportunity structure for persons with disabilities in more recent years. As an outgrowth of the minority group perspective, Barnartt and Scotch (2001), among others, began tracking how persons with disabilities have sought to regain power and self-determination by participating in protests and other actions to improve (and, at times, reclaim since many acquired disability at later ages and at one time had lived as the "standard" of expectations) their status in society. In many ways, the upsurge of the disability movement, which began to be evident in the early 1970s, was not unlike the civil rights movement and the women's movement, although it took quite a while for the movement to gain the widespread support and recognition those earlier movements received.

Social movements are a form of collective behavior that occurs outside of the usual social structural context. Sociological theory provides discussion of the membership and goals of social movements as well as the types of tactics used in social movement activities. Basically, these movements are a reflection of power and politics and are generally focused on change of some sort. What is interesting about a social movement on disability is that the participants need to develop a collective consciousness to see beyond their individualized impairment. With the development of this consciousness on the part of persons with disabilities, the purpose of moving the social structure beyond the individualized perspective is solidified.

Early social movement activity by parents and caregivers for persons with disabilities, particularly mental retardation and mental illness, was aimed at improving conditions for these individuals who were often living in institutions. But those early movement activities did not reflect a collective consciousness on the part of persons with disabilities themselves, which was essential to develop the emotion needed to engage in the risky actions necessary to demonstrate the issues. The development of this collective consciousness across impairment types and the ability of those with disabilities to see themselves as one group with boundaries and also as one group with common experiences of prejudice and isolation was an important step in changing the social structure not only attitudinally but also physically.

As with blacks in the civil rights movement and women in the women's movement, a very important issue for the disability movement was equal opportunity, as represented by equal access to education and employment. However, the demands of the disability movement go further to address the issues of environmental accessibility of the built environment so that the buildings housing the education or work opportunity, as well as the shopping areas and other commercial areas, are useable for the population. Even governmental entities such as motor vehicle offices, public transportation, and the voting place have been areas for the focus of equal access.

## MEASUREMENT AND COUNTING

The success of the disability social movement in changing both the social structure to protect the civil rights of persons with disabilities (as represented by the Americans with Disabilities Act) and the environmental access of people with disabilities to the built structure (through the Architectural Barriers Act) has created an imperative to be able to measure and count persons with disabilities to monitor the success of these laws. Sociology methodological studies have made an important contribution to this activities. However, measurement and counting are very tenuous activities. Measurement of a phenomenon is very much influenced by how it is defined, and the definition is associated with the purpose of the counting activity. The policy issues associated with these laws and other programs focused on the disabled population create a need for a fixed and dichotomous way to identify the population similar to a measure of sex or race. However, in fact, disability is more accurately conceived of as fluid and continuous. Irving Zola (1993), whose work made well-known contributions to the sociological study of disability, wrote about this problem with measuring and counting persons with disabilities and identified many of the problem areas.

A well-known analysis about the political aspects of enumeration concludes that "political judgments are implicit in the choice of what to measure, how to measure it, how often to measure it and how to present and interpret the results"(Alonso and Starr 1987:3). How we define disability, often a political decision, can make a great difference in how many we count and who we count. For example, if we define disability in terms of chronic disease conditions, we will undoubtedly find a different number than if we define disability in terms of specific functional limitations experienced by the individual. Not only will the numbers be different, but the people who are counted can also be different, at least partially, since not all persons with chronic conditions have functional limitations, and not all persons with functional limitations have chronic conditions.

Today, several groups, involving sociological methodologists, are seeking to define disability and measure it for a variety of purposes. Concern with the employment rates of persons with disabilities has prompted the Bureau of Labor Statistics to develop a measure of disability to use in its surveys that track employment rates of the working-age population. At the same time, another group associated with the census also seeks to develop a useful measure to identify the population with disabilities for the purpose of distributing resources and developing programs nationwide. This measure is of concern to the Social Security Administration as well since workers who can no longer work because of disability are eligible for benefits. Budgeting for this group requires accurate estimates of the potential numbers who will seek those benefits.

Once again, measurement of disability in large social surveys or in the census focuses on the individual and identifies a person as disabled based on his or her conditions, impairments, level of physical functioning, or ability to participate in major roles such as work roles and family roles. While the social movement activity and the theoretical models that explain disability have introduced the very important element of the environment to understanding that disability is the result of the interaction of the person with his or her environment, we are not yet able to adequately measure environment. Much of the social science research that contributes to our understanding of disability and the circumstances of the person with a disability is based on large national surveys whose methods for measuring disability vary widely. Great care must be taken in developing the measures, using the measures, and interpreting the measures and the results of analyses, be it levels of employment, living arrangements, or the use of assistive devices. Sociology has taken a lead in this important work.

As this brief discussion of the application of sociological theories, methodologies, and perspectives shows, sociology has been a rich source of intellectual ideas to help in understanding disability. Sociology contributes to a clear understanding of how the human variation that is identified as disability has come to be defined, both interpersonally and structurally. It has also contributed to developing measures of this phenomenon and interpreting the measures and the counts of persons with disabilities that result. Sociology also holds the potential for further contributions to the study of disability by providing a greater understanding of the role of the environment and the larger political context as a counterbalance to the interpretation of the individual responsibility for the problem. The important contributions of sociology to understanding the causes and consequences of poverty, the role of gender in the life of an individual, and the structure and functioning of social organizations are indicators of the largely untapped resource that sociology can provide to this field. In addition, the study of disability provides an important challenge to the field of sociology. Disability is a multifaceted construct, with all the complexity of gender or race but with additional dimensions as well. It can provide a test of the theories and methodologies that have been so carefully crafted over the past 100 or more years and will undoubtedly improve and refine those theories and methodologies in the process.

*—Barbara M. Altman*

***See also*** Disability Studies; Models; Research.

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## SOCRATES 469–399 BCE

*Greek philosopher*

According to his intellectual heirs, Plato and Aristotle, Socrates ceaselessly engaged his fellow citizens in an examination of the right way to live by a method of cross-questioning. Socrates's contemporary, the comic Aristophanes, shows us another side of the Athenian perception of Socrates, in which his interests are esoteric and his methods are annoying. From the perspective of disability studies, Socrates is especially interesting for two reasons. First, he is characterized in literature and in artistic representation as extremely unattractive, a counterpoint to the idea that the Greeks believed that wisdom and beauty were inseparable. Second, Socrates's characteristics, such as his susceptibility to trances and his unkempt appearance, would be categorized today as a medical diagnosis, perhaps schizophrenia or autism. Temple Grandin, in *Thinking in Pictures* (1995), points out that genius is, after all, an abnormality. Grandin describes geniuses such as Albert Einstein, who had little sense of social convention or personal appearance—"he just did not care" (p. 183). At the height of classical Athens, Socrates was tolerated—and venerated by some—for carrying out what he thought was his duty to be a stinging fly biting the horse of Athens so that Athens would not become complacent. After the disastrous Peloponnesian War, when Athens had crumbled and its citizens were nervous, a jury of his peers condemned Socrates to die in 399 BCE.

*—M. Lynn Rose*

***See also*** Aristotle; History of Disability: Ancient West.

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## SOKOLOV, SERGEY I. (1888–1945)

*Russian organizer of the Moscow Society of the Deaf*

Sergey I. Sokolov was one of the organizers of the Moscow Society of the Deaf (1912) as well as chairman of the All-Russian Union of the Deaf (1917–1920). In the 1930s, he organized and was the director of a training course for sign language interpreters.

*—Anna Komarova and Victor Palenny*

***See also*** Deaf, History of the; Sign Language; Sign Language Interpretation.

## SOUTH ASIAN ARCHETYPES

In the Indian epics *Mahabharata* and *Ramayana,* characters such as blind King Dhritarashtra and his blindfolded wife, Gandhari; Ashtavakra, the "eight ways disabled" scholar; and the crafty hunchback Manthara (also known as Kubja) may be hard to link with historical people having dates of birth and places of residence. However, over centuries, they have been popular South Asian archetypes of disabled persons, known to hundreds of millions of people through local dramas drawn from the epics and, more recently, on film, video, the Internet, and schoolbooks.

Dhritarashtra, born blind, was thereby disqualified from kingship. He managed, nevertheless, to acquire the kingdom after his half-brother Pandu died. His disability and legitimacy thus became pivotal to the conflict between his own sons and Pandu's sons, providing the frame story for the *Mahabharata.* Dhritarashtra married Princess Gandhari, who immediately began wearing a blindfold to avoid the shameful situation of knowing more than her lord. Later, Dhritarashtra complained to his driver that because he was blind and could not engage actively in the conflict, his eldest son Duryodhana considered him a fool and paid little heed to his words.

Ashtavakra also appeared in the *Mahabharata.* When the learned Kahoda's wife became pregnant, the fetus, who was already well versed in the Vedas, found fault with Kahoda's reading. Kahoda cursed his yet unborn critic to be eight ways crooked. At King Janaka's court, Kahoda was defeated in academic debate by Vandin and forfeited his life. Later, as a young man, Ashtavakra went to King Janaka, but the guards refused him entry. He then asserted his rights as a Brahmin over "the blind, the deaf, the women, carriers of burdens, and the king respectively." He gained admittance and defeated Vandin in debate. Kahoda reappeared and reflected that weak men may have strong sons, stupid men may have clever sons. Ashtavakra later entered the river Samanga, and his limbs were straightened.

Manthara, hunchbacked maid to Queen Kaikeyi, was the hinge on which the *Ramayana* frame story turned. When King Dasaratha, the (earthly) father of Rama, became decrepit and nominated Rama to succeed him, Manthara persuaded the junior Queen Kaikeyi to campaign for enthronement of her own son instead. Manthara's wiles resulted in Rama's exile to the forest with his wife Sita. In Valmiki's *Ramayana,* Queen Kaikeyi thought that women with deformities were usually sinful and perverse, but Manthara's "hunch" contained her knowledge and wisdom. In some versions, Rama later reflected that in his boyhood, he teased Manthara about her disability, and this was why she took revenge on him or was the instrument by which the consequences of his mistaken conduct were visited upon him. (Such reflections do not appear in later versions that emphasize the divinity of Rama.)

*—Kumur B. Selim*

***See also*** Experience of Disability: India; India, Impact of Gender in; India, Marriage and Disabled Women in.

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# SPECIAL EDUCATION

## THE HISTORIES

Depending on the perspective taken, special education can be defined as follows: a legally mandated system of services that ensures access to educational provision for disabled students and their families; a mechanism that ensures some, but not all, children will be afforded access to life opportunities as a consequence of historically inequitable educational provision; or as an institutional safeguard to protect students and teachers in the general education system from the problems posed by disability and difference in public schools. Despite recent efforts that call for "inclusion" in public schools through the return of disabled students to the general education classroom and their neighborhood schools, special education continues to predominate within practice. In teacher education programs, inclusive education now forms part of the curriculum, either replacing "special needs" provision or coexisting uneasily with it. According to Slee (2001), inclusive education has been adopted enthusiastically by special educators because it has enabled them to continue their practices from a publicly acceptable base and to convert the student teacher into a "card carrying designator of disability" (p. 171).

Rather than retell the often-told story about special education and its origins in the Western world, what is offered here is an attempt to trouble that which Brantlinger (2003) casts as the "peaceable kingdom" narrative of continuous progress in the field of special education. We draw from primary sources and the analyses of some historians (Foucault 1977; Richardson 1999; Trent 1994) to question the naive interpretation of linear progress that typically frames special education despite its obviously problematic core assumptions. These include the following: (1) disabilities are pathological conditions that students have, (2) differential diagnosis is objective and useful, (3) special education is a rationally conceived and coordinated system of services that benefits diagnosed students, and (4) progress results from rational technological improvements in diagnostic and instructional practices (Skrtic 1991). We also draw on contemporary scholars (Baker 2002; Slee 2001, 2004) to trace some of the key elements in the trajectory of special education and to analyze the nature of its resilience.

## THE GENESIS OF SPECIAL EDUCATION

Depending on the perspective taken, special education histories trace back over centuries, with origin stories that generally begin with a recounting of educational provision in special schools for deaf and blind students early in the 1800s and, later, for students with physical, cognitive, and emotional disabilities. The creation of the special school in contexts across the world isolated the disabled individual from the community as such facilities were typically located in rural settings where educational provision was impairment specific and cast in the rhetoric of individual and specialized instruction. Undeniably, contemporary special education is informed by multiple histories, some more nuanced than others and some that remain, as yet, unexcavated. Our analysis aims to inform awareness of the conditions that emerged to establish the need for special education and its unyielding resilience. Our insights fall outside the narrative of rational technical progress in the field of special education "proper" as this remains a naive and unproblematized history of self-congratulation among professionals for the hard-won rights of children. The trajectory we provide considers issues of practice and the resulting effects of special education on children and their families. Likewise, our analysis troubles the critical links between special education and class issues rooted to economic need and the growth of industrial capitalism in both the United States and the United Kingdom.

## COMPULSORY SCHOOLING AND SPECIAL EDUCATION

Richardson (1999) provides insight into the effects of compulsory attendance laws that ultimately served as an "essential precondition" for the development of policy and the systematic provision of special education services. The evolution of European-based practices of book learning and apprenticeships in the trades, accompanied by mandatory "enrollments of indenture" that included a range of student abilities, would, no doubt, inform inclusion as it is cast in the present moment. What is pertinent here, however, is that by the mid-nineteenth century, "standardized" education across society was becoming common. At roughly the same time, the "invention" of idiocy signaled the launch of processes to differentiate dependent people throughout society. In the language of contemporary special education discourse, the early nineteenth century signaled the beginning stages of the development of qualification criteria, needs identification, assessment, and the necessary legal authority to act on behalf of children with special needs. Through these established disciplinary mechanisms for social control, as Foucault (1977) has argued, communities were empowered to exercise compassion and benevolence toward the "poor and the infirm." This nascent form of special education turned on securing the legal authority to supersede the traditional rights of parents in favor of arguments for the promotion of a broader welfare. Over time, these disciplinary mechanisms advanced a form of professional zealotry common among many special education professionals who position themselves as advocates driven to act in the "best interests of the child." Despite mounting evidence that long-term placement in special education yields poor academic and social gains for children (National Council on Disabilities), the profession maintains that theirs is a moral calling to act on behalf of children with disabilities (for an insightful critique of the profession, see Skrtic 1991; Slee 2001, 2004; Tomlinson 2004).

## SPECIAL EDUCATION PRACTICE

Public school classes for mentally defective children were common throughout Europe in the late 1800s and as early as 1867 in Germany. Although some institutions in the United States imported the European model, others pressed for a community-based response to the education of feebleminded children. Citing decades of limited success among the American institutions to sort successfully the feebleminded from the "merely" backward youth, Walter E. Fernald, superintendent of the Massachusetts School for the Feeble-Minded, called for improved technologies and the creation of special classrooms in urban public schools (Fernald 1904). He was at once sympathetic to families forced to institutionalize their children in their "tender" years and critical of those families who "lacked" the desirable moral and intellectual influences necessary for encouraging proper developmental gain among their offspring. This early campaign to relocate children from institutions to their local community and schools slowly shaped the view of special education as a place rather than a service—an enduring problem inherent in our dual system of service delivery model in the twenty-first century.

## SPECIAL EDUCATION AS PLACE

By 1917, compulsory schooling was well under way in the United States, and for students unable to progress through the system of a graded curriculum, the "special class" emerged. Similar in structure to the special school, provision in the special class was disability specific and cast in the rhetoric of individual and specialized instruction. A close examination of the historical record of compulsory education provides insight into the organizational dilemmas posed by enacting schooling for the "backward child"—the then commonly used terminology for students in need of schooling that was "less for the head and more for the hand," as Ware (forthcoming) has observed. Earlier distinctions of difference included terms such as "troublesome, truant, backward, defective, retarded, slow, mentally deficient, those with excessive 'badness' and those with physical and mental markers of imbecility or idiocy" (Ware forthcoming). Buried within these descriptors was reference to the foreign-born and burgeoning immigrant population. Under the auspices of improved social welfare, kindergarten-age students at the Training School at Vineland, New Jersey, were enrolled in a curriculum that emphasized "punctuality, obedience to authority, patience, teamwork, and respect of the rights of others" (Trent 1994:109). Vineland researchers noted this population included "those whose minds have not developed normally" and "American born children of parents who have not succeeded . . . [and who] . . . are deprived from birth of the possibility of even a moderate degree of success" (Irwin 1913:67). Armed with new protocols to medicalize difference, these early researchers contrasted the "familiar" East Side neighborhood populated by first-, second-, and third-generation Americans with their target community—one in which the "foreign-born population swarms the streets and a strange language meets the ear from every hand" (Irwin 1913:67).

It was initially projected that roughly 1 percent of children younger than 14 years of age enrolled in the public schools were "defective mentally," but data collected in 1920 indicated that in New York City, 31 percent of the population labeled "mental defectives" were immigrants. Exploring the intersections between immigration and special education would obviously enrich contemporary analyses of the overrepresentation of minorities in special education; however, in the United States, such excavations are rare compared to the rich analyses undertaken by British sociologists, who have persistently probed these critical connections. Their insights trouble the previously blurred lines between ensuring educational provision for those children who were formerly institutionalized and the creation of the urban special class that served as the mechanism to absorb increasing student diversity in the public schools. Although the threads may appear less evident when attempting to link the parallel development of curriculum for both populations, the section that follows indicates how disenfranchised youth on both sides of the Atlantic, whether disabled or ethnic, were tracked into a skills-based education that targeted vocational ends and minimized exposure to enriched educational experiences. Thus, their life options were circumscribed by institutionally sanctioned limits on learning.

## SPECIAL EDUCATION PEDAGOGY

In the example of special education pedagogy and practice, Edouard Séguin, celebrated by Pope Pius X as the "apostle to the idiots," remains a central figure (Trent 1994). Séguin, who was a student of Itard, developed pedagogy that assumed that all idiots shared the twin characteristics of dormant senses and an undeveloped will. His curriculum aimed to awaken the senses through "physiological education" that emphasized the interplay between physical motor activity, sense stimulation to arouse the intellect, and moral intervention to shape the will. Trent (1994) notes that Séguin's approach has been modified very little in the past 150 years and remains "amazingly contemporary." However, the context and aims of his method and the subsequent curriculum shifted as a consequence of divided class interests and increasing pressures for social control. The dramatic decline of state-based provision and the increased availability of private care prompted a reappropriation of his curriculum for common usage as "habit training." In a culture enthralled by eugenic tendencies and the demand for regulating difference, correcting for atypical characteristics emerged as a worthy goal.

Researchers forged agreement on the problem of the feebleminded child as primarily a school problem, and thus the first step was to separate all children into classes best suited to their needs so as to "rid the normal children of this unnecessary burden" (Irwin 1913:68). The Binet test (later, Stanford-Binet) emerged to sort students into categories labeled as follows: the normal (those testing within two years of their chronological age), the backward (those testing between two and three years younger than their chronological age), and the feebleminded (those whose differences exceeded three years). This early research inspired the scientific approach to the diagnosis and treatment of difference, where the lines easily blurred between those with inherited or congenital difference and those whose ethnic difference marked their "strangeness" as troublesome within the same boundaries of feeblemindedness. Subsequently, the curriculum for both populations became one that aimed toward vocational training: the exact opposite direction originally conceived by Séguin. Although a seemingly subtle shift, the effect intensified over time as new emphasis was placed on human worth and one's ability to produce in a capitalist society.

These early influences ensured the development of special education as a technical field, located within a positivist framework, concerned with issues of diagnosis, assessment and causes of disability, and appropriate forms of treatment. New York City took the lead and organized special classes for "pedagogic reasons" into three levels: (1) bright truants, (2) normal children with sensory deficits, and (3) children truly mentally defective. Once the categories existed, school administrators could weed out those children from the normal classes, justified by the rhetoric of "relief." Fernald (1904) espoused the logic of bureaucratic convenience, arguing that relief was overdue for educational systems inundated by the influx of immigrant children who taxed the ordinary capacities of educators. These early arguments influenced the development of special education as an institutional safeguard to protect general education students and teachers from the problems posed by disability and difference in public schools. Although Fernald also claimed that "relief" was due to families who suffered "ceaseless anxiety and sorrow caused by the presence of the blighted child" (p. 34), his claims were issued in the same era as the nascent formation of a factory/machine bureaucracy for school organization—one that privileged bureaucratic convenience over student needs. This vestige of the past, as noted by Skrtic (1991), guarantees the inability of schools to meet the needs of individual learners.

## THE SPECIAL EDUCATION LEGACY

The stigmata associated with disability have historically centered on perceptions of deviance; as a consequence, individual conditions have been considered alternately mysterious and deserved, dangerous but exploitable, and alien yet innocent. While interactions with the nondisabled community were infrequent, the public perception of disability was readily shaped by fear, pathos, and scorn so as to fix our gaze on the person labeled mentally retarded. As a consequence, research aimed no further than individual pathology and social problem. That the original interventions of Séguin's system of physiological education have witnessed little fundamental innovation in more than 150 years is both evidence and indictment of special education's enduring legacy—an inability to move beyond pathologizing discourses that unproblematically demand perfecting technologies, as Baker (2002) has noted. Not only does this lesson endure, but we are temperamentally unable to unlearn it and unable to resist the "hunt for disability." Slee (2001, 2004) concurs, arguing that the continuing dominance of special education has had a domesticating and taming effect on inclusive education. Special education continues to be preserved, while inclusive education discourses are silenced, not least of all by professionals in the United States who hold a vested stake in protecting their own interests in segregated education by issuing dire warnings about the "illusion" of full inclusion. In the United Kingdom, the defense of special education is less emphatic but no less effective. Both Baker and Slee contend that the legacy of special education can only be challenged by reframing it as cultural politics and by encouraging professionals to turn the gaze back on themselves and, thus, to better understand their own complicity in preserving special education.

*—Linda Ware and Julie Allan*

***See also*** Education, International; Education and Disability; Educational Assistive Technology; Edouard Onesimus Séguin.

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## SPECIAL OLYMPICS

*See* Classification in Paralympic Sport; Paralympics

## SPEECH AND LANGUAGE PATHOLOGY

The field of speech-language pathology encompasses both human communication behaviors and disorders, as well as swallowing functions and disorders. Speech-language pathologists are professionals who work with individuals of all ages to provide prevention, screening, assessment and diagnosis, intervention, counseling, and follow-up services for a variety of disorders that affect communication and swallowing. The practice of speech-language pathology also includes elective modification of communication behaviors that may result from cultural and linguistic factors, as well as enhancement of personal or professional communication performance. By affecting measurable and functional changes in the individual's communication or swallowing status, speech-language pathologists help the individual to participate as fully as possible in all aspects of life—social, educational, and vocational—thereby enhancing quality of life for the individuals they serve.

### COMMUNICATION DISORDERS

Speech-language pathologists work with individuals who have communication disorders. A communication disorder may be developmental or acquired and may range in severity from mild to profound. A communication disorder may result in a primary disability, or it may be secondary to other disabilities. An estimated 46 million people in the United States, of all ages, races, and gender, have experienced some type of communication disorder. Communication disorders include disorders of speech, language, cognition, and hearing. Individuals may demonstrate one or any combination of these disorders.

A speech disorder refers to difficulty with the articulation of speech sounds, fluency, and/or voice. An articulation disorder, the atypical production of speech sounds, is characterized by substitutions, omissions, additions, or distortions that may interfere with intelligibility. Articulation disorders are among the most prevalent communication disabilities among preschool and school-age children. Children with articulation disorders may be at risk for reading and writing disabilities. The goal of speech therapy is to improve the accuracy and use of speech sounds and to achieve maximum intelligibility in single words and connected speech in all settings in which communication occurs.

When the speech impairment is caused by neurological damage, it is called a dysarthria and is characterized by slow, weak, uncoordinated movements of the speech musculature. Dysarthria can be congenital (e.g., cerebral palsy) or acquired (e.g., Parkinson's disease, stroke). In developing and implementing a treatment plan for speech disorders associated with degenerative diseases such as amyotrophic lateral sclerosis, speech-language pathologists match the intervention to the stage of the disease because such diseases frequently progress through a series of stages from mild speech impairment to loss of speech.

Fluency disorders, or stuttering, are another category of speech disorders. Fluency disorders are characterized by a disruption in the flow of speech and include repetitions of speech sounds, hesitations before and during speaking, and the prolonged emphasis of speech sounds. This may be accompanied by excessive tension, struggle behavior, and secondary mannerisms. Clinical evidence shows that individuals who stutter can benefit from treatment provided by speech-language pathologists at any time in their lifespan. Treatment typically focuses on changing the timing of speech (e.g., slowing down, stretching out sounds) or reducing the physical tension during speaking (e.g., gentle onsets of speech movements). Treatment also focuses on improving the speaker's attitudes toward communication and minimizing the negative impact of stuttering on the speaker's life.

A voice disorder is characterized by abnormal pitch, loudness, or vocal quality resulting from disordered laryngeal function and may cause pain or vocal fatigue. Voice disorders range from mild hoarseness to complete voice loss and limit the effectiveness of oral communication. Voice disorders can be caused by an injury resulting in paralysis of a vocal fold, an improper breathing pattern, or misuse of the voice. Voice disorders can also be due to medical or physical conditions, or they may be neurological in nature. Studies find that voice treatment, including vocal hygiene, can improve voice function and reduce the occurrence of laryngeal pathology.

A language disorder refers to impaired comprehension and/or use of spoken, written, and/or other symbol systems. The disorder may involve the form of the language (phonology, morphology, syntax), the content of the language (semantics), or the use of the language in context (pragmatics). Language disorders may affect individuals across the lifespan. For children who do not use language normally from birth or who acquire an impairment during childhood, language may not be fully developed or acquired. Many adults acquire disorders of language because of stroke, head injury, dementia, or brain tumors. One role of the speech-language pathologist is the establishment of augmentative and alternative communication techniques and strategies, when needed. Augmentative/alternative communication systems attempt to compensate and facilitate, temporarily or permanently, for the impairment and disability patterns of individuals with severe expressive and/or language comprehension disorders. Speech-language pathologists may also coordinate the selection and use of other kinds of assistive technology.

Cognition and language are intrinsically linked and reciprocally related in both development and function. Cognitive-based impairments of communication are referred to as cognitive-communication impairments. Speech-language pathologists work on improving cognitive aspects of communication, including attention, memory, perception, organization, reasoning, problem solving, and executive functions. Speech-language pathologists also may address other areas of function affected by cognitive-communication impairments, including behavioral self-regulation, social interaction, activities of daily living, learning and academic performance, and vocational performance.

Speech-language pathologists may provide services to individuals with hearing loss and their families/caregivers. Services may include auditory training, speech reading, speech and language intervention, and visual inspection and listening checks of amplification devices for the purpose of troubleshooting.

## SWALLOWING DISORDERS

Speech-language pathologists identify, assess, and treat individuals of all ages—infants, children, and adults—with dysphagia. Treatment approaches include compensatory strategies designed to have an immediate effect on the swallow (postural changes or diet manipulation), as well as direct muscle-strengthening exercises for improving the swallowing physiology. Treatment approaches improve nutritional status and hydration and reduce morbidity from pneumonia.

## SPEECH-LANGUAGE PATHOLOGY SERVICES

Speech-language pathologists deliver services that are consistent with the framework and components of the World Health Organization's International Classification of Functioning, Disability, and Health (2001). Assessment is conducted to identify the strengths and deficits related to underlying structures and functions that affect communication and swallowing performance, as well as the effects of these impairments on the individual's activities (capacity and performance in everyday contexts) and participation. Assessment also identifies the contextual factors that serve as barriers to or facilitators of successful communication/swallowing activities and participation.

Intervention is designed to capitalize on the strengths and address the weaknesses related to underlying structures and functions that affect communication/swallowing. The goal of intervention is to facilitate the individual's activities and participation by facilitating the acquisition of new communication/swallowing skills and strategies. Intervention also includes modifying contextual factors to reduce barriers and enhance facilitators of successful communication/swallowing activities and participation, as well as providing appropriate accommodations and other supports. Since speech-language pathology services are provided to individuals of all ages, intervention strategies reflect changing developmental stages and language needs and proficiencies throughout the lifespan.

At the present time, there are a number of acceptable treatment approaches for each type of communication and swallowing disorder. However, the field of speech-language pathology is dynamic and evolving. Speech-language pathologists keep current with best practices in prevention, assessment, and intervention. Research and outcome data alter assessment and intervention techniques, influence models and theories of practice, and expand the scope of practice of speech-language pathologists.

Speech-language pathologists provide services in a wide variety of settings, which may include the following: public and private schools; health care settings (e.g., hospitals, medical rehabilitation facilities, long-term care facilities, home health agencies, community clinics, behavioral/mental health facilities, neonatal intensive care units); early intervention settings, preschools, and day care centers; group homes and sheltered workshops; community and state agencies and institutions; correctional institutions; private practice settings; universities and university clinics; individuals' homes; corporate and industrial settings; and research facilities. Although speech-language pathologists are autonomous professionals, successful delivery of speech-language pathology services often requires the collaborative involvement of other professionals, as well as the patient, family, and significant others.

The American Speech-Language-Hearing Association (ASHA) is the professional, scientific, and credentialing association for speech-language pathologists, audiologists, and speech, language, and hearing scientists in the United States and internationally. The mission of the American Speech-Language-Hearing Association is to promote the interests of and provide the highest quality services for professionals in speech-language pathology, audiology, and speech and hearing science and to advocate for people with communication disabilities. The association was originally founded in 1925 as the American Academy of Speech Correction. The current name, the American Speech-Language-Hearing Association, was adopted in 1978.

*—Leora R. Cherney*

***See also*** Dysphagia; Hearing Impairment.

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# SPINAL CORD INJURY

Injury to the spinal cord can be caused by acute or chronic trauma as well as by medical conditions. Frequent causes of chronic compression injury are herniated intervertebral disks and primary or secondary tumors. Acute deterioration of blood perfusion, as seen in anterior spinal cord syndrome, can also severely compromise spinal cord function. However, probably the most dramatic setting for spinal cord injury (SCI) is acute trauma.

## EPIDEMIOLOGY OF ACUTE SPINAL CORD TRAUMA

Estimates of incidence vary, depending on country and mode of reporting, ranging from 15 to 71 per million. According to estimates by the Canadian Paraplegic Association, about 35 new cases per million population are seen each year in Canada. Of the 12,000 new cases of paraplegia and quadriplegia that occur in the United States each year, 4,000 patients die before reaching the hospital. Causes for acute SCI include motor vehicle accidents, work-related accidents, recreational accidents, and violence (shot and stab wounds). Men are afflicted four times as often as women. About 60 percent of the injury victims are 30 years or younger. A long-term outcome study of patients ages 25 to 34 who had suffered acute traumatic SCI while still in the pediatric age group showed that the employment rate was only 54 percent, while the employment rate in the general population for the same age group was 84 percent. Limitation or complete loss of the capability to achieve economic independence following SCI can cause severe economic hardship for the afflicted person and his or her immediate family. Further limitations to participation in social life are caused by architectural barriers (i.e., buildings accessible by stairs only, lack of ramps on boardwalk intersections) and barriers created by negative or overprotective attitudes of healthy, noninjured people toward persons with spinal cord injury. Where reintegration of young SCI victims cannot be achieved, society might suffer a double loss: not only are contributions to society lost, but heavy expenses are incurred to pay for special lifelong care. In 1990, the costs for acute and long-term care of surviving spinal cord injury victims were estimated at $4 billion annually in the United States alone.

## THERAPEUTIC APPROACHES AND CHANGING ATTITUDES

The first known description of acute spinal cord trauma and resulting neurological deficits was found in the so-called Edwin Smith papyrus, which is believed to be more than 3,500 years old. In this ancient Egyptian document, typical conditions encountered in medical practice were presented as case descriptions, and advice regarding treatment was offered. According to the papyrus, spinal cord injury was "an ailment not to be treated." This was possibly an expression of helplessness on the side of the medical profession at the time. A doctor's value would be measured by the extent of cure achieved. Since no strategies that ensured long-term survival for patients with spinal cord injury existed, the doctor would waste time and efforts and endanger his reputation. This basic attitude toward victims of spinal cord injury lasted well into the twentieth century.

Medical statistics from World War I show up to 95 percent mortality for patients with spinal cord injury, attributed mainly to urinary sepsis and pressure sores. During World War II, the number of both military and civilian casualties, including those with spinal cord injuries, increased dramatically in Europe. The success of specialized hospital units (so-called peripheral nerve centers), developed between the wars in Germany and the United States, had demonstrated the advantages of concentrating special-needs patients under specialized care. Great importance had been attributed to the unique opportunities offered by such specialized units—namely, to gain new insight in the natural course of the disease and to further the development of new therapeutic strategies. Building on those experiences, several specialized spinal cord units were opened throughout England in the 1940s. Pioneered by the team of Dr. Ludwig Guttmann at the Spinal Cord Unit of the Stoke Mandeville Hospital, new treatment approaches included frequent repositioning of paralyzed patients to avoid development of bedsores as potential source of sepsis and intermittent sterile catheterization to prevent urinary sepsis. The success, measured in patient survival, was dramatic enough to require the development of completely new strategies for social reintegration of patients with spinal cord injury. The creation of adapted workplaces and wheelchair-accessible housing, as championed in the 1940s and 1950s by the English Red Cross, has today become an integral component in the framework of social politics in most industrialized countries. While respiratory complications are now perceived as the leading cause of death in patients admitted with SCI, the runners-up are heart disease, septicemia, pulmonary emboli, suicide, and unintentional injuries.

## THE PARALYMPIC GAMES

Guttmann and his colleagues viewed physical rehabilitation as the basis of social reintegration, both physically and psychologically. Consequently, they supported the idea of athletic competition in disciplines adequate and adapted to the physical capacity of their patients. Starting with a two-team competition in 1948, paralleling the Olympic Games in England, the idea of competitive sports for the paralyzed developed rapidly. In 1960, the first Paralympic Games were held in Rome. Not only were competitions held in the same year as the Olympic Games for the able-bodied, but both the Olympic and Paralympic games were using the same facilities, a tradition that has been followed ever since. The idea of competitive sports has long since been extended to include people with a multitude of physical handicaps other than spinal cord injury.

## INITIATIVES AND PUBLIC AWARENESS

Noticeable is the number of initiatives that have sprung up at communal and national levels in many countries, with the intent to decrease the incidence of spinal cord trauma, to lend support and advice to patients with spinal cord injuries and their families. Some also offer financial support for basic science and clinical research. The prevention-oriented "Think First" initiative, Canadian-based CORD and Wheels in Motion, the Christopher Reeve Paralysis Foundation, the U.K. Spinal Cord Trust, and the Paralyzed Veterans of America, to name but a few, maintain informative sites on the Internet, where further valuable information on the subject of spinal cord injury can be found.

Although the overall incidence of SCI has not yet decreased noticeably, there is an appreciable decrease with regard to the severity of injuries (i.e., fewer complete injuries and an increased survival rate have been reported). This has been attributed to improvements in prehospital care, including widespread instruction in the principles of first aid as well as introduction of the principle of spinal cord immobilization during rescue and transport. Increased public awareness of risk factors leading to head trauma and spinal cord injury, the introduction of the mandatory use of safety belts, and the installation of air bags in cars furthermore are suited to decrease trauma severity.

## RESEARCH

Until fairly recently, a dogma underlying the approach to spinal cord injury research postulated that, once spinal cord trauma had occurred, nothing could be done to alter the natural course of developing pathology, that damage to the central nervous system (CNS) was permanent and repair impossible. At the beginning of the twenty-first century, this dogma ceases to exist in the minds of scientists, clinicians, and patients and their families. In laboratories around the world, research is focused on two general approaches: prevention of *secondary injury* and repair of manifest damage. The term secondary injury is used to describe the observation that CNS structures, which have survived the primary, mechanical trauma, die at a later time point due to deterioration of the milieu at the site of injury. The volume of secondary tissue injury can be significantly larger than that caused by the primary injury. Research is focused on the identification of substances and therapeutic methods that help to minimize secondary injury. New methods in the field of cell biology allow the study, isolation, and manipulation of specific cell types. Efforts are being made to induce certain cell types, including stem cells and olfactory ensheathing cells, to help repair damaged CNS structures.

The focus of clinical research is on ameliorating the consequences of spinal cord injury (i.e., stimulators for bladder control, orthopedic correctional procedures) and on physical mobilization. Integration of biomedical research (i.e., pattern generators, mechanics and kinetics of movement) with the latest developments in computer science and engineering has led to the creation of neuronal networks. On this basis, neuroprostheses are being developed, which allow completely paraplegic persons to ambulate.

*—Elisabeth Schültke*

***See also*** Accidents; Orthopedics; Paralympics; Paralysis; Wheelchair; Wheelchair, Electric.

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# SPORTS AND DISABILITY

Sport plays an important role in the lives of many people, and sports programs have high visibility in many communities around the world. Participation in sports activities is an important goal for many persons with disabilities, and it has been shown to have significant and positive effects on physical function, psychological and emotional status, and general health. People with disabilities who participate in sports have higher self-esteem and quality of life, and their participation in sports activities, limited for many years for the able-bodied, contributes to the elimination of myths and misconceptions surrounding disability and the removal of barriers to integration into society. Among other things, sports participation can be used to (1) maximize the benefits of the rehabilitation process early after injury or disease, (2) facilitate community reintegration efforts after rehabilitation, (3) provide leisure-time recreational opportunities, (4) enhance skill- and health-related fitness and general health, and (5) provide the high-performance competitive experience that many athletes enjoy.

## REHABILITATION

The restoration of form and function (i.e., rehabilitation) after injury or illness can be achieved using a wide variety of therapeutic strategies and interventions.

These include occupational and physical therapy, speech therapy, recreation therapy, nutritional counseling, psychological interventions, and pharmacological management. Most people with disabilities have mobility limitations, and it is not surprising that sports programs can be used to provide some of the occupational, physical, and psychological therapy that is needed early in the rehabilitation process. Furthermore, sports participation can also be included in the process of "habilitation" of children with congenital disabilities or impairments acquired very early in life. Recovery or development of muscle strength, cardiorespiratory endurance, balance, and coordination, all fitness-related attributes lost as a result of injury or disease, can be facilitated through the participation in sports activities. Traditionally, gym-based activities have been used for this purpose, but the addition of sports activities (outdoors and indoors) such as windsurfing, horseback riding, and kayaking has brought much-needed diversity to the traditional programs. Patients in a rehabilitation hospital may be more motivated to do their exercises if the activity providing the stimulus is similar or more relevant to their favorite sport. The use of sport during the rehabilitation process was pioneered by Sir Ludwig Guttmann in the United Kingdom.

## RECREATION

Leisure-time physical activity is an important component of a healthy lifestyle. People who participate in recreational activities develop confidence in their ability to participate in and contribute to society. Through recreational sports participation, people with disabilities can learn to enjoy life, reduce stress, develop special skills, improve functional capacity, and take control over their lives. Furthermore, many recreational activities can include the family. In fact, participation of husband or wife and their children can enhance compliance with activity programs. Also, leisure time can provide that much-needed opportunity to socialize with friends who share the same recreational interests. By eliminating barriers such as poor self-image and low self-esteem, recreational activities increase the chances of a successful return to community life, including family and occupational obligations.

## HEALTH AND FITNESS

With advances in health care, many people with disabilities have a longer life expectancy. The causes of death in some groups of people with disabilities, such as those with spinal cord injuries, are more similar to those in the general population now than 20 years ago. For example, the incidence of chronic diseases, including coronary heart disease and atherosclerosis, is increasing in this population. Therefore, interventions that can reduce risk factors for chronic disease such as high blood pressure, sedentary lifestyle, and high cholesterol levels and enhance cardiovascular and metabolic functions can be of great benefit for persons with disabilities. The benefits of physical activity and exercise in men and women of all ages have been extensively studied and documented in the past 50 years. People with disabilities should receive the same benefits, and participation in several sports is one way of providing the exercise stimulus needed to enhance fitness and health. Sports such as wheelchair racing, swimming, and cycling provide that stimulus necessary to develop cardiovascular fitness and reduce the incidence of risk factors. Furthermore, fitness programs in sports clubs designed to enhance flexibility, strength, and aerobic capacity have become more popular among people with disabilities.

Sports participation can be used to enhance fitness in persons with disabilities due to chronic illnesses. Examples of chronic diseases that could benefit from sports programs include asthma, high blood pressure, obesity, stroke, osteoarthritis, osteoporosis, diabetes, and others. The use of sports programs in this context can be considered a form of secondary prevention. The benefits are many and could include better medical control of the disease, a reduction in the amount of medication needed to treat the disease, a reduction in the rate of complications, and an improvement in the functional capacity and tolerance to regular activities.

## COMPETITIVE SPORTS

Competitive sports represent a real option for persons with disabilities who like the challenge of high-level athletic performance. Sir Ludwig Guttmann organized the first international sports competition for people with disabilities at Stoke-Mandeville in the United Kingdom. The Paralympic Games became part of the Olympic program, starting in 1960 with the summer games and in 1976 for the winter sports.

Many people with disabilities can participate in sports using standard equipment, depending on the requirements of the sport and the level of disability. However, an important consideration for persons with disabilities interested in many competitive sports programs is the need for special equipment that could make their participation possible and/or safer. Dramatic improvements in technology and biomaterials have allowed persons with a wide range of disabilities to participate in sports such as wheelchair racing, archery, golf, cycling, quad rugby, goal ball for the blind, horseback riding, boating, weightlifting, basketball, tennis, snow skiing, swimming, ice hockey, and many others. New prosthetic devices for amputees and ice hockey players, lightweight wheelchairs for racers and basketball players, and field event chairs for the javelin throw are some examples of devices that enhance the individual's activity and participation level.

Participation and competition in different sports are facilitated by the use of classification systems to make sure that athletes with disabilities competing against each other have equivalent levels of impairments and disabilities. This is consistent with the Olympic principle of "fair play" and may be consider equivalent to the classification systems based on, for example, body weight used in sports for people without disabilities. Sophisticated classification systems have been designed for use in local, regional, national, and international competitions such as the Paralympic Games. One example is the classification used by the U.S. Cerebral Palsy Association, which divides the competitors into eight groups based on the level of involvement of the limbs and torso, the need for a wheelchair, coordination, and related characteristics. Other examples are the classification system used for people with spinal cord injuries based on eight levels of injury and impairment and the classification of sports for three classes of visual impairment. More recently, the participant's functional capacity and performance in real sports activities has been proposed as the most effective way of classifying athletes. Although sometimes controversial, classification systems must be developed for all sports and understood by those who organize competitions for people with disabilities. These systems, however, may not be useful or necessary in recreational activities or when sports participation is used to enhance fitness and health.

Participation in sports per se can be positive, but persons with disabilities involved in serious sports competitions must follow a training program designed to enhance fitness and sports performance. Many training principles followed by athletes without disabilities also apply to the preparation for events such as the Paralympics. A sound training program must (1) include appropriate training loads that vary according to the dates of the competition, (2) be specific for the sport, (3) include the technical and tactical aspects of the sport, (4) monitor closely the health of the athlete, (5) include adequate nutritional support, and (6) never use doping agents or boosting techniques to artificially enhance performance during competition. Because many sports are practiced using a wheelchair, particular attention must be given to the training of the upper limbs and torso. It is important to keep in mind that athletes with disabilities have the same risk of injury per athletic exposure for an athlete without a disability. Physicians practicing sports medicine must understand the risk factors for overuse and traumatic injuries in this population. In addition, the specific medical needs that may result from the interaction between the medical condition that resulted in a disability (high-level spinal cord injury, diabetes) and the demands of training and competition must be taken into consideration. For example, some athletes with spinal cord injuries may be intolerant to the heat and high humidity typical of many cities during the summer. Also, exercise may alter the metabolism and effects of drugs such as insulin, requiring adjustments in the dose before training sessions or competitions.

*—Walter R. Frontera*

***See also*** Exercise and Physical Activity; Paralympics; Participation; Recreation.

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## STANDARD RULES

*See* United Nations Standard Rules

## STEIFF, MARGARETE (1847–1909)

*German toy manufacturer*

When the German toy manufacturer, Margarete Steiff, died at the age of 61, she left behind a world-famous enterprise. She was born on July 24, 1847, in Giengen, south Germany. At the age of 1, she contracted polio, which left both legs and her right arm paralyzed. Steiff, along with her three siblings, had a carefree childhood. She took part in the games of the neighborhood children—while sitting in a wooden wagon—and attended the local elementary school. Two long stays in a children's hospital were combined with the hope that she would walk again. This hope proved futile. Also, an operation brought no success. Steiff stated in her memoirs, "The useless search for a cure does not let an individual come to peace."

Economic independence was very important to Steiff for she was dependent on her mother and, later, on her sister-in-law with respect to her caretaking needs. She bought herself a sewing machine and maintained a sewing room at first. Later, she got some assistants and soon produced felt slips and coats, which were very successful. In 1877, she opened a "Filzkonfektionsgeschäft," a ready-made felt business. A little later, she began to produce stuffed animals as children's toys. Her business—which she built with the help of her nephews—flourished. She placed a great amount of worth on the quality of her products. Her success made it possible for Steiff to build a new, ramped residential and business house in 1903.

In the same year, the Steiff firm introduced a new stuffed animal at the toy fair in Leipzig: a bear with a hump. Shortly before the fair closed, an American dealer purchased the entire bear collection, and soon thereafter, the new toy had a catchy name. The bear was named "Teddy" after American President Theodore Roosevelt. Provided with the well-known brand name "Knopf im Ohr" ("button in ear"), it soon became a huge international success. At the 1904 World's Fair in St. Louis, Steiff was awarded the "Grand Prize" for her life's work. She died unexpectedly on May 9, 1909, from pneumonia.

*—Anneliese Mayer*

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## STEREOTYPING

*See* Stigma

## STERILIZATION

The earliest use of sterilization in North America likely occurred in institutions for "feebleminded" people around 1890. The procedure used was *castration,* a term that institutional authorities applied to both sexes. (Besides hysterectomy, female castration included salpingectomy, the removal of the fallopian tubes, and ooephorectomy, the removal of the ovaries.) In 1892, Isaac Kerlin, superintendent of the Pennsylvania Training School for Feeble-Minded Youth, argued for "asexualization" before his colleagues at the annual meeting of the Association of American Institutions for Idiotic and Feeble-Minded Persons. Kerlin told his fellow superintendents that castration controlled "epileptic tendency" and aided in the "removal of inordinate desires which [are] . . . an offense to the community." He noted that he had allowed the sterilization of one inmate at the Pennsylvania Training School. That case involved the removal of the "procreative organs" of a young woman. When Kerlin referred to "inordinate desires," he alluded to a problem that he and other superintendents faced in their institutions—inmates who publicly masturbated. Especially troublesome during Sunday visits from church groups or during the visits of relatives, inmates who masturbated were an ongoing embarrassment for the superintendents.

Two years later in March 1894, F. Hoyt Pilcher, the superintendent of the Kansas State Asylum for Idiotic and Imbecile Youth, began castrating older boys and men who masturbated. By 1895, he had castrated 11 inmates. Around 1895, he expanded the castrations to women. His practice drew the attention of several regional medical journals and local papers. Eventually, the publicity became a state scandal, with officials expressing both support and opposition for Pilcher's surgeries. Nevertheless, he continued his practice, and by 1897, he had castrated 47 additional inmates, 14 women and 33 men.

What began as a curiosity in the 1890s would become, after 1900, an increasingly discussed practice among superintendents of institutions for the so-called feebleminded. By the end of the first decade of the new century, superintendents of insane asylums, penitentiary officials, and social welfare authorities joined their colleagues in feeblemindedness to show their interest in sterilization. Two factors influenced this growing attention. First, eugenics, along with the newly discovered work of Gregor Mendel, opened institutional officials to new ways of linking heredity and mental disability, heredity and crime, and heredity and pauperism. Second, two new surgical procedures, the vasectomy and the tubal ligation, made sterilization a more socially acceptable practice.

In 1899, Harry C. Sharp, a physician at the Indiana State Reformatory, developed the vasectomy. The surgery achieved male sexual sterility without castration. In 1902, he published a paper on the new procedure. In it, he made an explicit connection between sterilization and heredity. Although the first tubal ligation was performed around 1880, the procedure became an involuntary means of sterilization after 1900 in institutions that housed "feebleminded" women. By the first decade of the new century, then, new views about heredity, as well as new and less invasive procedures, would allow institutional officials to expand sterilization from behavioral control to the control of heredity. These same officials would appropriate the term *eugenics,* first coined by Francis Galton, to identify and justify their new interest in hereditary control.

With the support of the State Board of Charities, in 1907, Indiana became the first state to pass a sterilization statute. Focusing on habitual criminals and rapists, the legislation also allowed for the involuntary sterilization of the state's institutionalized insane, epileptic, and "feebleminded" populations. By 1917, in the name of eugenics, 11 more states had authorized the use of sterilization. After World War I, 15 additional states passed sterilization legislation. In most states, institutional superintendents (at least behind the scenes) led support for the legislation, and usually they did so in the name of eugenics. Joining these institutional officials were academics such as sociologist E. A. Ross and biologist Michael F. Guyer, who advocated for sterilization before the Wisconsin legislature; businessmen such as New Jersey real estate executive Bleeker Van Wagenen and Michigan's John H. Kellogg of the cereal fortune; and religious leaders such as Ohio's Washington Gladden, Harry Emerson Fosdick in New York, and Louis Poteat in North Carolina.

Not all of the institutional superintendents supported involuntary sterilization, and some would change their support over the years. Opposition also came from state and national figures. By 1921, of the 15 state statutes, only 10 were still law. The New York Supreme Court declared its sterilization laws unconstitutional in 1918. After that, statutes in New Jersey, Nevada, Michigan, and Indiana were thrown out by their respective state courts. In 1911, the governor of Indiana, where the first law had been signed, declined to release state funds to any institution that performed involuntary sterilizations. In Oregon, Vermont, Nebraska, and Idaho, governors vetoed sterilization legislation.

Although it lost much of its steam by the 1940s, involuntary sterilization continued to find pockets of state-sanctioned support. In New Jersey, North Carolina, and California, state-sanctioned sterilization mechanisms continued even into the 1960s and 1970s. Since the 1970s, various federal and state court rulings along with regulations from the executive branches of the federal and various state governments have reduced, if not eliminated, involuntary sterilization.

*—James W. Trent*

***See also*** Eugenics; Racial Hygiene (*Rassenhygiene*); Reproductive Rights.

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## STEVENSON, ROBERT LOUIS (1850–1894)

*Scottish writer*

The Scottish-born writer Robert Louis Stevenson suffered from severe lung problems, possibly including tuberculosis, in addition to other chronic ailments. His major works include *Treasure Island* (1883), *Kidnapped* (1886), "The Strange Case of Dr. Jekyll and Mr. Hyde" (1886), and *A Child's Garden of Verses* (1885). Advised to go abroad for relief from his lung problems, Stevenson wrote about his travels in *An Inland Voyage* (1878) and T*ravels with a Donkey in the Cevennes* (1879), both about France; *The Silverado Squatters* (1883), about California; and *In the South Seas* (1896). He found better health during the last five years of his life in Samoa—the backdrop for his late fiction and political writings. Much of his work is concerned with physiological trauma and with spiritual, emotional, or physical compensations. Dr. Jekyll's quest to transcend human limitations through an elixir that produces instead the deformed, malignant Mr. Hyde is the best-known instance, but debilitated, neurasthenic, and melancholic characters proliferate in his work, as do fantasies of unrestrained adventure and magical power. He died of a cerebral hemorrhage.

*—John Kucich*

***See also*** Novel, The.

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## STIGMA

The ancient Greek term *stigma* referred to tattoos or other bodily marks, but in modern times, stigma has come to refer to any signs that expose something unusual or bad about a person. According to Erving Goffman (1963), there are three main types of stigma. These include abominations of the body (physical deformities), blemishes of individual character, and tribal stigma of race, nation, and religion. The bodily signs differentiate a person from what society considers normal. This deviation from societal norms is classified as deviant, and those who fall into this category often face discrimination from other members of society. Attitudes toward individuals with tribal stigmata depend on the ways the tribe or group is viewed.

Although the term *stigma* is still used today, it now refers more to the disgrace itself than to the mark, bodily or otherwise, that reveals it. Today, stigma refers to any persistent quality of an individual or group that evokes negative or punitive responses from others. Individuals are said to be stigmatized when they are singled out from the population for ridicule or maltreatment due to differences in physical, mental, behavioral, or other attributes. When they encounter prejudice or discrimination due to their perceived limitations, persons with disabilities fit this definition of stigma. They are the recipients of unwanted and unfavorable identities. At one time, the problems faced by persons with disabilities were attributed to their impairments and/or medical conditions alone. Recently, however, attitudinal and environmental factors are coming to be seen as important in the definition of disability. Many today believe that it is societal restrictions and social responses rather than functional limitations or personal impairments that constitute the greatest problems faced by individuals with disabilities. This perspective is a core belief of the social model of disability and places the process of stigmatization front and center in the lives of persons with disabilities.

## THE ORIGINS OF STIGMA

The process of stigmatization excludes certain individuals from particular types of social interactions due to characteristics they possess or due to their membership in a certain group. Stigmatization occurs when members of a society reject members of a group due to a particular characteristic shared by group members, such as the color of their skin, their inability to see, their age, or some other quality. Persons with disabilities may be stigmatized in social interactions if they do not meet the normative expectations of others. This has often been the case when individuals with disabilities are stigmatized by society. Goffman's (1963) theory of stigma is that it occurs when a mark becomes linked to an attitude that negatively views the bearer of the mark. The negative attitude associated with the mark may at first be associated with one activity or type of social interaction and later be generalized to other areas of life and society. Similarly, once members of a group are marked for exclusion from one activity or type of interaction, they may be excluded or ignored in others as well. Not only may stigma generalize outwardly to apply to multiple social contexts, but it may also generalize inwardly to the individual's own self-concept. For this reason, stigmatized individuals may come to possess negative perceptions of themselves as well as the quality or characteristic that signifies a social identity that is devalued in one or more social contexts. For people with disabilities, the quality or characteristic that leads to stigma may be a physical disability (e.g., paralysis, quadriplegia, etc.), a sensory disability (e.g., blindness, deafness), an emotional disability (e.g., schizophrenia, bulimia), or an intellectual disability.

Why do people participate in stigmatizing others? Three functions have been suggested. People may stigmatize others to (1) enhance their self-esteem, (2) enhance their social identity, or (3) justify a social, political, or economic structure. From an evolutionary perspective, stigma may serve any of several functions for those who are not stigmatized:

*Dyadic Cooperation.* Stigma may be an adaptation designed to lead an individual to avoid interactions with others who are viewed as poor partners for social exchange, who pose greater costs than potential benefits in social exchange, or who fail to meet any other criteria for being potentially valuable social partners. Individuals with disabilities may be seen as being unable to fully contribute to social roles (e.g., job, family duties, and social relationships) and to require high levels of care. Their strengths and abilities go unrecognized.

*Coalitional Exploitation.* This refers to adaptations designed to cause the exclusion of individuals from enjoying benefits widely available to members of society and to exploit these excluded individuals. Nondisabled individuals may dissociate themselves from persons with disabilities to prevent them from using scarce resources and exclude them from certain groups (e.g., the educated, the employed, and homeowners) and take advantage of them. For example, the public transit system may require a person who uses a wheelchair to get up at 5:30 a.m. to schedule a ride with the public paratransit service for that day. A sheltered workshop may pay people with intellectual disabilities a dollar an hour to assemble lamps at a time when the customary wage in society is $8 an hour for the same work.

*Parasitic Avoidance.* This may arise from the belief that persons with disabilities are likely to carry communicable pathogens. These adaptations are designed to prevent contact with individuals who may transmit their condition to others. The belief that persons with disabilities have defective genes and are undesirable sexual partners may also result in parasitic avoidance. Since only some disabilities involve a genetic predisposition and/or can be socially transmitted, the factual basis for this kind of adaptation is quite limited. In sum, this evolutionary approach offers these adaptations as perhaps a partial explanation for why members of groups can agree on who should be stigmatized and why the stigmatization of persons with disabilities is present in most, if not all, cultures.

## DIMENSIONS OF STIGMA

### *The Experience of Stigma*

Having a disability not only means limitations to one's physical or mental capabilities but also involves experiencing discrimination, vulnerability, and assaults on one's identity and self-esteem. Stigma is, thus, a form of oppression through social restrictions and disapproval. Many believe that these experiences are a result of the undesired differences that separate people with disabilities from the general population and give way to stigmatization.

### *Stigma and Expectations*

Stigma causes discomfort and stress to persons with and without disabilities. It has been suggested that such tension may be a result of persons with and without disabilities not understanding each group's expectations of the other. Neither knows what the other expects. The tension created by misunderstood and unexpressed expectations may increase the tendency for persons without disabilities to ostracize those with disabilities and for those with disabilities to avoid contact with persons who do not have disabilities.

### *Cultural Values and Stigma*

The expectations of Western culture concerning certain desirable characteristics of persons also may perpetuate the stigmatization of individuals with disabilities. Western culture places a great deal of value on independence, self-reliance, beauty, and health. Because they may differ from traditional expectations concerning these qualities, persons with disabilities may both be stigmatized and feel stigmatized.

### *Media and Stigma*

Media in Western society tend to portray persons with ideal forms of the cultural values noted above, especially beauty, thereby heightening their relevance. Media also frequently present persons with disabilities in stereotypical ways. This is particularly true for persons with mental illness, who are often characterized as more dangerous or threatening to persons without disabilities than they are in fact. Such negative portrayals foster stigma and may justify poor treatment of persons with disabilities in the popular mind.

### *Stigma and Self-Perception*

Stigma affects the self-perceptions of persons with disabilities. Not only does the stigmatization of individuals with disabilities affect the perceptions of others, but the stigma can also have a tremendous effect on the person with the disability as well. A stigmatized person may have some sense of normalcy and of being like other people and may be treated by most others in a manner consistent with such a perception. However, this individual may perceive quite correctly that whatever others profess, they do not really accept him or her and do not meet him or her on equal grounds. Therefore, despite some sense of normalcy, the person with a disability also may accept the premises and values that underlie a discredited social identity. Such a spoiled identity may increase the likelihood of internalized shame, withdrawal from others, and even social rejection and financial insecurity as the individual shies away from opportunities that might provide personal and substantive rewards. Spoiled identity may lead to loss of social status and a sense that one is discounted and discredited. Such internalized shame can focus a person on the label "disabled" as a central and primarily negative focus of the person's identity, engendering greater anxiety, shame, and withdrawal.

## CONCEALABLE AND VISIBLE DISABILITIES

Even though there are many types and effects of disability, all disabilities are either concealable (e.g., bulimia) or visible (e.g., physical disability). People with concealable disabilities are often able to hide their disabilities at least temporarily in the attempt to avoid stigmatization. In fact, societal stigma is so substantial that even people with what are commonly considered visible disabilities, such as blindness, report passing as nondisabled, so as not to call attention to their limitations. However, people who conceal their disabilities are often in some important way not accepting themselves. Consequently, they appear to be more likely to demonstrate effects associated with negative self-perceptions such as depression, anxiety, or suicidality than individuals with visible disabilities who do not conceal them. Because their disabilities are concealable, and others with these disabilities are also concealing them, a state called pluralistic ignorance may exist. That is, individuals with concealable disabilities are less likely to be aware that others share their situation. They may even believe that there are few, if any, other people like them. They lack the benefits of similar others, such as meaningful group membership, successful social interactions, and moral support. Contact with similar others can buffer the negative effects of stigmatization on the mental well-being of culturally stigmatized persons.

Persons with concealable disabilities may find it difficult to find people who share their group membership. To do so, they are faced with a dilemma: either risk social rejection in hopes of finding social contact or shun social contact to avoid social rejection. Individuals will be most vulnerable to negative self-perceptions when they are unable to find similar others for support. Research has shown that, compared to participants with conspicuous stigma, individuals with concealable stigma felt worse about themselves and were more anxious and depressed. Only in the presence of similar others did these individuals improve in mood and self-esteem. Similar others may provide positive self-perceptions because they decrease individuals' sense of isolation and feelings of being different. Being with similar others may also result in more positive attitudes about the group. Despite these potential benefits, the fear of negative social evaluation may be more potent than the anticipated benefits of interaction with similar others.

According to a preoccupation view of secrecy, attempts at keeping a concealable disability secret activate a set of cognitive processes, which may lead to an obsessive preoccupation with the disability. The preoccupation results in renewed attempts to keep such thoughts suppressed. Eventually, intrusive thoughts and thought suppression occur cyclically. This cycle yields a continuous preoccupation with the individual's disability that can extend beyond the circumstances that prompted the initial secrecy. This obsessive preoccupation, combined with lack of support from similar others, can be of great harm to individuals with concealable disabilities. They may be overly distracted by the task of impression management and suffer in performance of cognitive tasks.

Individuals with disabilities that cannot be concealed are also subject to internalized negative evaluations and anticipated negative behavior of others. There have been numerous examples in which individuals who believed others were aware of their disabilities also believed that such awareness caused them to be less appreciated or to be judged in a negative manner. Persons with visible and concealable disabilities may have difficulties in social interaction. These may be partially due to how they believe others will react to their disability. Stigma consciousness (i.e., the extent to which individuals focus on their stereotyped/stigmatized status) may have important implications for how the individual experiences being stereotyped. People who are high in stigma consciousness are more negatively affected by the stigmatization of their disability. However, individuals with conspicuous or visible disabilities have an easier time identifying groups of similar others. Constructive connections with similar others often create positive self-perceptions among group members, which may decrease the extent to which stigma consciousness affects their reactions to stigma.

## OTHER FACTORS AFFECTING THE DEGREE OF STIGMA

The degree of stigmatization also depends on other factors. These factors include the type of disability, the perceived responsibility of the individual for the disability, the perceived consequences of the disability for others, the outward manifestations of the disability, and the perceived impact of the disability on an individual's level of socially valued competence. Research also shows that the permanence of the disability affects others' perceptions and responses. Those with observable physical impairments have been found to suffer relatively fewer effects of stigmatization, whereas those with mental illness seem to be stigmatized to the greatest degree. Greater stigmatization of persons with mental illness may be due to perceived danger posed by the person to others and perceptions that a person with mental illness is responsible for his or her disability.

## WAYS TO REDUCE/DISCREDIT STIGMA

Research offers three strategies to diminish the stigmatization of disabled individuals and groups: protest, education, and positive contact with stigmatized individuals. Protest may increase awareness of and decrease negative attitudes and beliefs about people with disabilities. However, to date, research suggests that it does not promote positive attitudes or increase knowledge about disabilities. Protest may also lead to short-term reactive effects; that is, it may make negative information about the disabled group more salient for a time. However, little research has been done on the effects of repeated protests on attitudes or beliefs. It is possible that reactive effects may be less likely to occur with repeated protests. To date, research has only examined the effects of protest on attitude change. It will be important to examine the effects of protest on behavior toward persons with disabilities.

Education facilitates greater understanding of persons with disabilities by providing accurate information. People who have a better understanding of a stigmatizing condition are less likely to endorse the stigma and discrimination. The type of information received may affect responses toward persons with disabilities. Participants in one study were either told about an individual's symptoms or his or her after-care plan. Those who received information regarding psychological symptoms increased their negative attitudes about the mental illness, while the after-care information reduced negative judgments. Greater knowledge of a disability prior to participating in an education program reduces stigmatizing attitudes after completing the program.

Personal contact with persons who have disabilities also decreases stigma. This decrease may be due to the positive effects of attitudes and beliefs about the common humanity and empowerment of persons with disabilities. Ultimately, greater social inclusion and changed societal attitudes may be the key to addressing the negative effects of all aspects of stigmatization.

The recent developments in the disability rights movement are creating stronger awareness of a positive disability culture. The development of disability culture identifies and affirms the strengths of people with disabilities, their high degree of life satisfaction, and their contributions to others with disabilities and to society at large. For people with disabilities, disability culture can be an effective antidote to stigma and its deleterious effects. For people without disabilities, it can provide important information about the impact of mainstream society, positive and negative, on people with disabilities. It can provide mainstream society with a more complete and ultimately positive perspective concerning people with disabilities. Thereby, disability culture may promote the development of mainstream cultural values that are inclusive of all people, as well as media reports that accurately reflect the challenges and celebrations of living with a disability.

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***See also*** Attitudes; Inclusion and Exclusion; Representations of Disability, Social; Stigma; Stigma, International.

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## STIGMA, INTERNATIONAL

The stigma associated with disabilities can be seen in every culture regardless of religion or ethnicity. In some cultures, people with disabilities are viewed as unclean or dangerous. Individuals with disabilities may be seen as the cause of societal "pollution." People with disabilities may also be viewed as being in a transitional state between sickness and health. Some aspects of the stigma associated with disabilities are quite consistent cross-culturally. For example, mental illness is strongly stigmatized in most cultures, with exceptions including some Native American and Russian societies. Across many cultures, disabilities that manifest themselves in unpredictable or odd behavior are associated with greater stigma (e.g., schizophrenia, addictions) than are other disabilities that do not (e.g., polio).

Despite these similarities, the stigma associated with disability does differ across cultures. Because societal views of disabilities are socially constructed, stigma associated with disabilities varies among cultures in many respects. The lives of persons with disabilities around the world are usually far more limited by prevailing social, cultural, and economic constraints than by specific physical, sensory, psychological, or intellectual impairments. Cultures differ in their popular explanations for why some individuals and not others have disabilities and how persons with disabilities should be treated. Societies differ in what roles are appropriate and inappropriate for persons with disabilities and what rights and responsibilities individuals with disabilities are either entitled to or denied.

Besides differences in the content and rationale for stigma, there is also a difference in the degree to which stigmatization occurs in different countries and cultures. There are differences in which and how many disabilities are viewed negatively and therefore are stigmatized to a greater extent. Popular wisdom and mythology regarding the causes of disabilities vary across cultures and lead to different levels of stigmatization.

The treatment that persons with disabilities receive is based in part on cultural beliefs about how and why they became disabled. Explanations for disabilities may include factors as diverse as divine displeasure, witchcraft, evil spirits, reincarnation, negative parenting, tainted blood, and genetics. More positive mythologies also exist. For example, in northern Mexico and Botswana, the birth of a disabled child may be welcomed as evidence of God's trust in the ability of specific parents to care for a delicate child.

Variations in cultural values may also be, in part, responsible for differences in stigma across cultures. The valued and devalued attributes or qualities admired in a society play a role in influencing which disabilities are more heavily stigmatized. Typically, those with disabilities are socially and culturally devalued and therefore are discriminated against in many forms. For example, in a society where survival is based on the success of hunters and gatherers, physical stamina and strength are of particular importance. Individuals with physical disabilities who cannot contribute to these tasks are likely to be more stigmatized than they would be in a society that relies on a virtual economy in which one can earn a good living working in physically accessible offices and meeting rooms. Moreover, because views of disabilities are socially constructed, the degree to which a particular disability is stigmatized may depend on factors unrelated to the disability itself, such as gender or income. For example, in North American society, bladder control problems are associated with stigma more for men than for women. In some Pacific Island societies, a man's status is determined in part by his ability to speak well in public. Therefore, hearing loss or a speech impediment will be stigmatized more heavily than other disabilities.

Another source of cross-cultural differences in the perceptions of disability is the extent to which collectivism, rather than individualism, is a cultural value in a society. Disabilities are often more heavily stigmatized in collectivist societies than in individualistic societies. Collectivist societies view the individual as an extension of the family or community collective. In a collectivist society, an individual may choose an occupation because it is needed in the community. The individual's achievements and failures may be viewed as sources of pride or disgrace to his or her family more than is the case in more individualistic cultures. Persons with disabilities will be stigmatized based on the extent to which the disability limits their contribution to the collective and the extent to which a disability is a source of shame for the collective.

Collectivist societies emphasize conformity to a greater extent than do individualistic societies, where nonconformity may be valued. The strong emphasis on conformity in collectivist cultures results in stigmatization of those who deviate from the norm in any respect. Persons with disabilities may be unable, because of their disabilities, to conform and thus may be stigmatized more heavily in collectivist societies. Another reason those with disabilities are more apt to be stigmatized in collectivist societies is that those with disabilities are associated with the inability to fulfill contributory roles in society. If they are not able to fulfill their part and contribute meaningfully to society, they are stigmatized.

In 2000, it was estimated that approximately 80 percent of the world's persons with disabilities lived in Third World nations in Asia or Africa. In these countries, malnutrition and unsanitary conditions contribute to low birth weight and birth defects and thus children with disabilities. Disabilities in the adult population are often the result of wars, natural disasters, and traffic accidents as the development of safety regulations lags behind rapid modernization. Stigma can limit the claim of people with disabilities on the scarce resources available. Given the concentration of people with disabilities in Asia and Africa, we will focus our attention on these parts of the planet as we consider stigma of persons with disabilities internationally.

## STIGMA AND DISABILITIES IN ASIA

Across the many cultures of Asia, nations tend to emphasize the well-being of the community over that of the individual. In countries as diverse as India and Japan, this collectivist emphasis is closely intertwined with concepts of harmony and duty, and these values strongly influence the lives of individuals and communities. In Asian societies, people with disabilities tend to feel less shame at being dependent on others than would be the case in individualist countries such as the United States. It is common practice for family members to take care of other family members with disabilities. China has more people with disabilities than any other country in the world. A cultural norm among the Han Chinese, the major ethnic group, is to experience significant instinctive embarrassment at having a disability or having persons with disabilities in their midst. This embarrassment may be associated with an array of behaviors related to stigmatization, including discrimination and abandoning or euthanizing newborns with disabilities. In Thailand, families sometimes feel so ashamed of relatives with disabilities that they do not submit the birth certificates of babies born with disabilities to the government. Thai parents may see the disability of a child as a direct consequence of some previous transgression of the parent. In India, persons with leprosy go to great efforts to hide signs of it from view. They seek to avoid the judgment that they have engaged in sexual transgressions for which they are being punished and to avoid the further sanction of being excluded from their community. The Hindu/Buddhist idea of karma as the inevitable consequence of individual actions, even across generations in a family, is deeply entwined with perceptions of disability.

Social embarrassment at disability may also result in excessive protection of persons with disabilities, instead of considering them as having equal rights. It is not unusual for parents of children with disabilities to be unwilling to allow their children to go out by themselves. This same strong tendency to shelter or protect those with disabilities can be seen in the Philippines. Such protection, often done with the best of intent, can have serious long-term consequences. It is likely to limit opportunities for full development, reducing opportunities for people with disabilities in education, employment, marriage, and participation in community life. As is the case with the treatment of persons with disabilities in China and the Philippines, this belief system of shame and embarrassment results in people adopting stigmatizing extremes: overprotectiveness or discrimination, sometimes simultaneously.

In Japanese society, the pattern of stigma has been similar and now is showing some signs of change. The term used to refer to people with disabilities is *shougaisha.* This term conveys perceptions of people with disabilities as people of “obstacles,” “illness,” and/or “loss.” Similar to views in other parts of Asia, the Japanese believe that being sick or having a disability is the result of sin in the past or in a previous life. This belief results in feelings of shame for having someone with disability in one’s family. Japanese individuals without disabilities tend to perceive those with disabilities as being like children. In Japan, the distinction between persons with and without disabilities is clearly drawn. An example is the existence of disabled-only bathrooms, which, unlike their counterparts in some other societies, have stigma associated with them. The Japanese tend to have clearer categories and expect others to adhere tightly to the categorization.

Insights into stigma in Japan may come from the concepts of uncertainty avoidance and *Kegare.* People high in uncertainty avoidance perceive people and ideas that deviate from societal norms to be dangerous. Cross-cultural studies suggest that Japan has one of the highest population levels of uncertainty avoidance of any country in the world. *Kegare* is a Japanese term that implies impurity/contamination and encompasses everything that is outside the blessings of the gods. *Kegare* is thought of as contagious in Japanese culture and is associated with individuals with disabilities. *Kegare* also has a kinship connection. The mother of a child with a disability would be considered to be linked to the child’s perceived impurity. Historically, children with disabilities were often kept from public view and given fewer opportunities to develop their abilities.

Presently, there are efforts in Japan and nascent efforts elsewhere in Asia, such as China and Korea, to reduce the stigma associated with disability and its negative effects. Programs to reduce the prevalence of abuse of people with disabilities, to increase educational and employment opportunities, and to promote independent community living all can help reduce stigma and its sequelae. Advocacy groups are working to build greater awareness of the positive contributions of people with disabilities to Japanese society. Students planning to enter the human services have positive rather than stigmatizing attitudes toward people with disabilities. As other Asian economies strengthen over time, it is reasonable to anticipate reduced stigma associated with disability.

## PEOPLE WITH DISABILITIES IN AFRICA

In many ways, African conditions for persons with disabilities are similar to those in Asia. In African nations such as Botswana, the family rather than the individual is the primary unit of society. Persons with disabilities are involved in families and communities. For this reason, Western concepts such as inclusion, integration, least restrictive environment, and normalization may have little meaning. However, recent studies have shown that the introduction of Western education systems, which encourage greater focus on the individual, has led to segregated classes for pupils with disabilities.

The languages of many African nations and cultures have no term for disability. For example, the language of the Songye culture in Zaire has three categories of “abnormal children”: (1) ceremonial, (2) bad, and (3) faulty. The Songye tend to attribute the acquisition of disability to ancestral acts, insufficient payment by the wife’s family of dowry upon marriage, sorcery, or God’s punishments rather than to any sort of genetic/chromosomal cause. In a similar vein, the Maasai culture in Kenya views illness and disability as signs of cosmic disorder projected on the human body. The Maasai, however, do not make the direct link between physical limitation, on one hand, and stigma and resulting inferior treatment, on the other. Both the Songye and the Maasai include persons with disabilities into their subsistence-oriented community life.

In Uganda, the issue of insider-outsider status is crucial for an individual with a disability. Specifically, an individual with a disability who is part of the community will be integrated, whereas an outsider with a disability may be isolated and avoided by the rest of the community. Part of this outsider avoidance may be due to the perceived contagiousness of disability. Ugandans' initial concern is that the loss of function related to the disability will spread rather than how the persons with disabilities compensate for their impairment. The idea of spread posits that the loss of one function leads to a decrease of capacity in other physical functions. In contrast, the idea of compensation posits that the loss of one function is likely to lead to increased capacity of other functions. As is the case in other countries, the degree of stigmatization may differ by gender. Finally, similar to Asian societies and many others, the power differential between the genders has, in general, been found to lead to more stigmatization for disabled females than males.

In addition, as is true in Asia, African societies see the individual according to his or her ability to contribute to the well-being of the community. Although persons with disabilities may be viewed negatively because of religious or philosophical interpretations in both Asian and African cultures, they usually are included in family and community life, receiving care from family members. Recent years have challenged these traditional structures, however. The HIV/AIDS epidemic has taxed the resources of families and communities, created many more people with chronic illness and disability, and decimated the ranks of potential caregivers.

In sum, cultural, psychological, religious, and economic factors all affect the degree and form of stigma associated with disabilities across cultures. While progress is being made internationally to improve the status and reduce the stigma of people with disabilities, such improvements are subject to changing conditions and attitudes in every human society. If the past is prologue, then the future is likely to see progress that continues to be uncertain, uneven, and reversible.

*—Robert I. Westerholm, Laura Radak, Christopher B. Keys, and David B. Henry*

***See also*** Attitudes; Inclusion and Exclusion; Stigma.

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## STRESS

Stress is defined as a reaction to external situational pressures, resulting in both physical and psychological changes in the individual. It is most often viewed as negative in the form of anxiety-producing and compromising physical and mental well-being. In some cases, however, stress is seen as positive (eustress)—perhaps pushing an individual toward extra effort or associated with positive changes in the life course, such as marriage. Stress related to disabilities can be examined in terms of physical characteristics (e.g., sight/hearing impairment) as well as mental or cognitive characteristics and impairment (e.g., learning disability/dementia). A concept closely tied to disabilities and stress is stigma, or the real or perceived ostracism, labeling, and "devaluation" of individuals and groups, often resulting in compromised social status, associated with having a disability. Stress associated with disabilities must be examined from social and interactional perspectives. A significant factor in reducing distress and important to the acquisition of legitimacy for people with disabilities is self-esteem—both at the individual and group levels—which allows people to believe they are included as members of society and, therefore, strive for the achievement of integration.

The impact of disabilities on the family has been a particular focus related to stress. Parents of children with developmental disabilities have been shown to have greater stress, depression, and health problems than parents of children without disabilities. Of interest, while children with disabilities can have a negative impact on parents' marriage, it has been reported that children with disabilities can also bring parents closer together and that a strong marital relationship is one of the most important factors mediating parental stress. Coping resources that have been shown to minimize familial stress related to disabilities include social support from friends and individual personality and beliefs (e.g., religious faith). Literature on the coping responses of adolescent siblings of children with disabilities indicates the need for professional support and the establishment of strong support networks to facilitate coping.

Research on disability and job stress indicates that people with work disabilities often experience increased risk for physical and psychological complications of job stress. Disability management programs implementing stress management interventions—targeting such disorders as back pain, multiple sclerosis, HIV, chronic fatigue syndrome, arthritis, high blood pressure, headache, and general psychological distress—have been shown to improve physical and mental health, reduce costs to employers, and facilitate the reintegration of injured individuals into the work environment. Interventions include use of cognitive behavioral stress management and a team approach, including physicians, nurses, psychologists, occupational therapists, social workers, and physical therapists.

Understanding and addressing quality of life, including stress, in people with disabilities requires modifications in social and societal attitudes and behaviors. In medical encounters, people with disabilities, while generally satisfied with their medical care, report lack of satisfaction with doctors' understanding of their conditions, thorough discussions of health problems, and being hurried during medical visits. The concept of the "disability paradox" looks at the inconsistency between general perceptions of the undesirable daily existence of people with disabilities compared to their own views of good or excellent quality of life. In examining and addressing stress in people with disabilities, quality of life needs to be understood in the context of the individual's balance between mind, body, and self and relationships with the social and environmental context.

*—Michael L. Glasser and Karen E. Peters*

***See also*** Siblings of People with Disabilities.

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## STROKE

Stroke is one of the most common causes of acquired disability in adults throughout the world. The World Health Organization estimates that 15 million individuals worldwide sustain a stroke each year, with 5 million deaths. Of the survivors, approximately 5 million are left with significant disability.

The existence of stroke as a distinct condition has been known since antiquity. Psalm 137 appears to describe the symptoms of stroke. "If I forget thee, O Jerusalem, let my right hand forget her cunning. If I do not remember thee, let my tongue cleave to the roof of my mouth." Ancient Greek physicians, including Hippocrates and Galen, recognized the essential symptoms of "apoplexy," though they debated the causes and location of the disease. Characterization of the anatomical basis of stroke syndromes, such as Broca's aphasia, occurred during the nineteenth century. A clear understanding of the mechanisms and major risk factors for stroke occurred during the twentieth century.

Because of its prevalence and ability to cause substantial disability, stroke has affected numerous world figures and altered the course of history. A prominent example from the twentieth century is the severely disabling stroke sustained by Woodrow Wilson during his second term as U.S. president. This stroke prevented him from exercising his duties as chief executive. The extent of his disability was hidden from the public and even from most of his cabinet; a small inner circle, including his wife and personal physician, controlled all access to the president during the remainder of his term. Subsequent recognition of the inadequate provisions in the U.S. Constitution for the disability of the president ultimately contributed to the adoption of the 25th Amendment in 1967. Other contemporary examples of the impact of stroke on world history include Franklin Roosevelt's death while in office from a cerebral hemorrhage in 1944 and Joseph Stalin's death from a stroke in 1953.

Strokes are broadly divided into two categories based on the cause of damage to the brain. Approximately 88 percent of strokes are ischemic and result from the loss of the supply of blood to an area of the brain that occurs when a blood vessel becomes blocked. The remaining 12 percent of strokes result from bleeding either within the brain (hemorrhagic stroke) or adjacent to the brain from the blood vessels that supply it (subarachnoid hemorrhage). The destruction of brain tissue that results from these various etiologies results in neurologic deficits that are the hallmark of stroke.

Risk factors for ischemic stroke are well established, and many are amenable to behavioral or medical preventive measures. Age and race are important nonmodifiable risk factors, with men having a higher risk than women (approximately 1.25 times the risk) and African Americans having a higher risk than Caucasian Americans (nearly twice the risk). Hypertension, smoking, inactivity, and obesity are all important modifiable risk factors that may be addressed in part through behavioral changes and in part through medical treatments. Behavioral modifications include smoking cessation, regular exercise, limiting caloric intake, and reducing intake of saturated fats. Preventative medical treatments include the use of platelet-inhibiting medications such as aspirin and clopidogrel; in selected circumstances (such as atrial fibrillation), anticoagulants (primarily warfarin) are indicated. In individuals with a severely narrowed carotid artery (one of the major blood vessels supplying the brain), surgery to remove the blockage within the artery can reduce the risk of stroke significantly.

Stroke can cause disability by affecting one or more of a multitude of neurologic functions. Loss of muscle strength and coordination (hemiplegia) is the most common cause of physical disability after stroke. Aphasia (loss of the ability to comprehend and/or produce speech or other linguistic communication) is another major cause of disability. Cognitive impairments, including reduced attentiveness, memory loss, and loss of insight, are frequent sequelae of stroke and contribute to the burden of disability. Swallowing difficulties (dysphagia) can cause malnutrition, dehydration, and predisposition to pneumonia. The location of a stroke is the major determining factor in the resulting neurological impairments; a small stroke in a critical area can cause more profound symptoms than a larger stroke in a less critical region. Some strokes are "silent" inasmuch as they do not result in any noticeable symptoms. Prior silent strokes are commonly discovered incidentally when brain imaging is performed for a new (symptomatic) stroke.

Improved acute treatment of stroke remains a priority area of medical research. As recently as the early 1990s, acute stroke care largely consisted of supportive measures to prevent medical complications, and no interventions were available to limit damage from an ongoing stroke. Intravenous medications (such as alteplase) are used to dissolve blood clots depriving brain tissue of blood flow and are now an important part of the management of acute stroke. Unfortunately, relatively few individuals with stroke are eligible for thrombolytic (clot-dissolving) treatments due to the narrow time window for their use (typically within three hours of symptom onset). The use of catheters threaded through the blood vessels to instill these medications directly to the vicinity of the blood clot is under study, as are other interventional approaches to opening blocked arteries. A variety of medications have been studied as potential neuroprotectants to reduce the damage induced by a stroke, but none has yet reached routine clinical use.

Due to the limitations in stroke prevention and acute treatment, residual disability is a common result of stroke. Stroke rehabilitation has its roots in antiquity, and references to the use of a crutch after stroke are found in Babylonian texts from the second millennium BCE. Modern rehabilitation has increasingly emphasized the use of active participation by the stroke survivor to achieve maximal recovery, rather than the use of passive treatments provided by medical providers. Stroke rehabilitation in developed countries typically includes physical, occupational, and speech therapy for a period of weeks to months. Efforts to reduce hospital or other institutional stays are ongoing, with increasing emphasis on rehabilitation in the home environment. Rehabilitation hospital stays after stroke now average two or three weeks in the United States; they remain longer in other countries, such as Japan.

Rehabilitation in less developed countries varies widely. Some rely more on family members and informal rehabilitation than on medically directed rehabilitation. Little data are available to compare functional outcomes between the various rehabilitation systems in different countries.

Recent research has found considerable plasticity in the adult human brain. Both changes in brain function, as demonstrated with the use of functional magnetic resonance imaging and other techniques, as well as changes in motor abilities have resulted from therapeutic exercise programs. This plasticity can be harnessed by structured exercise programs to improve motor outcomes after hemiplegic stroke. Intensive exercise programs appear to provide greater benefit than lower dose exercise programs and are being actively studied. Some centers are also exploring the use of technological aids such as robotic exercise devices to facilitate the delivery of exercise after stroke. The use of medications, growth factors, and stem cells to expand the capability of the brain to recover from stroke is being studied and is likely to be combined with rehabilitation programs in the future.

Plasticity clearly affects other impairments resulting from stroke, such as aphasia and cognitive deficits, and therapeutic interventions directed at these impairments appear to facilitate recovery. The optimal program of therapeutic interventions to stimulate brain plasticity and maximize functional recovery remains to be elucidated.

Functional outcome after stroke can be measured using a variety of tools, including the Functional Independence Measure, the Barthel Index, and others. Among ischemic stroke survivors in the United States who are at least 65 years old, 26 percent are institutionalized in a nursing home six months after a stroke. Depression is a common consequence of stroke, and as many as 40 percent of stroke survivors experience significant depression within the months following a stroke.

*—Joel Stein*

***See also*** Aphasia; Dysphagia; Physical Medicine and Rehabilitation; Traumatic Brain Injury.

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# SUB-SAHARAN AFRICA

*See* Experience of Disability: Sub-Sahara Africa

# SUBSTANCE ABUSE

## EPIDEMIOLOGY

Substance abuse is one major source of health problems afflicting individuals worldwide. It is estimated that one fourth of Americans experience a lifetime substance use disorder. Substance-related disorders are covered under the Americans with Disabilities Act of 1990. Therefore, problems derived from substance abuse can be viewed as disabilities.

Even excluding substance abuse as the primary disability diagnosis, persons with cognitive and physical disabilities are more likely to have a substance use disorder than the general population, yet they are less likely to obtain and complete treatment for it. Treatment barriers include not only those related to physical accessibility but also poor professional training to deal with the particular needs of individuals with concurrent substance abuse and disabilities.

It is estimated that 20 to 40 percent of persons in treatment for substance use disorders have some sort of mental or physical disability (mostly a comorbid psychiatric condition, followed by mobility, developmental handicaps, and sensory—vision and hearing—impairments). Often undetected, the presence of a disability, even subtle, may affect treatment effectiveness. A high prevalence of comorbid disability and substance use is also observed in other settings such as prison and court populations, where approximately 50 percent of offenders with an intellectual disability also have an alcohol problem.

## ETIOLOGY

Substance abuse is often a factor in trauma-related physical injuries. Driving under the influence of alcohol contributes to traffic accidents and related disability. Despite the fact that legal blood alcohol concentrations (BACs) vary widely across countries, evidence shows increased risk of car crashes with BACs above 0.02 percent (that translates to approximately one bottle of beer, but factors such as sex and body weight may interfere with this estimate).

A relationship between unfavorable childhood conditions, early deviant behavior, and later alcohol abuse and related disability has been demonstrated. Drunken driving and criminal behavior in young males were related with more disability pensions and sick leaves on a 20-year follow-up. Thus, monitoring of such behaviors may help identify at-risk populations for disabilities. The relationship between substance abuse and disability seems more complex than just one of cause and consequence, with substance abuse working both as a risk factor and a maladjusted response augmenting disability after injury. For instance, substance abuse that develops after an injury can be a hindrance to rehabilitation.

Aside from physical disability, substance abuse is also implicated in psychological maladjustment, particularly among young people, demonstrated by increased rates of conduct and personality disorders (mainly those characterized by intense impulsiveness, such as antisocial and borderline). A number of psychiatric conditions are also overrepresented in substance-abusing populations, including affective, anxiety, and psychotic disorders. The risk of other addictive disorders is increased (polydrug abuse and eating disorders, particularly bulimia nervosa, for instance). Adding to the physical sequels of addiction, pathological gambling is another concern, with its associated impulsiveness (with greater likelihood of suicide attempts and criminal offenses), risk of bankruptcy, discredit, and deeper social disruption. Rates of attention deficit disorder are increased among substance-abusing individuals. Women are at higher risk for psychiatric comorbidity and to develop iatrogenic substance abuse/dependence as they are more likely to be prescribed medications such as benzodiazepines. Worries about body image also put them at risk of abusing amphetamines and other diet pills. Theories to explain these increased associations include (1) self-medication of a primary mental disorder, (2) substance abuse leading to the development of secondary psychopathology, (3) coexistence of substance abuse and psychiatric morbidity independently, and (4) a common etiologic factor leading to both substance abuse and psychiatric morbidity.

Substance abuse is also etiologically related to development of a disability during pregnancy. For instance, fetal alcohol syndrome (FAS) represents the third most common cause of mental retardation (the leading cause if genetic causes are excluded), with increasing risk in association with binge drinking. It produces long-term consequences, particularly social maladjustment and communication deficits. The full syndrome is present in about 30 percent of the offspring of women who consume 10 standard drinks daily. Fetal alcohol effects (FAE) are often underdetected. Symptoms may include central nervous system abnormalities, with mental retardation in about half the cases of full syndrome, facial dysmorphism (characterized by short palpebral fissures, epicanthic folds, and maxillary hypoplasia), and other birth defects (microencephaly, altered palmar creases, and heart abnormalities). Diagnosis after puberty is even more difficult, as the facial dysmorphism is usually not as pronounced. FAS and FAE are often associated with increased psychiatric comorbidity, substance use disorders, antisocial behavior, and multiple pregnancies in adolescence and adulthood. Early detection and appropriate referral may prevent further morbidity. Because safe levels of alcohol consumption during pregnancy are not defined, it is best to recommend complete abstinence to prevent FAS and FAE.

Tobacco use during pregnancy is also associated with perinatal problems (e.g., fetal growth retardation, obstetric complications, premature delivery, low birth weight and height, neonatal mortality, sudden infant death syndrome, and hypertension), with some long-term physical and behavioral consequences to the offspring (such as reduced lung function, substance abuse, criminality, and antisocial behavior), independent of other factors. Both alcohol and tobacco (by far the substances that cause the most problems if consumed during pregnancy) have addictive effects in combination with other substances. Besides the effects of substances themselves, the lifestyle often associated with substance abuse, including poor nutrition, lack of resources, and appropriate medical care, further contributes to these long-lasting disabilities in offspring.

Environmental circumstances faced by persons with disabilities may contribute to substance use and abuse, such as job problems and unemployment, lack of leisure opportunities, social isolation, poverty, homelessness, and various forms of abuse (emotional, physical, and sexual, both from domestic and external sources).

To improve detection of coexisting disabilities among persons entering treatment for substance use disorders, it is strongly recommended that every person should be specifically screened for disabilities, not only those obviously affected. More important than diagnosing a potential disability—a task that most professionals in addiction treatment centers are not prepared for—the levels of functionality need to be assessed since adjustments in the treatment protocol will be based on these aspects. This is important because even people with similar disabilities may have very different abilities and limitations. Assessment should be tailored to the nature of the disability (e.g., finding alternatives to self-report questionnaires for the mentally handicapped or to visual-analogical scales for the vision impaired).

In addition, the assessment team needs to be sensitive to the fact that some people have more difficulties accepting an eventual disability than others (depending on issues such as severity, age, marital status, income, and sociability). Likewise, a confidential climate needs to be ensured (particularly important when the disability implies that family members and friends will accompany the client) to enable the collection of relevant and accurate information. Clients should be referred for additional assessment by a qualified professional if initial screening indicates that a disability diagnosis might be present. Screening can be part of the usual assessment process for potential clients and can incorporate indirect questioning (such as questions about environmental factors that may be related to disabilities; prior medical history, including medications and hospitalizations; and accidents) and direct questioning (such as questions about history of any disability or health benefits and learning, hearing, reading, communicating, writing, decision-making, or mobility difficulties). Besides work absences, effort to function should be considered. Recently, the 36-item short form health survey of psychosocial functioning has been proposed as a tool for screening and measuring disability due to psychiatric conditions.

Attitudes toward persons with coexisting disabilities in addiction treatment should emphasize accommodation of any special needs and requirements.

In addition to avoiding rigid rules and deadlines that may make treatment participation virtually impossible, professionals must attempt not to enable clients' negative attitudes (such as accepting a client's refusal to attend mutual-help meetings for fear of not being accepted by peers) that could erode treatment efforts. Arranging for alternative groups and schedules is a more desirable option. Many clients with coexisting disabilities may be under a medication regimen. Some addiction treatment programs demand that potential clients discontinue any medications before entering treatment, which is obviously not feasible in many circumstances.

Finally, getting acquainted and networking with disability-related resources in the community, by ensuring referral to properly equipped services, may save time and effort that can be best directed to treatment itself.

*—Monica L. Zilberman and Hermano Tavares*

***See also*** Fetal Alcohol Syndrome.

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# SUBSTITUTE DECISION MAKING

Substitute decision making occurs when a person lacks mental competence to make a decision, and the situation requires that a decision be made. Substitute decision making ordinarily becomes controversial when the decisions concern very serious financial or health matters. The controversies tend to center on two main issues. The first issue is the choice of who should be the substitute decision maker. The second issue is concerned with how the decision should be made.

## DECISION MAKERS

There are numerous ways that a person can be chosen to be a substitute decision maker, and the legalities of the process vary across jurisdictions. Generally speaking, there are three types of decision makers: a decision maker appointed by the incapacitated person prior to incompetence, a decision maker appointed by the state, and a decision maker in an emergency.

### *A Decision Maker Appointed by the Incapacitated Person*

Many jurisdictions allow individuals to appoint someone to take care of their property and health matters in the event that they become unable to make decisions for themselves. For example, in parts of the United States, Britain, Australia, New Zealand, and Canada, it is possible to create an *enduring* or *durable power of attorney,* which grants a substitute decision maker the power to act on behalf of a person who has become mentally incompetent. These powers of attorney are described as "durable" because, unlike ordinary powers of attorney, they continue to be effective after the grantor of the power has become incompetent.

In addition to choosing a decision maker, powers of attorney will normally define the role of the decision maker and contain instructions on the types of decisions that can be made and the preferences of the person subject to the power. It should be noted that these documents are different from advance directives or living wills because they allow the substitute decision maker to make the ultimate choice. In an advance directive, the patient is the decision maker.

One limitation exists with this method of choosing a substitute decision maker. These documents cannot be created by a person who has always lacked mental competence.

### A Decision Maker Appointed by the State

The state has a role in protecting people who are unable to make decisions for themselves. In the common-law tradition, this is evidenced by the *parens patriae* jurisdiction, an eleventh-century English concept, which granted to the sovereign the power and responsibility to care for infants, "lunatics," and "natural fools and idiots." The parens patriae jurisdiction has survived into modern times and is still relied on by courts in Australia, Canada, New Zealand, and the United States as the source of power to make substitute decisions for mentally incompetent adults and children. It is also used to appoint other decision makers. Strangely, England no longer has a parens patriae jurisdiction over adults because of an administrative error in 1969, which removed it from the list of prerogative powers enjoyed by the sovereign.

Most jurisdictions provide for state-based appointment of substitute decision makers, ordinarily when the person has not exercised a choice via a power of attorney, either using the parens patriae power or legislative powers. Most commonly, state-appointed substitute decision makers are referred to as *guardians,* but the terms *conservator, custodian,* and *curator* are also employed in parts of the United States. Courts or specialist guardianship tribunals are ordinarily given the task of appointing guardians. Ordinarily, a relative or close friend is chosen because they are best equipped to look after the person under guardianship.

If no suitable candidate is available to be appointed as a guardian, a public body or official (such as a court, guardianship tribunal, adult guardian, or public guardian) may be appointed in the role.

### A Decision Maker in an Emergency

It may be necessary in an emergency for someone to make a substitute decision for another because that other person is mentally incapable and has never appointed a substitute decision maker. The most common example of this occurs in medical emergencies, when a person is unconscious or seriously injured and unable to make a decision about treatment.

In parts of the United States, it has been assumed that relatives automatically have the power to consent in such situations, and in emergencies, doctors will ordinarily seek the consent of a relative unless the situation demands immediate treatment. In countries in the British Commonwealth (such as Australia, Canada, New Zealand, United Kingdom), relatives only have power to consent to treatment when the patient is a child. Relatives cannot consent to emergency treatment for incompetent adults. This gap in consent has led some legislatures to grant powers to relatives so that they can consent to emergency medical treatment, without the need for a power of attorney or an order by the courts. For example, in the Australian states of New South Wales, South Australia, Tasmania, Victoria, Queensland, and in the Australian Capital Territory, legislation allows relatives to consent to treatment when the patient is not competent. If no relative is available, a doctor may continue to treat the patient according to the patient's best interests. There are moves to adopt such laws in England and Wales.

What if a person's relatives cannot be contacted? In such emergencies, the common law empowers health professionals to treat an incompetent person, even in situations when the treatment is quite invasive. Such situations are seen as an exception to the general rule against touching another person without his or her consent. Health professionals can raise the defense of emergency (sometimes called the defense of necessity) to any claims of battery or wrongful interference. To properly mount such a defense, the health professional must be able to show that the patient was incompetent, that there was no substitute decision maker to seek consent from, and that the treatment was a necessary and proportionate response to the illness or injury of the patient.

Some jurisdictions (e.g., parts of Australia, Scotland, and the United States) have enshrined these rights of emergency medical treatment in legislation.

## HOW SHOULD DECISIONS BE MADE?

Generally speaking, two approaches can be employed in substitute decision making.

### The Best-Interests Approach

The best-interests approach requires the decision maker to choose the course of action that can be considered on objective grounds to best serve the interests of the incompetent person.

For example, in the United Kingdom case of *Airedale NHS Trust v. Bland* (1993), the House of Lords had to decide whether it was in the best interests of a young man in a permanent vegetative state to continue to be treated with artificial feeding and hydration. The House examined the issues of the probability of success of treatment, the likelihood of recovery, and issues concerning the man's lack of quality of life. The House took evidence from doctors and other health professionals to assess these factors and decided that it was no longer in best interests to receive such treatment.

The best-interests test is the standard of substitute decision making most commonly employed in the United Kingdom, Australia, New Zealand, and Canada. It is also employed in some states in the United States.

The problem with the best-interests approach is that it can be vague, and best-interests assessment can often be disputed. It is difficult to pinpoint exactly what objective factors should be considered in different types of decision, and the approach says nothing about how those factors should be weighed against each other. There is also the possibility that the decision maker's own prejudices will be disguised as "objective assessment." The best-interests test also runs the risk of reducing the autonomy of the incompetent person because of its focus on objective factors rather than the subjective desires of the incompetent person.

### Substituted Judgment

The substituted judgment approach requires the decision maker to take into account the subjective beliefs, feelings, and desires of the incompetent person. A person exercising substituted judgment must choose the course of action that (according to the decision maker) would be the course of action chosen by the incompetent person.

The substituted judgment approach originated in English equity courts in their supervision of an incompetent person's property. It was primarily used to justify gifts from the estate of the "lunatic" to the lunatic's family or friends on the basis that such gifts would have been what the incompetent person would have wanted. In modern times, it is widely employed in the United States as the method of substitute decision making.

We can compare the best-interests approach used in *Bland* above with the substituted judgment approach used in a similar case, *Matter of Quinlan* (1976). In this case, the father of a severely disabled patient sought to be appointed her guardian, so that he could authorize the cessation of her respiratory support. The court appointed the father as guardian and said that he should exercise his best judgment as to whether the patient would have refused treatment in the circumstances that arose. Later, in *Superintendent of Belchertown State School v. Saikewicz* (1977), a case concerning a never-competent man with cancer, it was said that the substitute decision maker dons the mental mantle of the incompetent and substitutes herself or himself as nearly as possible for the individual in the decision-making process.

Several criticisms have been made of substituted judgment. The first is that it is a fiction to presume that another person knows what would have been decided by the mentally incompetent person. To counter this critique, some jurisdictions require clear and convincing evidence of what the incompetent person would have decided, such as statements made by the incompetent person or evidence of similar decisions made by the person previously. Others have said that this raises the standard so high that the evidence required is the same evidence that would be required to substantiate advance directives.

Problems also occur when the incompetent person never expressed an opinion or desire or never had the ability to express a desire or opinion. In Canada, the substituted judgment test has undergone judicial criticism for this reason. In *Re Eve* (1986), Justice La Forest denied that the test had any bearing on the issue of the sterilization of a mentally handicapped woman who had suffered from the disability since birth. Justice La Forest saw the substituted judgment test as "sophistry" and "speculation."

### *Combined Approaches*

To counter the difficulties with both approaches, some jurisdictions (such as New Jersey) have adopted a combined approach, whereby substituted judgment is attempted first, and if it is not determinative, best-interest factors can be considered. Alternatively, an expanded best-interests test is employed in some jurisdictions, which contains elements of substituted judgment (see, e.g., cases from Minnesota and New Zealand).

*—Cameron Stewart*

***See also*** Caregiving; Decision Making; Family; Social Support.

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## SUGIYAMA, WA'ICHI (1610–1694)

*Acupuncturist*

Sugiyama Wa'ichi lost his sight in childhood. As a young man, he went to Edo (Tokyo) and studied acupuncture under the teacher Kengyō Yamase. However, "because he was too slow to learn he was expelled by his master." Later, Sugiyama overcame his difficulties, developed an innovative technique for guiding the insertion of needles, and eventually became a famous practitioner and official acupuncturist to the Shogun Tsunayoshi. Kengyō Sugiyama Wa'ichi founded his own school, wrote books on the field, and at the end of his life achieved the highest position in the powerful Guild of the Blind. He is credited with "establishing acupuncture as a common occupation for the blind" and organizing them into a cohesive group during the seventeenth century.

*—Kumur B. Selim*

***See also*** Acupuncture; Complementary and Alternative Medicine.

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## SUICIDE

The relationship between disability and suicide hinges simultaneously on scientific, political, and moral questions. The scientific question is whether disability represents a significant risk factor to suicide and why. The political question is whether people with disabilities who threaten suicide should receive the same response from health professionals as nondisabled people. The moral question involves the question of "quality of life" and whether disabilities make "life not worth living." Underlying all three of these questions is our cultural attitude toward self-sufficiency and interdependency.

### THE SCIENTIFIC QUESTION

Very little data have been gathered with regard to suicide risk factors for people with disabilities, but there is no reason to assume that they differ from risk factors for nondisabled people. Warning signs for suicide for both groups can be found in (1) disruptive family history factors such as abuse or neglect in childhood, enmeshment, separation, loss, and suicide itself; (2) toxic personal history factors such as depression, schizophrenia, substance abuse, low self-esteem and frustration tolerance, demoralization/hopelessness, and rigid/constricted thinking; and (3) personal stressors such as relationship loss or abuse, loss or control over life, social isolation, and problems in work, housing and finances. People with disabilities may face social discrimination that heightens some of the above triggers for suicide.

For example, people with disabilities may face difficulties with the legal and medical system, difficulties of obtaining personal assistance, social devaluation, and threatened loss of independence. These factors may be especially overwhelming for people with newly acquired disabilities. Physically disabled people are no different in this regard from many people with mental disorders such as schizophrenia. The risk for suicide, for example, is much higher in the first few years after a diagnosis of schizophrenia and diminishes after that as schizophrenia turns into a more chronic condition, suggesting some adjustment to illness. However, individuals with schizophrenia are again at increased risk when psychotic symptoms such as auditory hallucinations return, suggesting that adjustment to illness and symptoms themselves may independently be suicide risk factors. People may adjust to physical disability in the same way.

There is concern and debate around the issue of physician-assisted suicide for patients with terminal illness and/or disabilities. Data suggest that disability is a risk factor in people seeking physician-assisted suicide and/or perhaps in being selected by medical personnel for this “treatment.” However, the data also suggest that it may not be disability per se that leads people to seek suicide but psychological factors associated with suicide that would also push nondisabled people to attempt to end their lives.

For example, there is a case on record of a woman with cerebral palsy who expressed the wish for physician-assisted suicide after a series of severe losses, including a miscarriage and a marital separation that left her essentially homeless and impoverished. A videotape of another patient revealed a highly accomplished patient with the beginning of Alzheimer’s who found that much of her activities and abilities were now discounted and belittled. For example, although she could still play tennis, she could no longer keep score on her own. Even though she could still play piano, she could no longer sight-read.

## THE POLITICAL QUESTION

The political question stems directly from these examples. Are disabled people who threaten suicide treated the same or differently than nondisabled people who threaten suicide?

When a person comes to a health professional with suicidal desires, such desires are typically interpreted as the product of a temporarily self-destructive and tumultuous state of upheaval leading the person to be temporarily tunnel-visioned and to temporarily see suicide as the solution to problems. The person may be hospitalized, friends and family will be notified, and the suicidal wishes will be interpreted as profoundly irrational—indeed, a permanent solution to a temporary problem. The health professional will attempt to keep the person safe until the temporary madness has passed.

For example, a young woman may have just ended a destructive romantic relationship and feels that nothing in her life has any value. The woman’s feelings are interpreted by the professional as only temporary. The professional may emphasize that when one is in a depression, he or she always views the future through a negative lens. Likewise, a man whose spouse has died may be devastated and, in his bereavement, may become highly suicidal. Similar examples can be found in many life crises, including loss of a job, infidelity of one’s spouse, and death of a loved one. Before a person is able to gather social support networks and can cope sufficiently to envision a future after the loss, he or she may be very drawn to suicide as an alternative to the pain of living. The mental health professional will work to minimize the effects of the loss to prevent collateral damage. The therapist must emphasize to the patient that although he may have failed, he is not a failure. He will get another, perhaps a better, job. The therapist must play for time with the patient, until the person’s coping mechanisms activate and he or she is able to reassert a drive for life. Consider these examples if the person is disabled.

Here the temptation is to see the person's suicidal desires as not irrational at all but rational, stemming from the disability, rather than from the actual psychosocial stressors underlying the suicidal wishes. The desire to die may not be interpreted as suicidal but as an attempt to free oneself from suffering. This may be especially true if the person depends on medical intervention to remain alive. A desire for suicide may be euphemized as "refusing treatment."

The person's suicidal desires may be interpreted as rational, rather than irrational, even though the triggering factors are the same as for a nondisabled person. This fixation on disability represents what the disability community labels a "deadly compassion," which may emerge because of one's own fear of becoming disabled. The professional in such a situation may not try very hard to prevent the person's suicide and, if not actively assisting him or her in it, may well give implicit approval that the suicide is quite understandable. Indeed, in the physician-assisted suicide case discussed above, the husband of the patient suffering from the beginning of Alzheimer's opined that he would take his own life if such a calamity befell him. Such a double-tiered approach to suicidal wishes is profoundly troubling to the disability community. Suicidal wishes in a nondisabled person will be labeled as irrational and evoke suicide prevention responses on the part of health professionals. The same wishes on the part of a disabled person might be labeled as rational and evoke silence or even calls to assist the person to carry out his or her suicidal wishes.

## THE MORAL QUESTION

The moral question is whether life is of unconditional worth or whether it is only worthwhile if it has a certain "quality." This debate goes back to biblical Israel and Greece of classical antiquity. The Greek and Roman stoics advocated suicide if life no longer conformed to a person's expectations or desires. Disability, as well as simply boredom, could well represent a rational reason for suicide. Suicides were abundant in ancient Greece and Rome, and Greek tragedy is filled with such instances. The Judeo-Christian biblical world, in contrast, does not view suicide as rational and indeed equates it with homicide. Strikingly, no such concept as "quality of life" exists in biblical thought. Life is not seen as divisible but as having an intrinsic and infinite worth. Suicides are rare in the Bible and not associated with disability. There are data also to show that people living in countries where religion imposes strict taboos against suicide have lower rates, but again, these data have not been separated for disabled people only.

One major concern to address when considering the suicide-disability relationship is how society views dependency and independence. There are cultures that highly value or arguably overvalue independence, and in such societies, a disabled person may feel unvalued and even a burden, making suicide a natural action to consider. Other societies highly value connectedness on interdependency within the context of extended family or cultural group. In such societies, being dependent might not have the same pejorative connotation and therefore not as likely to lead to suicidal thoughts.

*—Kalman J. Kaplan and*
*Martin Harrow*

***See also*** Infanticide; Physician-Assisted Suicide; Refusal of Life-Sustaining Treatment; Values.

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## SULLIVAN, ANNE (1866–1936)

*Special educator*

Anne Sullivan was born in 1866 near Springfield, Massachusetts. At the age of 4, she became totally blind due to trachoma, an eye disease associated with poor sanitation. Her mother died when she was 10, and she and her younger brother were sent to the almshouse, at Tewksbury. Shortly after their arrival, her brother died from tuberculosis, but Annie lived there for another four years and then was sent as a charity student to the Perkins Institution for the Blind in Boston. Her sight was partially restored through a series of experimental surgeries, though her vision remained impaired, and eventually she became blind again at the end of her life.

In 1887, Sullivan was chosen to travel to Tuscumbia, Alabama, to serve as the teacher of a young deaf-blind girl named Helen Keller. Using methods develop by Perkins founder Samuel Gridley Howe, in his work with the deaf-blind girl, Laura Bridgman (1829–1889), she trained Keller to communicate with the manual alphabet for the Deaf. Sullivan's innovation was to simulate the way a hearing child learns to speak by being constantly surrounded by spoken language. She did not restrict her instruction to scheduled lessons but spelled constantly into Keller's hand. She remained Keller's companion for nearly 50 years, helping her to pursue her education and acting as her interpreter at lectures and as an editor of her numerous publications. In 1905, she married John Macy, Harvard professor and editor of Keller's first book, *The Story of My Life.* The couple separated a decade later, though they were never divorced.

Sullivan and Keller never felt that Sullivan's work as an educator received the recognition it deserved. She was alternately lauded as a miracle worker and critiqued as a self-promoting charlatan who exaggerated the accomplishments of her pupil. Both views reflect a general belief that Keller's accomplishments were exceptional, far in excess of what should be expected from a deaf-blind child.

*—Georgina Kleege*

***See also*** Helen Keller; Special Education.

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## SUMMARY MEASURES OF POPULATION HEALTH

The generic label *summary measures of population health* (SMPH) refers to a class of statistics that describe and quantify different elements of population health. The relatively large number of SMPHs is attributable to the variety of uses for SMPHs and the fact that each use might, in principle, require a somewhat different SMPH. The resulting set of SMPHs reflects the various and evolving approaches to measurement that have been used over time by different researchers and health-related organizations.

**Table 1** Purposes of SMPHs

1. Intrinsic interest: Indicating how long and in what state of health different individuals are likely to live
2. Cross-national comparisons and benchmarking
3. System planning: Indicating the likely future health profile population for social and economic planning
4. Planning time: Time-series data to monitor health and plan health services and health workforce
5. "Micro" planning: Disease-specific population measures
6. Comparison of subpopulations within a country
7. Measuring the *burden* of different diseases in health sector planning
8. Measuring health benefits from medical or other interventions
9. Epidemiological and health services research
10. Prioritizing medical research

Table 1 lists 10 possible uses for SMPHs. Broadly, these include the intrinsic interest, benchmarking, social and health sector planning, and the evaluation of performance at both national and program levels. The resulting SMPHs vary along a number of dimensions, some of which are summarized in Table 2. While some of the differences in SMPHs are attributable to different technical approaches to measurement, most differences in Table 2 arise because of differences in the concept being measured—for example, life versus the value of life and prevalence or incidence of a disease.

Different concepts, in turn, arise because of the different purposes for which they were created. For example, the measurement of the current burden of disease uses a prevalence-based metric, whereas measuring the total impact of new health policies often uses an incidence-based concept. These decisions tend to be pragmatic and arbitrary, depending on ease of access to appropriate data.

Depending on the purpose, the construction of an SMPH can involve up to seven stages:

1. defining the objectives of the measure;
2. defining the populations to be described, such as a whole country or a randomized controlled trial study group;
3. defining the time span of the measure, such as a human lifetime or a five-year period;
4. defining the range of health states and illnesses to be included in the measurement process;
5. measuring the numbers of people in the different health states and illness in the population;
6. estimating the severity of the health states of the people in the population by a process of valuation;
7. defining the health target or goal to be achieved in the population.

## HEALTH EXPECTANCIES AND HEALTH GAPS

The most basic distinction in Table 2 is between the measurement of health expectancy and health gaps, and this is used to classify the SMPHs in Table 3, which summarizes the different measures. Health expectancies are based on the actual health experience of a population. Health gaps estimate the difference between actual health and some theoretical norm or goal of population health.

*Health Expectancies.* Health expectancies (HEs) estimate the expectation of years of life lived in various health states, expressed as average survivorship from fixed ages (e.g., life expectancy from birth). This includes expectations for specific health states (e.g., disability-free life expectancy) and for value equivalents of different health states (e.g., disability-adjusted life expectancy).

*Health-Adjusted Life Expectancies.* Health-adjusted life expectancies (HALEs) are those HEs that estimate the expectation of equivalent years of good health, calculated for health states defined in terms of valuation of disability severity. HALEs give a weight of 1.00 to years of good health and weights between 0.00 and 1.00 to other states of less than good health. Healthy life expectancy is now used as a synonym for HALE, rather than its previous usage for a health state expectancy for perceived (self-reported) good health. Disability-adjusted life expectancy (DALE) is a synonym for HALE but uses a different valuation methodology. HEs are of two main classes: those that use dichotomous health state weights (including disability-free life, disabled, demented, or dead) and those that use health state valuations for an exhaustive set of health states (based on specific valuations of measured ICD disease prevalence and the measured distribution of different disability states within the diseased populations).

**Table 2** Characteristics of SMPHs

| |
|---|
| **Quantity Measured** |
| Health expectancy versus gap |
| Lives versus life years |
| Incidence versus prevalence |
| Unadjusted data (mortality/1,000) versus adjusted data (life expectancy) |
| Life versus value of life |
| **Technical issues** |
| Cohort versus period measures |
| Mean versus median |
| Dichotomous versus continuous |

*QALYs.* Quality-adjusted life years (QALYs) are generally used for measuring the outcomes of health services or programs but could be interchanged with disability-adjusted life years (DALYs) as an SMPH. Years of full health are assigned an index (index) value of 1.00. Morbid years are weighted by an index of utility (strength of preference), as measured by the time trade-off, standard gamble, or rating scale techniques. DALYs are a form of QALY estimated with a particular methodology, which includes age weights and the use of the person trade-off technique of preference elicitation.

*Health Gaps.* Various health gaps have been defined that vary according to (1) the selected normative target used to measure the difference (health gap) from the current health conditions in a population, (2) the method used to value time spent in health states

**Table 3** Table of Terms

| *Measure* | *Date* | *Description* | *Reference* |
|---|---|---|---|
| Health Expectancy (HE) | | Generic term for summary measures of population health, which estimate the expectation of years of life lived in various health states. | Chiang, C. L. 1965. *An Index of Health: Mathematical Models*. Vital and Health Statistics Series 2, No 5. Washington, DC: National Center for Health Statistics. |
| Life expectancy (proposed) | 1964 | A weighted average time to death from different ages (e.g., birth, 21, 50, 75): usually based on the current mortality rates extrapolated into the future. | Sanders, B. S. 1964. "Measuring Community Health Levels." *American Journal of Public Health* 54(7): 1063-1070. |
| Life expectancy (developed) | 1972 | | Sullivan, D. F. 1971. "A Single Index of Mortality and Morbidity." *HSMHA Health Reports* 86(4): 347-354. |
| Quality-adjusted life expectancy (QALE) | 1970 | A form of health-adjusted life expectancy (HALE) that is based on a question on activity restriction in the Canada Health Survey. | Fanshel, S., and J. W. Bush. 1970. "A Health-Status Index and Its Application to Health Services Outcomes." *Operations Research* 18(6): 1021-1065. |
| Active life expectancy (ALE) | 1983 | A form of disability-free life expectancy (DFLE) based on survey questions on limitations in activities of daily living (ADL). | Katz, S., L. G. Branch, and M. H. Branson. 1983. "Active Life Expectancy." *New England Journal of Medicine* 309:1218-1224. |
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| Health-adjusted life expectancy (HALE or DALE) | 2000 | A weighted average time to death from different ages, with the value of the time between onset of disability and death reduced by standard fractions for different diseases based on some community judgment of the impact of those disabilities. | World Health Organization (WHO). 2000. *The World Health Report 2000. Health Systems: Improving Performance*. Geneva, Switzerland: World Health Organization. |

*(Continued)*

**Table 3** (Continued)

| *Measure* | *Date* | *Description* | *Reference* |
|---|---|---|---|
| Quality-adjusted life year (QALY) | 1978 | QALYs for full health and death are assigned scores of 1.00 and 0.00, respectively. Marked years are weighted generally by the standard gamble, time trade-off, or rating scale techniques by the strength of preference (utility) for the state. Various SMPHs are derived from the use of different techniques for conceptualizing and quantifying the numerical value of years of ill health. | Torrance, G. W. 1986. "Measurement of Health State Utilities for Economic Appraisal." *Journal of Health Economics* 5:1-30. |
| Health gaps (HG) | | A generic term for summary measures of population health; estimates the gap between the current population health and a normative goal for population health. | |
| Years of life lost (YLL) | 1947 | The component of the DALY (q.v.) that measures the years lost through premature mortality, with morbid years weighted by the extent of the disability. | Dempsey, M. 1947. "Decline in Tuberculosis: The Death Rate Fails to Tell the Entire Story." *American Review of Tuberculosis* 56:157-164. |
| Disability-adjusted life years (DALYs) | | The health gap attributable to a disease, with marked years weighted by a person trade-off (PTO)-based assessment of the severity. Conceptually similar to the QALY. | Murray, C. J. L. and A. D. Lopez. 1996. World Health *Organization Global Burden of Disease*. Geneva, Switzerland: WHO. |
| Years of healthy life (YHL) | 1995 | A form of DFLE (q.v.) based on two questions collected in the U.S. National Health Interview Survey, which are concerned with activity limitations and perceived general health. | Erickson, P., R. Wilson, and I. Shannon. 1995. *Years of Healthy Life*. CDC/NCHS, Healthy People, Statistical Notes No. 7. Hyattsville, MD: U.S. Department of Health and Human Services, National Center for Health Statistics. |
| Healthy life years (HeaLYs) | 1998 | A health gap (q.v.) measure calculated on the basis of the incidence of pathological processes and the future nonfatal health outcomes and mortality from those processes. | Hyder, A. A., G. Rotllant, and R. Morrow. 1998. "Measuring the Burden of Disease: Healthy Life-Years." *American Journal of Public Health* 88(2): 196-202. |

less than ideal health, and (3) the inclusion of other social values, such as age weights, time preference, and equity weights.

The normative targets may be a fixed age (e.g., years of life lost to age 75), the expectancy of the healthiest known populations within countries, or a mathematical projection of the expected optimum life expectancy based on the mortality and morbidity experience of the whole world (e.g., the HALE of the World Health Organization's [WHO's] World Health Report 2000). Fixed-age health gaps are simple to calculate but place no value on life beyond the age threshold. Normative targets based on national or international comparisons are more complex to calculate but do not contain implicit age biases.

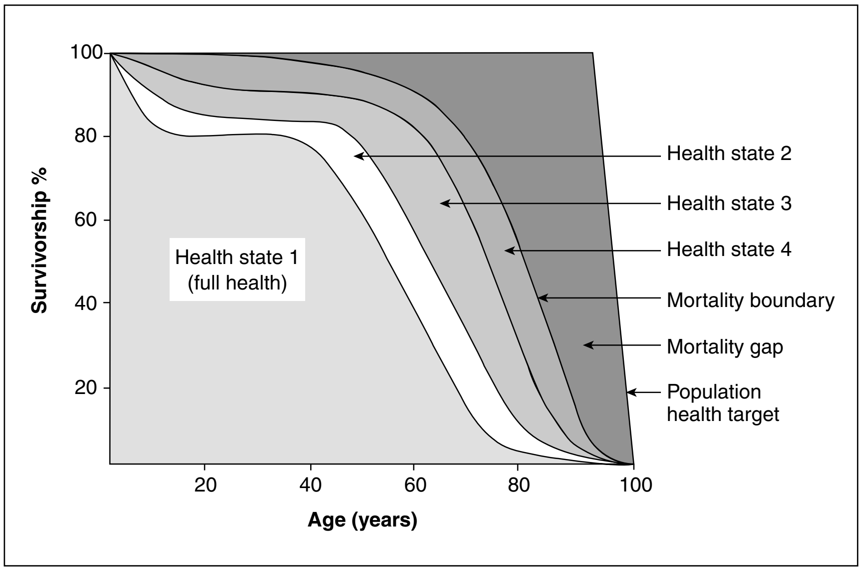

**Figure 1** Survivorship Curves Used to Calculate Health Expectancies and Health Gaps

Health gap estimation is most useful when it identifies the constituent populations and causes of the loss of health and allows planning for the elimination of the gaps. The WHO Global Burden of Disease studies estimate the mortality and morbidity incidence and prevalence based on reported national mortality statistics and other estimates of disease prevalence. This approach assumes that all causes of loss of health are understood and can be identified by the disease classification systems. Its measurement is not always independent of the activity of health services.

*Measurement of Health Expectancies and Health Gaps.* Health expectancies are estimated for populations using routine mortality statistics, supplemented by measurement of morbidity rates using a variety of routine health service activity measures and health surveys. Period HEs are used to predict the future by assuming that the age-specific mortality and disease prevalence rates today will be the same as those that will be achieved by the corresponding age-specific cohorts in the future. These are constructed mathematically by applying the observed mortality and morbidity rates to a theoretical population existing only in a computer. Cohort HEs are the actual measure of the survival and health experience of a real age cohort observed over decades, but these can only be known in retrospect and so are not available for service planning.

Figure 1 schematically represents a limited number of survivorship curves constructed from the measured mortality and morbidity rates in a population. HALEs measure the area under the survivorship curve, taking into account different weighting for years lived in different health states. The position of the population health target is an entirely "political" construct.

SMPHs are calculated using the following formulas:

Life expectancy = $\mathrm{HS1}_{\mathrm{area}} + \mathrm{HS2}_{\mathrm{area}} + \mathrm{HS3}_{\mathrm{area}} + \mathrm{HS4}_{\mathrm{area}} + \mathrm{HS}i_{\mathrm{area}}$

Health-adjusted life expectancy = $\mathrm{HS1}_{\mathrm{area}} + \mathrm{value}_2 \times \mathrm{HS2}_{\mathrm{area}} + \mathrm{value}_3 \times \mathrm{HS3}_{\mathrm{area}} + \mathrm{value}_4 \times \mathrm{HS4}_{\mathrm{area}} + \mathrm{value}_i \times \mathrm{HSi}_{\mathrm{area}}$ population

Mortality gap = $\mathrm{PHT}_{\mathrm{area}-}$Life expectancy

Health gap = $\mathrm{PHT}_{\mathrm{area}-}$Health-adjusted life expectancy

where $\mathrm{HS}i_{\mathrm{area}}$ is the average years in health state $i$ (measured by area under the curve), $\mathrm{value}_i$ is the weighting assigned to health state $i$, and $\mathrm{TPH}_{\mathrm{area}}$ is the total number of years if the entire population achieves the population health target.

While population sizes and mortality rates may be fairly accurately known, morbidity rates are more problematical. If the purpose of the SMPH is to judge the effectiveness of health services, it may be inappropriate to use health service activity alone as a measure of morbidity. Unmet needs will be unmeasured, and service activity data may not include sufficient information to determine the disease severity levels in a way that can be translated by valuation into life-year equivalents in reliably comparable forms. This issue is important for common, high-impact conditions that are underdiagnosed, such as depression and chronic pain syndromes. Health surveys may measure symptoms of illness, whether or not the illness is being managed, but may not be able to accurately diagnose the cause of the symptoms.

## DISCUSSION

SMPHs are often composite measures that combine the quality and quantity of life according to some algorithm. Some have argued that the resulting composite is conceptually confused—that it is not possible to add apples and oranges. The appropriate response to this is that apples and oranges are not combined. Rather, it is the *value* of the different attributes that is combined. It is legitimate to criticize the combination rule (algorithm), but this is a separate issue from the conceptual validity of combining dissimilar attributes, something done routinely in what is probably the most useful construct in the social sciences—namely, the gross domestic product (GDP), which compares the *value* of a vast array of goods and services.

A second methodological issue concerns the way in which SMPHs are selected. One approach is to presuppose that a single broad concept exists that is the correct measure in any health-related context—namely, the concept of "health" per se. This approach has elsewhere in the physical and social sciences resulted in a search for the "essence" of the concept associated with general terms and an attempt to codify the essence in a precise definition that can then be used in deductive argument or for the guidance of measurement. The approach has been historically associated with intellectual stagnation. Karl Popper's (1974) summation of the impact of "essentialism" is as follows:

> The development of thoughts since Aristotle could, I think, be summed up by saying that every discipline which still uses the Aristotelian method of definition has remained arrested in a state of empty verbiage and barren scholasticism, and the degree to which the various sciences have been able to make any progress depends upon the degree to which they have been able to get rid of this essentialist method. (This is why so much of our "social sciences" still belong to the middle ages.) (p. 9)

The alternate preferred approach is to commence with the problem of interest, to determine, conceptually, the likely solution and then to select or create the definitions that help to describe and summarize the relevant concepts and operationalize the solutions ("nominalism"). SMPHs have arisen not as a result of differing attempts to capture the essence of a healthy population but (generally) as a result of the differing "problems" involving population health, the differing solutions, and the concepts, definitions, and metrics implied by these solutions. A life insurance company may be interested in its future financial obligations. For this purpose, life expectancy is the most useful metric. Health authorities may be interested in "that which society wishes to maximize." This might lead to the concept of a QALY or DALY, possibly with importance weights for equity and probably with preference weights for the timing of the benefits (i.e., discounting).

Finally, the field of SMPHs is evolving. This commonly involves disagreement, and in the SMPH literature, there have been and remain contentious issues. These include the choice between period- and cohort-based life expectancy, the theoretical life expectancy used in gap measurement, the measurement of quality or "disability," the use of incidence- and prevalence-based measurement, and the inclusion of age or other social weights.

Ongoing debate over both technical issues of measurement and social objectives makes it highly likely that the field of SMPH will continue to evolve.

*—Jeff Richardson and*
*Iain Robertson*

***See also*** International Classification of Functioning, Disability, and Health (ICF/ICIDH); Epidemiology; Quality of Life; Research; World Health Organization.

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# SUPPORTED EMPLOYMENT

Supported employment is an approach to helping people with disabilities find and keep jobs in the community. It is defined as competitive work in integrated settings, with ongoing support for individuals who have traditionally been excluded from the workforce. Although it emerged as an approach for people with developmental disabilities in the United States, supported employment is currently being practiced in many countries around the globe for individuals with various disabilities, including psychiatric, physical, intellectual, and cognitive disorders. The emergence of supported employment has dramatically changed the lives of many individuals with significant disabilities who were previously denied access to employment opportunities outside segregated settings.

## VALUES AND GOALS OF SUPPORTED EMPLOYMENT

Supported employment is based on the fundamental belief that all citizens should have opportunities to participate in the workforce and earn a competitive wage. The underlying assumptions are as follows: every individual can be gainfully employed if provided with the proper supports, each person has something unique to offer, and people with disabilities can be dedicated, hardworking employees. Supported employment entails principles of choice, empowerment, and equality. Accordingly, no person should be denied access to such services due to limitations caused by their impairment. Supported employment is about finding the right support to enable persons with disabilities to reach their full potential as workers.

The main goal of supported employment is to promote active social inclusion and community participation of people with disabilities through the workplace, by providing opportunities to find permanent competitive employment and to receive the individualized support required for successful job performance. It is through workplace participation that supported employment strives to increase the capacity of local businesses and communities to provide the support their citizens need to realize their full potential as contributing members of society. The success of supported employment is measured in terms of its capacity to build meaningful relationships among community members and to increase the quality of life of citizens with disabilities.

Several factors strengthen the rationale for supported employment from the perspective of people with disabilities, employers, and community members. First, it addresses the inadequacies of the traditional approach to vocational services for people with disabilities by helping people maximize their potential within competitive work opportunities. At the same time, there is a growing recognition of the importance of meaningful work experiences in building relationships with others, formulating a self-identity beyond the disability, and developing increased self-esteem and self-worth. The underlying philosophy and goals of supported employment represent an important progression toward equality and empowerment of people with disabilities in society.

## COMPONENTS OF SUPPORTED EMPLOYMENT

Supported employment contains three basic components: competitive work, integrated settings, and the provision of ongoing, individualized support. Competitive work refers to a job that may be available to all citizens, regardless of their ability, in which the worker is paid the labor market wage for the position. Integrated work settings are workplaces where persons with disabilities work alongside those without disabilities. This component reflects an emphasis on social inclusion and involvement of persons with disabilities in the workforce, a critical aspect of community life. Placing individuals with disabilities in the workplace with nondisabled peers is a vital aspect of supported employment and a shift from previous models of vocational services.

The provision of ongoing, individualized support is the most distinctive characteristic of the supported employment approach. While traditional vocational programs provide only time-limited support, supported employment calls for support that is ongoing and individualized. That is, support by an employment specialist (or job coach) is made available to workers with disabilities for as long as each individual wants and needs it. The frequency and intensity of the support are flexible and designed to meet the ongoing and dynamic needs of the worker on the job.

Traditional sheltered workshops and vocational programs typically provide lengthy employment readiness assessments and preemployment training. Once placed, support is often reduced or terminated. Thus, the traditional approach has been referred to as the “train-place” model. Supported employment, by contrast, uses the “place-train” approach, where the preemployment phase is relatively short and the focus is on rapid placement and time-unlimited support on the job in the actual work setting.

## HISTORICAL OVERVIEW

The concept of supported employment evolved with shifts in social values and beliefs, especially dissatisfaction with the inability of traditional sheltered workshops and vocational programs to move beyond segregated or “practice” settings. Transition from traditional vocational programs into competitive employment was extremely slow, if not impossible. Most individuals did not progress to competitive employment and experienced few opportunities for advancement. As awareness of these limitations and shortcomings increased, people began to search for alternative ways of providing employment opportunities and choices to people with disabilities. Some revolutionary programs emerged that transformed the perceived employment potential of people with disabilities. For example, the clubhouse model, which was developed in 1948 by former psychiatric patients at Fountain House in the United States, is considered an early precursor to supported employment.

In the early 1970s, the growth of the disability rights movement and the emergence of the principles of social inclusion and “normalization” emphasized the need to provide all persons with opportunities to participate in valued social roles in the community. Implementing these ideas into employment practices meant a move toward real work in the community, rather than “make-work” in segregated facilities. In this way, employment programs using the principles of supported employment were developed.

The success of supported employment spread from the United States to other countries. In Canada, the Metropolitan Toronto Association for Community Living and the Sioux Lookout-Hudson received government funding in the mid-1970s to provide long-term support in the workplace to people with disabilities. Supported employment services also emerged in Asia and Europe. For example, supported employment has existed in Hong Kong since the late 1980s and in Finland since the mid-1990s. Although local modifications to the supported employment approach may alter the target population and the level of success achieved, the basic premise and components remain the same internationally.

## MODELS OF SUPPORTED EMPLOYMENT

A number of different models of supported employment are being practiced, including some that focus on individuals in supported work settings, others on groups of individuals with disabilities who are placed in supported work settings. The individual placement model (IPM) offers intensive and individualized training and support for individuals with disabilities. It is the most common approach to supported employment and the most effective, with employment outcomes surpassing those of group models. The IPM is also less stigmatizing, as there are no special groupings at work, and the person with a disability is generally hired as a regular employee, earning the same wages as other workers.

The IPM incorporates job development (finding or creating appropriate jobs), job placement (carefully matching the person to the job), on-the-job training (skill training by a specific staff member who is aligned with the worker), ongoing assessment of work performance, and job maintenance strategies (including problem solving, job modifications, and advocacy for job retention). An employment specialist is usually responsible for these functions and remains involved as a formal support on a long-term basis. The expectation, however, is that the intensity of support will fade over time. The individual approach is more challenging to maintain for clients whose job skills, rate of work, and work behaviors do not match job requirements.

A modified version of the IPM can be found within the psychiatric literature and service delivery system. The individual placement and support (IPS) model incorporates rapid job search, integration of rehabilitation and mental health services, attention to consumer preferences, continuous and comprehensive assessment, time-unlimited support, and competitive employment as the goal.

The enclave model involves groups of individuals with disabilities working with ongoing support within a business or industry. It is the second most common form of supported employment and is frequently found in the developmental disability literature and service delivery system. Full-time support, training, and supervision are provided by an employment specialist or enclave supervisor, who may be employed by an outside supported employment agency or by the business itself. The supervisor locates and develops jobs from the company, trains the workers, and supports them through their integration into the workplace. Most often, the outside agency employs the workers and is subcontracted by the business to provide the labor force. Workers may also be hired directly by the business. Examples of enclave models vary in their documented rate of pay: some are at minimum wage; others are lower and based on production. Enclave models have been criticized for low pay and the potential for isolation from the general workforce. Accordingly, work in an enclave is recommended as a stepping stone to individual placements for those workers who meet job demands and become acclimatized to the workplace.

An adapted form of the enclave model is the cluster model, where workers are dispersed throughout a work area and integrated with nondisabled coworkers. Often, these cluster placements evolve as workers are added to a job site. These placements can look like individual placements, but an enclave supervisor is available on an ongoing basis within the business.

Work crews or mobile work crews are small businesses with small groups of persons with disabilities, which perform work for an employer on a contract basis at the employer's work site. An employment specialist secures the work, supervises and trains the workers, supports them in adjusting to the workplace, and ensures that quality work standards are met. Ideally, the work crew is established as a small business and manages the quantity and type of work according to the changing needs of its employees. Staff responsibilities include not only employment support services but also tasks of managing and marketing a small business. Most commonly, the work performed by work crews consists of housekeeping, janitorial, or groundskeeping services. Workers are usually paid by the supported employment program from contract revenue.

## EFFECTIVENESS

Literature comparing the effectiveness of supported employment models as they cross disability groups is very limited. Most outcome research on supported employment deals with the effectiveness of a single model for a defined population. The few studies that do cross models and disabilities reveal that everyone, regardless of disability, benefits from supported employment and that individual placement models generate employment outcomes superior to those from group models. Differences in employment outcomes across groups have been found in the areas of wages, type of employment, and job retention, but the paucity of research on this issue prohibits firm conclusions. The most common populations discussed are psychiatric and developmental disability groups.

In the psychiatric disability literature, randomized controlled trials that compare supported employment with prevocational training reveal that clients in supported employment earn more and work more hours per month than those in prevocational training. Other studies reveal that although placement rates for people in supported employment programs are strikingly higher than those generally cited for this group, employment outcomes such as wages, job satisfaction, and long-term job maintenance are questionable. Characteristics of exemplary supported employment programs for this group include use of multiple funding sources, integration of mental health and vocational services within the same programs, early entry into competitive employment with intensive support, a high degree of involvement of the employment specialist in the interview process, and an interest in evaluating supported employment services.

Outcomes in the developmental disability literature have been very positive: rates of people entering the workforce through supported employment opportunities have grown over the past decade, and integration and wage benefits are strong when compared with sheltered work and segregated settings. Components of service delivery associated with successful outcomes within this group include an emphasis on collateral behavior (social and communicative interaction), client advocacy, a focus on job analysis and job matching, follow-up support, and the use of advisory councils or local businesspeople to assist with marketing. Supported employment with persons with developmental disabilities is often criticized because those most often placed in supported employment settings are only mildly or moderately disabled, thus excluding individuals with more severe disabilities. Others have raised concerns regarding funding disincentives, that is, the way the system reduces or cuts levels of social assistance as people earn wages. Therefore, supported employment is sometimes used as an additional service option rather than the standard course of action.

## COST EFFECTIVENESS

Some evidence is available to show that supported employment programs approach or achieve cost efficiency. However, many studies of cost-benefit draw on such small samples that the results need to be interpreted with caution. A few studies suggest that while costs may initially exceed benefits, the reverse is true several years after the establishment of a supported employment program. Savings to public income support vary across funding systems. Studies in the United States suggest that savings are generally low, possibly due to low salaries of employees and the resulting need to draw on social assistance even while working. Canadian research reports substantial reduction in individuals' need for social assistance. Furthermore, every individual in supported employment programs pays and contributes to pension and employment insurance plans. Reports documenting the conversion of existing programs to supported employment programs demonstrate improved vocational outcomes without increasing costs.

Supported employment offers hope and work opportunities to people with disabilities within mainstream employment. Businesses and communities at large are recognizing the multiple benefits possible through supported employment opportunities.

*—Bonnie Kirsh and Rebecca Gewurtz*

***See also*** Employability; Employment; Employment, International; Inclusion and Exclusion; Worksite Modification.

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## SUPPORTED SERVICES

In the past, people with disabilities had little choice about what kind of services, if any, were open to them. Institutions smothered individual differences, while an absence of any form of help meant that many individuals were simply left adrift in an unforgiving environment. By contrast, *supported services* refers to an array of supports that are available when and where individuals require them. What unifies these personal, social, instrumental, and tangible interventions is the notion that, whether or not they have disabilities, people live their lives connected to their environments and the people with whom they live and work.

A human story unearthed from sites where humankind's remote ancestors lived shows that they must have cared for their young and also for others who were evidently vulnerable. From the current vantage some thousands of years later, one can only infer their motives—whether affective or whether calculated to ensure that more people in a group would thrive and thus be strong enough to protect each other. All humans need support in infancy and childhood. And most will do so into their old age, an ever more certain horizon in the future for people in both developed and still developing countries. Even in the prime of life, people look for help to prosper, to keep healthy, and to fulfill obligations to families and employers.

In every society and every age, there are individuals who need much more support than others. Those with disabilities, for instance, may have particular needs for support that punctuate the course of their adult lives. The place that people with diverse needs should hold in a modern democratic society is but one issue fuelling today's debates in political philosophy. The debate is whether to embed social contracts on the premise that some individuals are more vulnerable than others, not merely as infants or older, dependent people. Given that *disability* is a construct whose boundaries are fuzzy across time, cultures, and contexts, it follows that the nature of optimal support made available to individuals in a society will vary as well. In addition, individuals identified as having the same disabling condition may manifest distinctive patterns of living, and thus uniform solutions to meet their support needs are not useful. Typically, individuals draw on support from family members and friends. In societies where formal systems of health and social services have been organized, they may also depend, at least in part, on these sources of support. Private and public domains intersect at the point where an individual with disability encounters support—perhaps personal intimacy, friendship, instrumental assistance in carrying out daily tasks, income, or other benefits in kind.

In the past, people with disabilities were often numbered among the deserving poor, albeit a drain on society's purse if alms were not forthcoming. Separate but unequal systems of providing support for people with disabilities became widespread. The industrialized countries built structures to classify and sustain people with disabilities within health and social systems shored up by public funds. An administrative solution might take the form of a segregated facility housing people with intellectual and other disabilities and associated conditions—mental illness or epilepsy, for example. Remnants of large-scale institutional care persist today, not only in former Eastern bloc countries of Europe but more widely. In many less prosperous countries, whether through tradition or simply through lack of means, large-scale institutions were never built.

Yet it is striking to reflect that worldwide, most people with disabilities live with their families and rely on them for care and support. Today, adults in societies where independence is valued may chafe at what they perceive as intrusive services and aspire to live in their own homes. As people with disabilities grow older, it is more likely for them to move away from the family home if alternatives are available. While some developed countries have embraced community living for their citizens with disabilities as the standard for adults, others have been slow to give up large residential centers.

As institutions have declined in prominence in many industrialized countries, supported residential services aim to help people with disabilities find a good place to live by themselves or with the people they choose. Since the last decades of the twentieth century, many thousands of people with disabilities began to leave old-style institutions, moving to ordinary homes and workplaces. In their stead, *supported services* have come about to meet the needs of individuals with disabilities in their pursuit of satisfying life outcomes. The ultimate aim of such services is to support individuals so that they can live and work as they wish. The springs of this sea change flowed in part from radical rethinking about the injustice of segregation for any marginal social group and the primacy of self-determination expressed in fresh policies and laws. In the United States, for example, disability advocacy groups, federal legislation, and judicial decisions converged in policies promoting individualized supports to achieve the person's own preferred goals. *Person-centered planning* is a programmatic tool developed to identify and attain these goals with the support of the individual's named allies, including family members, human service staff, and others. A focus on the person as director of his or her life plan turns the tables on previous practices, which tried to shape individuals so that they would fit into preexisting forms of social support devised for groups. Today, many people with disabilities live satisfying lives of their choosing in their own homes, perhaps with coresidents of their choice. Service agencies are charged not with herding people under a single roof for ease of administration but rather with tempering supports to suit particular needs in the individual's own home.

Typically, adults with disabilities experience very high rates of unemployment. Many thousands of these individuals have no jobs at all or work only in sheltered settings where prospects are modest and where there are no employees who do not have disabilities. For those who wish to do so, supported employment services help them to find, get, and keep preferred jobs. Many individuals with disabilities will in time outgrow the support needed at the outset as they enter the ordinary workplace, such as through in-service job training. Others will require coaching throughout their careers from a mix of specialist and natural sources such as coworkers. Supported services have made it possible for thousands of men and women with disabilities to enter the ordinary workplace and earn an income for the first time. However, supported employment—offering an ordinary job, full- or part-time—is not as widely available as may be indicated by policies favoring social and vocational integration in Europe and other regions of the world.

The widespread transfer from block services to individualized supports for people with disabilities yields dilemmas. Individuals and their family members may reasonably be anxious if the balance between autonomy and risk shifts to their disadvantage. They have concerns regarding the adequacy of support for people with complex, significant disabilities and those with physical disabilities of such scope that they need others to help with every aspect of their personal care to aspire to anything like independent living.

The abandonment of large institutions can potentially leave a vacuum in the lives of some people with disabilities if sufficient supports are not in place.

Those who believe that vulnerable people thrust into a complex world may lose out in terms of stability and companionship argue that some individuals will always need the special supports available in professionally run, separate residences or workshops. Others argue that society, in time, will simply care less about people inserted into the mainstream without the trappings of special status. Furthermore, many people with disabilities living in very poor circumstances—sharing conditions of deprivation, with little opportunity for a comfortable, secure life—need additional supports. There is an ongoing debate about whether independence in the community is the only legitimate goal for these people.

Independence was a foremost goal as people with disabilities moved away from the confines of institutions and separate forms of care. Sometimes social isolation resulted, fomenting pleas for a return to old ways of gathering together people with disabilities. More recently, interdependence has emerged as a crosscutting principle in all aspects of society. On the world stage, globalization is founded on the premise that the political and economic fortunes of all countries are linked. At the personal level, interdependence is expressed in transactional models of human development: individuals interact with family members, friends, and the socioeconomic and physical contexts in which they grow and develop. From infancy through old age, individuals are both influenced by their environments but also shape these environments actively. People with disabilities may seek supports to help negotiate these reciprocal relationships.

No injection of funds and no political decision can confidently produce an ideal form of support for each person in every circumstance: some argue forcibly that it is not society's business to try to do so. Rather, questions about how society values people who are dependent or especially vulnerable and responds to their distinctive needs for support reflect dilemmas springing from the human condition. For as the American philosopher Martha Nussbaum (2001:34) reminds us, "The way we think about the needs of children and adults with disabilities is not a special department of life." Supported services are a tangible sign that society recognizes that individuals have needs that are worth meeting and that to do so is for everyone's sake.

*—Patricia Noonan Walsh*

***See also*** Independent Living; Peer Support; Social Support; Social Networks.

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## SUR DAS (1480s?–1580s?)

*Indian musician and poet*

For four centuries, Sur Das has been the most famous blind musician and poet of North India, with the result that "Sur Das" as a nickname could get attached to any (male) blind Hindu or Sikh who sang or played music. The "original" Sur Das has become elusive, and no detail can be fixed with certainty. The theory that the celebrated poet and musician was identical with a documented Sur Das, son of Ram Das, who lived at Braj, was blind, and performed at the court of Akbar (regn. 1560–1605), is unquestioned by many Indian scholars and supported by some Westerners (Lehmann 1982; Vaudeville 1971). Most people concede that the legend originated with a real-life artist and poet, who composed most or all of the thousands of poems in the *Sur Sagar* (*Ocean of Song*).

Traditional assertions about Sur Das continue to be questioned—especially by those who dismiss Indian oral history, argue about the mentions of blindness in Sur's literary work, and are surprised that, "if Sūr was blind, he did not make a great point of it before the world" (Hawley 1984).

*—Kumur B. Selim*

***See also*** Experience of Disability: India.

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## SURGERY AND DISABILITY

A number of surgical procedures produce postoperative disabilities. Although these procedures may alleviate discomfort, save or prolong life, or provide a cure because the diseased tissue or organ is excised, they nevertheless leave a significant postoperative residue or set of new disabling problems with which the patient and their carers have to cope. In other words, because of the surgical rearrangement of the human body, impairment is created in the form of a loss, reduction, or change in function, which actually or potentially limits the full engagement of the individual in the social world.

The types of surgery that fall into this category include amputations; radical surgery to the head, face, and neck; mastectomies, colostomies, ileostomies, and urostomies; surgery of the prostate and the penis; and some gynecological operations. Not infrequently, these procedures are conducted to deal with life-threatening diseases, especially cancer, or with long-term chronic illnesses such as diabetes, colitis, and Crohn's disease. While the patient's life may be saved, the disease held in check for a further period of time, or a total cure effected, the postoperative period brings with it a new series of problems. These problems may temporarily or permanently make the patient's quality of life worse rather than better. From the patient's point of view, surgery may seem especially undesirable preoperatively. The surgical outcome may seem to be worse than the disease itself.

### LOSS OF FUNCTION

This is the most obvious type of postsurgical disability and the one most easily linked to the traditional literature on disability. Loss of the ability to walk or significant reduction in mobility following limb amputation would be good illustrations. Amputations of hands or arms or lower limb extremities have differing degrees of functional loss consequent on them. The extent of the loss of mobility will be determined by a range of factors. These are the extent of the amputation, the effectiveness of and ability to use prostheses, the age of the individual, the presence of other comorbidities, the home environment, and the degree of support provided by carers in the family or though health and social services.

Other types of surgical procedures involving loss of function have different, more attenuated functional consequences but are nonetheless very serious. Surgery of the mouth, tongue, face, and neck has potentially very significant functional implications for eating, drinking, and phonation. Surgery of the throat, voice, and larynx has impacts on the ability to speak and eat. Surgeries of the prostate, vagina, penis, anal sphincter, bladder, and gut all have a significant impact on the functions of urination, defecation, nutrition, and sex. Operations on the uterus may affect fertility, and a range of procedures may affect male fertility and potency. Bodily functions that the normal healthy human routinely takes for granted are undermined. In the postoperative state, patients have to relearn skills they originally acquired in childhood. So when surgery affects the ability to speak, eat, and control feces and the bladder, it is striking at some of the most fundamental aspects of our humanity.

What is at issue here is not that individuals cannot do what they used to do or that, with the aid of prostheses and appliances, they can find a functional alternative. It is rather that the skills and competencies that define what it is to be a competent adult member of society—to walk, manipulate objects in the environment, talk, eat, and control the anal sphincter—are changed.

One need not subscribe to a psychoanalytic view of the world to see that destroying the basic skills acquired in childhood of walking, manipulation, eating, drinking, talking, and emptying the bowel and bladder is to assault the human psyche, as well as the human body, in potentially profound ways.

## RESPONSE TO LOSS

It has been observed in many types of surgical procedures—especially but not exclusively coronary artery bypass grafts, mastectomies, and ileostomies—that the consequent emotional response is very powerful indeed. It is sometimes suggested that the destruction of body image is the problem. Among the responses noted are phantom limb experiences by people who have had amputations, denial, clinical depression, and something that mimics the well-described pathways of grief.

These responses can be severe, potentially disabling, and, in some cases, psychologically morbid. Helping patients work though their feelings about loss is very important. It is just as important as helping them to acquire new skills in using their appliances or their new prostheses. Arguably, the importance of allowing patients undergoing such procedures the space and time to grieve for the loss or express and ventilate other emotions is a critical way of beginning the psychological as well as the physical healing process.

## SOCIAL AND PSYCHOLOGICAL RESPONSES

A very useful way to conceptualize the overall social and psychological processes involved is to distinguish between the concepts of self and identity. The concept of self captures the idea that each and every human being carries a notion of what he or she is like as a human being. Some of these things will be attributes such as being friendly, vivacious, good looking, and hardworking. Other elements will refer to social roles and group membership. Some individuals may think of themselves as a man, father, husband, lover, writer, black, and middle-aged. Still other parts of the concept of self will refer to skills the individual thinks he or she possesses: "I can play basketball, I can drive a car, I can paint, I can play the piano," and so on. Some of the elements relate to more fundamental human skills and competencies: "I am an able bodied adult in control of my body and of my life."

Many of the procedures focused on here critically change the core aspects of self and very frighteningly result not only in the loss of control of some aspect of the body and its functions but also the ability to be in control of one's own destiny. Given that in Western society, control and self-control are highly valued, their loss is of considerable import. Not only that, their loss affects primal understandings of who or what we think we are. The assaults on basic activities such as eating, drinking, evacuation, walking, and talking are attacks on the very definition of what the able-bodied world takes to be human. This is because these skills and competencies spill over into and define other aspects of our sense of what we are and our place in the world.

It is not just the obstacles that arise because of the loss of function that are important. Physical barriers are significant because they prevent the postoperative patient doing things and participating in social activities. But also important is the meaning that not doing these things has for the personal biography. So no longer being able to have an erection and to have sexual relations, for example, is not just about not being able to father children or enjoy sexual relations—it is about what that means for the individual's sense of being a man, a husband, a father, and lover. Not being able to talk is not simply about learning new ways of communicating—it is about conversation, chatter, social intimacy, friendship, and being a member of the human community.

Consequently, because of the changes, postoperative patients have to develop a new or altered sense of self, a new sense of who and what they are, a new sense of their place in the world, and a new way of making sense of the world and of their lives. This is not an inconsiderable undertaking. We are basically setting the expectation that the patient will become, in effect, a different person. Not surprisingly, patients often resist and doggedly cling to their earlier sense of self, very reluctantly give it up, mourn its loss, and take a considerable time to embrace new aspects of their new self.

Another useful concept to help articulate the mechanisms involved is identity. The term *identity* is used to mean that public aspect of the person as it is known to others. Identity refers to the elements of role, social position, group membership, and personality as they are known to others. The labels that others apply to us are the key points of reference that we also use to categorize and organize the myriad of others with whom we come into contact. For ordinary able-bodied adults, the key aspects of public identity are usually things such as gender, age, appearance, ethnicity, style of dress, occupation, and all the well-known social signifiers that surround us most of the time. The important point about the kinds of surgery of interest here is that in certain circumstances, the sequelae of surgery are plainly visible to others and constitute a significant aspect of public identity. Amputation and radical face and neck surgery, for example, are immediately visible social signifiers to others. Some authors have talked about stigma in this context, arguing that certain external bodily markers are so significant that they constitute both ways of organizing perceptions (in the same way that things such as age and gender do) and also organizing public identity in very negative ways. In effect, the discrimination to which many disabled people are subject can be understood as a consequence, at the personal level, of the negative labeling and stereotyping and the stigmatizing response of others toward the functional impairment. This is distinct from the social level of discrimination that exists in legal codes and environmental and physical barriers to integration and full involvement in social matters. It is, generally speaking, a much more straightforward matter to change legal arrangements, to outlaw discrimination in the workplace, and to modify the physical environment than it is to change underlying stigmatizing attitudes and stigmatized public identities.

Some of the surgical conditions referred to in this section are invisible when someone is fully clothed. Someone who has had a mastectomy or a colostomy is like this. For them, the problem of public identity is slightly different. They of course have to manage their bodies, their functions, their appliances, and their prostheses. However, others who are not intimate and knowledgeable about the condition—strangers, fellow travelers on public transport, and fellow customers in a shop—would not be aware of the functional difference in their bodies. The question for those with these postoperative states is the extent to which they wish to tell others about their condition, their operation, or indeed the extent they might be compelled to reveal their situation. At these points, they face the possibility of their true identity being found out and their being labeled negatively.

## COPING

A number of types of coping are at the heart of learning to live with a disability that arises as a consequence of surgery. The first of these is technical. Technical coping relates to the specific management of the way the body now functions and to managing any associated prostheses, appliances, and drugs. It relates to the skills that are required to keep functioning despite the consequences of surgery.

The second type of coping skill is *intrasubjective,* meaning within the individual. This is the thinking, feeling, and emotional response to the situation. Having a chronic condition such as cancer, in which the patient has to deal with a sudden diagnosis, surgery, radiation, chemotherapy, rehabilitation, and perhaps reconstructive surgery, is a disruptive and emotionally charged experience. The patient has a lot to deal with, and for many, there will be varying degrees of intense emotional response. Dealing with these feelings and working them through is an important process the patient has to go through and cope with.

The third type of process relates to interpersonal relations. Because of changes to self and identity, interpersonal relations are inevitably disrupted and renegotiated with intimates and with a broader circle of friends and acquaintances. Just as the body is not the same after surgery as it was before, so too are relationships shifted. The size of the shift may well depend on the surgery; patients may also only experience a shift in their patterns of social contacts in the short run, but shifts in interpersonal relations are part of the process.

Finally, there is a process that is called *intersubjective,* which is about rendering the experience meaningful. All of us, to a greater or lesser extent, seek to make sense of our circumstances, our life, and our place in the scheme of things. When people experience life events that arise from these operations, not only will they find that their previous sense of what they thought and what the future holds will need to significantly reappraised, but new meanings for the new circumstances in which they now find themselves will also have to be found.

Some people find hope and great comfort in what they learn about themselves in such experiences; for others, it an experience devoid of anything positive, and they see the whole thing in personally tragic terms. Of course, it may matter a great deal if someone takes a very positive attitude versus someone who does not, not least because of the impact on quality of life and return to ordinary everyday things. But just being positive is not the whole answer by a long way.

The experience of the surgery, which alters the way a human body functions and looks and creates a disability, is physically and emotionally painful. Human suffering on a grand, albeit personal, level is involved. People going through these procedures do sometimes feel despair before they can experience and see things positively. This makes it all the more important to allow time and space for those emotions to be ventilated and the opportunity for the person to do his or her grieving. Even then, of course, if the harsh external world assigns these individuals a stigmatized and negative label and identity, the task is hard indeed. We should not seek to find out from a psychological point of view which personality types cope best, nor should we blindly encourage a positive attitude. We should instead recognize that there are stages in the process of coming through this type of surgery, and the various coping processes have to come into play at different times.

—*Michael P. Kelly*

***See also*** Amputation; Cancer; Identity; Phantom Limb Pain; Stigma.

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## SWEDEN

*See* Disability Law: Sweden; Social Model: Sweden

## SWITZER, MARY ELIZABETH (1900–1971)

*Developer of U.S. disability and rehabilitation policy*

Mary Elizabeth Switzer, distinguished public administrator and developer of U.S. disability and rehabilitation policy, was born in Newton, Massachusetts, on February 16, 1900. In 1921, as Radcliffe College's first graduate in International Relations, Switzer began a lifetime of increasing public service responsibility in Washington. Her career paralleled the development of social programs in the United States, stretching through the tenures of Presidents Harding to Nixon. Mary Switzer believed that bureaucracy existed to serve people and directed the forces of government to include persons with disabilities in the work and play of the nation.

Public Law 565 is the capstone of Mary Switzer's career. Switzer's effect on the quality of life for millions of persons with disabilities and their families is memorialized in bricks and mortar (the Switzer building in Washington and Switzer buildings at the Helen Keller Center, Assumption College, and the Woodrow Wilson Rehabilitation Center), in scholarships, by annual lectures and seminars, in 17 honorary degrees, and in dozens of awards she received during her lifetime.

—*Martha L. Walker*

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## SYDNEY PARALYMPICS

Some 20 years after the 1981 International Year of Disabled Persons, Sydney hosted an exceptional Olympic and Paralympic Games, in which people with disabilities were competitors, spectators, volunteers, media, or employees. At the Sydney 2000 Paralympic Games, some 4,000 athletes from 125 countries competed in 18 sports. Of these sports, 14 are common to the Olympic Games, with the sports of wheelchair rugby, boccia, goal ball, and power lifting being specific to the Paralympics. People competing were from the following disability categories: Amputee, Cerebral Palsy, Intellectual Disability, Vision Impaired, Wheelchair, and Les autres (literally, the "others"). The Sydney Paralympics claimed a number of records, including the following:

- the most number of spectators to witness a Paralympic Games,
- the most number of tickets sold, and
- the Paralympic Opening Ceremony being the most watched television program in the history of the Australian Broadcasting Commission.

Why was this so? The Paralympics followed the undoubted success of the Olympic Games and the party atmosphere created. People enjoyed themselves tremendously and wanted to continue enjoying themselves. The Sydney Paralympic Organising Committee (SPOC) had also undertaken a very successful Reaching the Community Program that targeted schoolchildren and seniors. The program was regarded as important to raise awareness of disability in the community and was essential to weekday crowd numbers because, unlike the Olympics, the Paralympics were not held during school holidays.

There was no research carried out in Sydney investigating the effect of the Paralympics on attitudes to disability. However, the positive images of athletes with disabilities competing in sport were empowering and challenged the stereotypes of disability portrayed in the media and film. Yet, the representations of athletes with disabilities by the SPOC and the athletes themselves were diametrically opposed. The Australian Paralympians identified themselves as highly trained elite athletes, whereas SPOC marketing sought to evoke the sympathy of the nondisabled public to support the "poor cripple." This image was based on the public finding inspiration in "the disabled" overcoming their "deficits" through sporting participation.

This polemic was epitomized by the words of the mayor of the Paralympic Village, who referred to the athletes as "Bravehearts." This term was viewed by the Australian Paralympians as patronizing and led to a debate in the Sydney media about the perceptions of the Paralympics. The debate discussed the merits of Paralympians as elite athletes and not "disabled people," the merit of the Paralympics as a "true" sporting spectacle, and the language of disability. Yet, it was the inspirational message that the majority of media focused on.

The Paralympics provided athletes and spectators with disabilities with an unprecedented accessible experience. However, while the games were heralded for their inclusive planning practices, there were documented discriminatory practices. These involved

spectator and volunteer services,

general mobility and sensory access issues,

equality of transport provision,

the ticketing program not providing people with disabilities with appropriate seating, and

information, ticketing, and online resources not provided in accessible formats.

Most recognize that the major legacy of the games was the provision of accessible infrastructure that was developed in a relatively short timeframe. The professionals involved in the planning of the venues, the common domain, and transport now understand the principles and practices required for an inclusive planning process. One tangible outcome of the Paralympics was the development of an online access resource for planning accessible environments and events. The resource has incorporated the games' planning, development, construction, and operations experiences for disability and access. However, what was overlooked was that most of the inclusive practices could not have been delivered without a human rights framework and the blood, sweat, and tears of the Australian disability community. The Paralympics were made better by the social changes instigated by people with disabilities and disability advocacy organizations in consultations, lobbying, and advocacy that occurred in the lead-up to the games.

*—Simon Darcy*

***See also*** Paralympics; Sports and Disability.

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## SYLE, EDWARD W. (1817–1890)

*Missionary and scholar*

The learned and genial English clergyman, Dr. Edward Syle, was a missionary, scholar, and founder of formal vocational work with blind people in China, at the Shanghai Asylum for the Blind. He worked with the American Episcopal Mission at Shanghai from 1845 to 1860 and kept a detailed journal, incidentally noting many aspects of disability. The journal gave much thoughtful description of Chinese life and customs and was serialized in the Episcopalian serial *The Spirit of Missions.* Syle studied the occupations of blind Chinese people and, in 1856, noticed an old woman “twisting some long sedgy grass into strings, such as are used for holding together, by hundreds, the copper ‘cash’ which are in such constant use.” Syle asked her to teach his blind pensioners this craft, and “thinking, perhaps, that I was slightly deranged,” she agreed. The craftwork soon expanded, as did the idea of elderly blind people being active contributors in the community. Syle later worked for seven years in Yokohama and Tokyo. His son, Henry Winter Syle (1846–1890), who lost his hearing at the age of six, became a deaf activist in Pennsylvania and was also ordained as a priest.

*—Kumur B. Selim*

***See also*** Religion.

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## SYPHILIS

For half a millennium, syphilis was a feared and stigmatized disease. Known as “the great imitator” for its ability to mimic the symptoms of other illnesses, left untreated, it can damage any organ of the body. Beginning as a small genital chancre or sore, syphilis can lay seemingly dormant for weeks to decades. Then its reappearance could bring a range of ills from rashes and gummas across the body, deafness, blindness, perforated palates, madness, mania, excruciating joint pains and deteriorating bones, damage to the aorta of the heart, and death. Its visual components were frightening to see and its debilitating effects devastating.

Secrets and silences often accompanied the disease as its transmission through sexual intercourse or congenitally from mother to fetus trailed moral judgments and state intervention in their wake. Seen as the grand disease of the “other,” its appearance often reached epidemic levels after wars and invasions and was usually blamed on someone else. Explanations for its existence, from heavenly wrath to promiscuity to betrayed innocence, underlay its power to evince interventions by priests, doctors, scientists, and healers alike. Both experimentation on patients, willing and unwilling, and self-experimentation by doctors in search of understanding and cures has characterized its long history.

Syphilis is caused by a microscopic spirochete called *Treponema pallidum.* Its modern name comes from a character in a poem by physician Girolama Fracastoro that was written in 1530 in Verona, in what is now Italy. Having offended the gods, Syphilius the shepherd was sent the disease as punishment for his sins and his name given to all who suffered as he did. The disease's common appellation often changed as it moved, labeled as the great pox, *lues venerea,* the French sickness, the Spanish disease, the Italian disease, Chinese ulcers, plum-tree poison, or sometimes bad blood.

The origins of syphilis are still being debated. Arguments have ranged for centuries on whether it was a disease of the Old World brought to the island of Hispaniola by Columbus's men in 1492 or a New World disease sent back in European bodies as revenge by the peoples who had been plundered. In 1495, the disease appeared in epidemic form during an invasion of the Kingdom of Naples by a French army with Spanish soldiers and sailors. Over sea and trade routes and following invading armies, the disease spread rapidly throughout the Mediterranean world to India, China, and Japan. Even before the spirochete was identified at the end of the nineteenth century, the various stages of the disease began to be mapped.

The primary infection appears usually on the genitals as a chancre that disappears, but not so the infection. In the secondary stage, rashes and sores, hair loss, swellings, and growths are common. In various parts of the latency stage, the disease's progress is often invisible, but chancres and rashes are possible. In the late stage, when the disease is not transmissible, the damage to major organs and death can occur. Pregnant women can pass the disease on to their fetuses with the risk of stillbirth, early death of a newborn, or serious medical problems. Reinfection can also occur.

By the sixteenth century, syphilis was widespread in the European population, counting as its victims both princes and paupers. The use of mercury, known to Arabic physicians for centuries as a cure for skin diseases, began to make its European debut. Those in the aristocracy could afford the ministrations of the learned doctors and were treated to a range of cures that usually involved purges, sweats, and rubs made from the bark of the gaiac tree as well as mercury. For those whose sexual conquests were a badge of honor, syphilis was more of an expected consequence than a sign of debauchery.

For the commoners, however, the stigma of the disease was much greater and shaming more widespread. Kept from the great physicians, such sufferers often found themselves locked in the back wards of institutions. They were treated by barber-surgeons and pox doctors who provided a wide variety of eclectic and often violent remedies, especially preparations of the frequently toxic mercury in the form of blue pills, rubs, and vapors. Historian Kevin Siena argues that in London between 1600 and 1800, a "gendered geography" was created, with men given admittance to the hospitals, women to the workhouses, while inventive efforts were made by all to hide their ills.

The adage that "a night with Venus might mean a lifetime with Mercury" reflected the connection that linked sex, syphilis, and the heavy metal "cure." With the rise of a more bourgeois sense of morality, as historian Owsei Temkin (1977) noted, by the seventeenth century, "acquisition of lues is proof of offence against morality, of an alliance with vice."

By the nineteenth century, syphilology was becoming a crucial branch of Western medicine. In search of understanding and cures, various kinds of experiments were carried out, often involving injecting both humans and animals with pus or blood. By the end of the century, syphilis and gonorrhea were shown to be separate diseases and the links between syphilis and a wide variety of other ills documented. In 1909, after a series of experiments in Berlin, Paul Ehrlich and Sahachiro Hata found that arsephenamine (an arsenical compound) would kill the treponema. By the early 1920s, mercury, neo-arsephenamine, and bismuth were used as cures (often taking more than a year to evince relief), and malaria was induced to create fevers for those with neurological complications.

In the United States, the twentieth century brought more research, the emphasis on statistical accounting for the disease, the opening of specialty clinics in major urban hospitals, and the beginnings of more open discussion of the disease in theatrical productions. In 1913, the American Social Hygiene

Association was formed to combat venereal diseases and the silences surrounding them. Posters, motion pictures, and educational campaigns began as Americans were warned to find marriage partners with "good blood." Blood tests required before marriages are a result of these efforts.

Syphilis became the focus of intense research. Under the leadership of the U.S. Public Health Service (PHS), a Cooperative Group Study in major hospitals was organized in the late l920s to understand the disease. In the 1930s, Surgeon General Thomas Parran, having been kept off the radio for attempting to use the word *syphilis,* wrote extensively about the disease and encouraged public education campaigns to make the warnings about venereal diseases more widely known and to open discussions. The PHS's Venereal Disease division lent doctors to local and state public health departments and provided clinics for indigent patients.

In both World Wars I and II, emphasis was placed on prophylaxis for soldiers and the rounding up and incarcerating of assumed to be diseased prostitutes and "khaki-wackies," young women who followed the soldiers around. After experiments done by the PHS in the mid-l940s, penicillin proved to be a drug capable of curing syphilis in its early stages extremely quickly, and its widespread use followed.

Perhaps syphilis's most enduring legacy, however, was research done by the PHS in the counties in and around Tuskegee, Alabama. The PHS thought it had a situation that would allow for a study of the "natural history" of the disease, especially in African Americans who were assumed to have higher incidences and perhaps even a different disease than whites. What was supposed to be a short study stretched on for 40 years (1932 to 1972) as approximately 399 African American men who were in the late latent stage of the disease and 201 controls were followed as their symptoms worsened and deaths began to occur. But the men were never told they were in an experiment or that the rubs, tonics, and aspirins they were being given were not treatment for their disease. Even when penicillin became widely available, efforts that were not completely successful continued to keep most men from treatment.

Public outcry against the research in Tuskegee rose in 1972, when a newspaper story spread knowledge about its existence outside the confines of the medical and public health communities. What followed was a federal investigation, Senate hearings, a lawsuit, histories, plays, poems, music, and, finally in 1997, an apology from President Bill Clinton. Rumors persist that the PHS infected the men, although there is absolutely no evidence for this. Tuskegee's legacy has continued, however, as a metaphor for the fears in the black community over research, and Tuskegee's story is told over and over again as a warning to scientists about the ethics of research.

With the rise of HIV and AIDS, concern with syphilis has reappeared and coinfections not uncommon. Syphilis may no longer be the scourge it was half a millennium ago. But it remains a stigmatized, debilitating if untreated, and dangerous systemic illness that should be either prevented or cured.

*—Susan M. Reverby*

***See also*** HIV/AIDS; Sex Industry, International; Stigma.

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# T

## T4 PROGRAM

The T4 Program (also called “T4 Action” or “euthanasia”) was the camouflage name for the mass murdering of thousands of mentally ill and disabled people during World War II in Germany. The name stemmed from the postal address of the central executive agency, the Tötungsbehörde (literally: “killing office”), at 4 Tiergarten Street in Berlin. The T4 Program was not officially legalized, but Adolf Hitler, the leader of the Third Reich, issued an authorization that was originally written in October 1939 but was dated back to September 1, 1939, the very day when World War II started. Hitler wanted to indicate that the beginning war was aimed not only against external but also against internal enemies.

The T4 Program was bureaucratically organized. It started with the registration of patients using specially designed forms. Every psychiatric hospital, medical institution, and charitable home in Germany had to fill out these forms about each of their patients, inmates, and clients. About 60 physicians recruited by the T4 agency served as experts. They reviewed the documents and decided who would live and who would be killed. After this step, the T4 agency sifted through the forms once more and made the final decision about life or death. Finally, the T4 bureaucrats compiled patient lists for each institution involved. The T4 agency also set up a special transport unit whose personnel were recruited from the SS, the notorious Nazi organization. This transport unit used seemingly neutral grey buses and was responsible for the victims’ deportation to the six sites selected as the places where the killing of the victims in gas chambers occurred. At these institutions, special registration offices were also set up; they had the task of issuing official declarations of death and sending the urns with the ashes of the cremated to their families. T4 locations existed in Brandenburg, Brandenburg; Bernburg, Saxony-Anhalt; Sonnenstein, Saxony; Hartheim, Austria; Grafeneck, Württemberg; and Hadamar, Hesse.

The T4 Program started in the autumn of 1939 and officially stopped on August 24, 1941. The reasons for this sudden stop were manifold. One important reason was that although the Nazis originally intended for the measures to be kept secret, the spread of rumors in the villages surrounding the extermination sites could not be prevented. People living near the buildings observed that a continuous stream of patients entered the institutions, but nobody ever came back. Neighbors saw the smoke that arose when the dead were cremated. Families also became suspicious when a family member had been physically healthy before he or she came to one of the “euthanasia” institutions. Often, “weakening” or “debilitation” was indicated in the death certificates issued by the registration offices. The Nazi propaganda machinery could not prevent the T4 Program from being debated in public, when Clemens August von Galen, a Catholic bishop of Munster in Westphalia, took up the issue in a prayer in his church. He openly condemned the measures. After this event, the national socialist government decided to reduce the mass murder program.

However, the official ending did not mean that "euthanasia" measures stopped. The extermination sites in Bernburg, Sonnenstein, and Hartheim stayed open and continued the killing. Furthermore, after August 1941, the so-called "wild euthanasia" started. One main target group was prisoners who had become ill in the concentration camps. On one hand, the centralized murdering in special institutions lost its importance; on the other hand, ordinary physicians in various psychiatric hospitals and medical institutions all over the country participated in the murdering. They killed their patients mostly with drugs or poison, often in combination with strategically aimed underfeeding of inmates. A further "euthanasia" measure was directed at children with inborn impairments; it had been put into operation before the official start of the T4 Program and was continued after that.

In summary, more than 70,000 disabled persons were killed prior to August 1941. When World War II ended in May 1945, about 120,000 "euthanasia" victims had lost their lives at the extermination sites and through the various measures carried out by the T4 agency in Berlin.

—*Volker van der Locht*

***See also*** Eugenics; Eugenics: Germany; Euthanasia; Nazism.

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## TAIWAN

*See* Experience of Disability: Taiwan.

## TELEREHABILITATION

Telerehabilitation is the delivery of rehabilitation services via information technology and telecommunication networks. It is related to the more general field of telemedicine. During a real-time consultation, clinicians can see and talk with the client by means of a remote video camera and can record still images and measurements from sensors.

Interest in delivering care remotely has been driven by demographic changes due to increased numbers of people living with chronic diseases and disability and high costs of hospital and clinic visits. Furthermore, rural areas may lack local specialists, and extended travel wastes time and increases costs even more.

Typical applications include post-discharge follow-up of newly disabled people by physiatrists and therapists, seating and mobility services (wheelchair adjustments, assistive technology prescription), monitoring and prevention of pressure sores, wound assessment, evaluation of home modifications, and training in the use of augmentative communication devices. Virtual reality simulations can be used to create an engaging environment for exercise, using games to alleviate boredom.

Initially, POTS (plain old telephone systems) were used, but their bandwidth (amount of data able to be transmitted in bits per second) is low, resulting in small picture size, low resolution, slow frame rates, and poor audio quality. These problems have been eliminated with fiber-optic cable networks, using integrated services digital networks (ISDNs) or digital subscriber lines (DSLs). A mathematical technique called compression also enables the available bandwidth to be used more effectively.

Wireless devices are now widespread, allowing caregivers and clients to stay in touch while moving throughout the community. Cell phones, pagers, and personal digital assistants (PDAs) support voice, text, and image communication. Wireless Ethernet (WiFi, IEEE802.11b), Bluetooth, and ZigBee transceivers facilitate transmission of data (telemetry) from wearable sensors for recording vital signs, movement, and other variables. Mobile wireless devices can also help caregivers to locate people who are at risk of wandering. Health management and rehabilitation information resources are also available through the wireless application protocol (WAP). Virtual reality may be used to provide a range of simulated environments for therapy.

Some limitations and challenges have become evident. Access to high-bandwidth networks is growing rapidly but is still not universal, and service coverage may be patchy, especially in rural areas. Display and interface design need more attention. Since the technology is new, there are often problems with interoperability, reliability, and lack of standardization. Training of clinicians as teletherapists will need to be instituted. Although prices continue to fall, cost is still a major consideration, and reimbursement is problematic because, currently, it is usually contingent on attendance by a caregiver. Security, patient rights, and privacy issues must be addressed, using encryption where appropriate. Theoretically, there may be a risk with medical equipment such as pacemakers and powered wheelchairs, although in practice this is rare. There is a need for more quantitative tools that can measure joint motion, pressure, and force (haptic) feedback. Finally, there may be a "fear factor" associated with the use of technology.

While telerehabilitation is unlikely to replace traditional therapy, it is likely to provide services to an increasing number of people in the future.

*—Chris Kirtley*

***See also*** E-Health Care/Telemedicine; Rehabilitation Medicine, International.

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Chris Kirtley's website, http://faculty.cua.edu/kirtley

## TELETHONS

The roots of telethons in the United States as a means to raise money to "cure" or "help" people with a variety of disabilities arose from charity efforts in the pretelevision era. According to the Disability History Project, the most direct precursors were the posters, speeches, radio spots, and movie star–studded events used by friends and associates of polio survivor President Franklin D. Roosevelt to raise funds for treatment and services for people with polio at Warm Springs, Georgia.

When television evolved as a mass medium in the late 1950s and early 1960s, it became the mechanism by which charities made their appeals for money. In their efforts to draw the sympathy of the TV audience, these telethons turned to those previously successful print charity campaigns by employing "poster children." Along with the other techniques employed by the pretelevision charity events, featuring disabled children became a mainstay of telethons as an effective strategy to inspire donations.

However, when these poster children grew into adults, some began to question the techniques of telethons that used pity appeals to gather money. By the late 1970s, disability rights advocates joined together in a cohesive civil rights movement, and the Rehabilitation Act made U.S. society more accessible to people with disabilities. With these efforts came an understanding that the images of people with disabilities in the media had a powerful impact on society's acceptance of disability issues and on the self-concept of people with disabilities. Telethon images further stigmatized people with disabilities in society, according to disability rights activists. Disability historian Paul Longmore explained in a 1993 *Vanity Fair* article, "The message of telethons is whatever condition people with disabilities have, that condition has essentially spoiled their lives, and the only way to correct that is to cure them. The message of the disability rights movement is that it's possible to be a whole person with a disability" (p. 92).

However, the most famous telethon host, Jerry Lewis of the Muscular Dystrophy Association (MDA), told *Esquire* magazine in 1991 that disabled people needed help because "God goofed, and it's up to us to correct his mistakes" (p. 100). This statement from the 1973 MDA telethon, according to *Esquire,* caused some outrage about his insensitivity. However, according to Mary Johnson of the *Disability Rag,* the first big wave of protests against telethons began in 1981, when the American Coalition of Citizens with Disabilities, which represented 126 disability organizations, and the Disability Rights Center in Washington, DC, put an ad in the entertainment trade magazine *Variety,* criticizing the MDA telethon. The director of the Disability

Rights Center, Evan Kemp (who later became head of the U.S. Equal Employment Opportunities Commission), wrote opinion columns for the *New York Times* and the *Washington Post* explaining that the telethon was a "pity-a-thon" that left an impression that people with disabilities are not capable or employable. Lewis, who began hosting the telethon in 1966, was angered by the criticism and debated Kemp on the Phil Donahue TV show. This event in 1981 kicked off more than 20 years of clashes between Jerry Lewis and disability rights activists.

Jerry Lewis and the MDA telethon became the focus of most antitelethon activists because they made few changes in their pity approach tactics, whereas other disability-related charities began retooling their telethon efforts as a result of criticism, financial resources, and changes in TV. For example, by 1984, no TV station in New York City would air the Easter Seals Society telethon. TV station directors said that even though the charitable organizations paid to use a station's studio and crew, the station lost money because those fees did not cover all expenses, and the station lost ad revenue it would have received during the telethon hours. The charitable organizations also began to see how costly telethons could be. A March of Dimes executive said in 1987 that the organization stopped its national telethon because it was spending 50 cents to make one dollar, so the cost became too high. In addition, by the late 1980s, cable TV had grown in popularity. With many more choices, TV viewers no longer had to watch a telethon.

By 1990, many national telethons went away. The efforts of disability rights activists paid off in other ways as well. Some disability charities understood their criticism and changed their fundraising tactics completely. For example, Easter Seals said in 1992 that it wanted to focus on public awareness and advocacy. It brought more people with disabilities into its decision-making processes. An executive from United Cerebral Palsy explained that the media-savvy general public did not want sappy, inspirational pitches any longer; they wanted to know what disability organizations were doing to make people's lives better.

However, the national MDA Jerry Lewis Labor Day telethon remained virtually unchanged, so disability rights advocates redoubled efforts to get it off the air. In 1990, Lewis himself solidified the efforts against him when he wrote a first-person *Parade Magazine* article titled, "What If I Had Muscular Dystrophy?" A 1992 *Newsweek* story on the controversy reported that after using a wheelchair, he called it a "steel imprisonment" and referred to "the courage it takes to get on the court with other cripples and play wheelchair basketball" (p. 29). He then reflected on what he believed life using a wheelchair was all about: "I realize my life is half, so I must learn to do things halfway. I just have to learn to try to be good at being half a person" (reprinted in the August 1992 *Mainstream* magazine, p. 12).

His offensive references reenergized efforts among disability rights activists to stop his involvement with the MDA telethon. Two disability activists in particular used Lewis's words to launch an antitelethon group called Jerry's Orphans. Mike Ervin and Cris Matthews, a brother and sister who had muscular dystrophy, had been MDA poster children in 1961 and organized Jerry's Orphans to lobby the MDA to change its fundraising methods and, most importantly, to drop Jerry Lewis from the telethon. In a September/October 1992 *Disability Rag* article, Matthews said the MDA was "expert in exploiting the worst side of disability and, with the eager assistance of Lewis, has made us out to be nothing more than pathetic burdens to society, whose only desire is to walk" (p. 5). The brother-sister team said they had no problem with research efforts or anyone's desire to seek a cure, but they disliked the patronizing methods used to raise money for those tasks. Jerry's Orphans organized antitelethon protests in seven cities. Other disability activists also began their own protests of the MDA telethon. Laura Hershey, another former MDA poster child in Denver, organized a "Tune Jerry Out" protest of the 1991 telethon.

Another issue regarding telethons was financial. Many activists and others were concerned by the small percentage of the funds raised that were actually used for medical research or disability services. The *Disability Rag* reported that the executive director of MDA was one the highest paid charity executives in the United States. Telethon protesters also targeted corporate contributors to telethons. They asked them to give their donations through some other venue. They never asked contributors to give less money to the MDA, just not to make donations via the telethon. Jerry's Orphans and the disability rights group ADAPT (American Disabled for Attendant Programs Today, also called American Disabled for Accessible Public Transit) spoke with many of the MDA's corporate sponsors and requested that they not appear on the telethon; however, most corporate sponsors did not honor the request.

The other major event that helped society at large to understand the stigma of telethons was the Americans with Disabilities Act (ADA) of 1990, which mandated equal rights for people with disabilities in most aspects of society from transportation to employment to building access. However, Jerry Lewis refused to change his language or behavior on post-1990 telethons and would not take the concerns of disability activists into consideration, according a *Vanity Fair* article. The article also cited some praise for Lewis from his "kids." Stephen Mikita, an assistant attorney general in Utah and one of "Jerry's kids," said that he was proud to be called one of "Jerry's kids." He said the term shows that Lewis cares about people with muscular dystrophy as if they are his own family. Mikita added that Lewis was one of the first people to bring disabled people out into the open. "Lewis spoke about persons with disabilities, and embraced persons with disabilities, long before it was politically correct or in vogue to do so," Mikita said in the 1993 *Vanity Fair* article (p. 92).

Although Jerry Lewis did not change his rhetoric, the MDA telethon began making some changes after 1990 to reflect a society that now had the ADA. For example, the 1992 telethon featured more empowering video profiles of adults with muscular dystrophy working and making their way in the world. One video profile featured Matt Schuman, a former poster child, working at his job as a sports reporter for the *Greeley Tribune* in Colorado. The MDA telethon also changed in length by the late 1990s. Depending on the TV station, the telethon shrunk to just a few hours, rather than a day and a night of programming.

However, controversies involving Jerry Lewis's comments continued. In 2001, while being interviewed by the CBS *Morning Show,* Lewis defended the pity approach to getting telethon donations. "I'm telling you about a child in trouble. If it's pity, we'll get some money. I'm giving you the facts. Pity. You don't want to be pitied because you are a cripple in a wheelchair, stay in your house," Lewis said on the May 20, 2001, CBS *Morning Show,* as reported in *The Washington Post* (p. C1). After these comments, he issued an apology, saying he did not mean what he said. The MDA issued a statement distancing itself from Lewis and his comments, explaining that they did not reflect the views of the organization or its leaders.

*—Beth A. Haller*

***See also*** ADAPT; Americans with Disabilities Act of 1990 (United States); Charity; Easter Seals; Poster Child; Franklin Delano Roosevelt; Television.

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## ▣ TELEVISION

The portrayal of disability on television shares traits with that of literature, drama, and film. Most typically, a disabled character appears on the small screen as a background figure, to provide comic relief, or to increase a sense of crisis. Although a number of made-for-television movies feature disability as a predictably melodramatic central concern, requiring cure and mourning while representing loss or enhancing the seeming mental fitness of other characters, more widely watched television shows rarely have disability as a regular central theme. Interestingly, disability has more prominence within the science fiction genre on television, indicating that a higher degree of fantasy allows for a higher degree of disability representation. Exaggerating this feature, the wave of offbeat comedies, often animated, in the late 1990s and early 2000s, such as *South Park, Malcolm in the Middle,* and *Family Guy,* frequently represent disability in an openly aggressive, perhaps satiric way that depends highly on the genre's clear distance from realism.

There are a number of stock plots that incorporate disability on television. The most frequent involves cure, in part because so many television shows are set in medical environments (e.g., *St. Elsewhere, ER, Scrubs*). Another common plot involves disability fraud. This shows up both in situation comedies (such as *Seinfeld*) and in dramas, especially those that feature the legal professions, both police and law, prominently (e.g., *Hill Street Blues, LA Law, Law and Order, CSI*). Disability arising from tragic accident or illness surfaces throughout television shows to create new, compelling interest on the part of viewers (e.g., *ER, The West Wing, Diff'rent Strokes*). Though not quite as laughable as the dramatic jumping of the shark tank on *Happy Days,* now widely recognized as a moment of television desperation, this spectacular turn to disability plots reinforces a popular misconception of disability as outside the bounds of everyday life.

## DISABILITY AND DRAMATIC TELEVISION

Although predictably rare as central figures, characters with disabilities make periodic appearances in dramatic television productions, usually in minor roles. In their study of a six-week period in which they viewed 1,286 dramatic prime-time British television shows, Cumberbatch and Negrine found that 1.4 percent of the shows portrayed a disabled character with a speaking part. A recent greater social awareness of the prevalence of disability, enhanced by the advocacy of such actors as Michael J. Fox, has increased the prominence of disability in television. However, as is the case in most narrative forms, disability is often present on dramatic television but is rarely adequately explored. Most often, disability invites humor, moves along a tired plot, or helps to provide insight into able-bodied characters.

Television dramas that do have a continuing character with a disability often turn to that trope to signify human fallibility. Wheelchair-using Robert T. Ironside's relationship with black caregiver Mark Sanger presents disability prominently as dependency. *Wiseguy*'s Daniel Burroughs, a mentor who is an apparent paraplegic and wheelchair user, plays on the stereotype of the intellect with the frail body. (Interestingly, on *Highlander,* the same actor also portrays a wheelchair user, in this case a Vietnam war veteran.) In *LA Law,* Benny's developmental disability allows other characters to seem helpful and sympathetic.

Television drama also takes the opportunity to turn to disabled characters to make a political point. For example, the 1992–1996 David Kelley vehicle, *Picket Fences,* Zelda Rubenstein portrayed short-statured receptionist Ginny Weeden (the show also included Marlee Matlin as a deaf character and Robert Cornthwaite as an elderly character with Alzheimer's disease). NBC's popular prime-time drama *The West Wing* debuted with a daring representation of the injured president predicting the physical fallibility encapsulated in a vague bad back the show continues to feature. Later, the president's controversial choice not to disclose his diagnosis of multiple sclerosis foregrounds the politics of disability identity along with the public signification of disability as a marker of fallibility. *Law and Order*'s repeated featuring of assisted suicide plots raises questions of disability rights, if not always constructively.

The depiction of cure, or desired cure, of disabling conditions dominates prime-time drama. Despite the subtle portrayal of Dr. Carrie Weaver as physically disabled, a remarkable instance since her disability is never a central issue on the show, *ER* focuses most of its attention on cure. This becomes clearest when Dr. Romano has an arm amputated by a helicopter and angrily seeks all surgical means to normalize himself. The intriguing subplot that had Grissom becoming deaf, as his mother had been, and put sign language onto the *CSI* screen was cut short by his surgery that has now cured the otosclerosis. As in *ER,* this cured disability is balanced by the presence of a continuing character with a chronic disability (in this case the chief pathologist with an amputated leg). Similarly, *Joan of Arcadia,* invested as it is in the miraculous presence of God, still portrays medical science as the only hope (though a dim one) for Joan's wheelchair-using brother.

## SCIENCE FICTION

Science fiction, with its frequent investment in mutant body forms, provides a sometimes restrictive and sometimes liberating view of disability. The familiar themes of cure and pity recur, but they are accompanied by some creative interrogations into the social (and sometime literal) construction of the body.

*Star Trek* continuously considers questions of differing bodily form and repeatedly returns to the idea that disability is contextual. The original captain of the Enterprise appears as a paraplegic in an episode that tries Kirk for misconduct. Though nonverbal, he communicates through a red and green light implanted in his chest. The original *Star Trek* series also features the famous episode "Plato's Stepchildren," better known for offering television's first interracial kiss than for the portrayal by Michael Dunn of Alexander, the dwarf jester. Levar Burton's depiction of Geordie La Forge on *Star Trek: The Next Generation* continues a relationship between racialized and ableist representation on this science fiction drama. La Forge "overcomes" his birth blindness by means of a VISOR that painfully requires such great focus that it also lends him incredible skill with warp engineering. This depiction is innovative in that he is at times less able and at times more able than characters without the VISOR, thereby contributing to a social constructionist or at least contingent model of disability.

Most often, science fiction television shows take familiar disability plots and add larger questions about the mutability of bodily form to their typical opportunistic forms. *Dark Angel* features the disabled avenger plot line, with a paraplegic mastermind, but he is one among mutants—with super and animal powers—so that he is rendered less powerful by comparison. The *X-Files* "Humbug" episode develops the freak-show plot and plays on Tod Browning's well-known "one of us" scene by having the small-statured ring master look at the always-dapper Mulder and say, "Ugh, can you imagine having to live your life like that?" Similarly, *Buffy the Vampire Slayer* satirizes disability stereotypes when Spike uses a wheelchair and when Xander has an eye poked out, so that disability is again the site of humor, but without being objectified.

## DISABILITY AND SITUATION COMEDY

Cumberbatch and Negrine found that only 9 percent of British sitcoms in 1980 featured characters portrayed as having a disability, and they did so usually to make the character the object of humor. This has also largely been the case in American sitcoms, where a disabled character, very frequently in a wheelchair, appears for an episode or two and is either the butt of many jokes, the means by which other characters learn about themselves and get to feel at first embarrassed and then altruistic or at least enlightened, or both. For example, on *Happy Days,* Fonzie, who had experienced temporary disability himself after tearing the ligaments in his leg during a TV motorcycle stunt, and temporary blindness after being hit over the head, hires a disabled mechanic with a stereotypical chip on his shoulder. A wheelchair user, Don Konig has worked as a mechanic before being hit by a drunk driver, and he now needs Fonzie's help both in giving him work and in signing a social security form. The family's straightforwardness cures Don of his bitterness, and the episode ends in a friendly family meal. On *Diff'rent Strokes,* Arnold's wheelchair-using friend shows up in episodes focused on Arnold's unhappiness with his short stature. He learns the hard way, by trying to support his friend, that disabled people are stigmatized, and the whole Drummond family becomes more smug as a result.

Also a sitcom but crossing over into drama, *M*A*S*H,* running for 11 years, from 1972 to 1983, follows and influences a big-screen pattern of depicting war veterans coming to terms with their disabilities. Not only do countless young soldiers come through the 4077th in the hopes of surviving their frequently mortal wounds, but this long-standing drama/comedy includes one of the most memorable cases of disability fraud on television. In the first season, Hawkeye fakes a mental illness to obtain a leave but fails to get a diagnosis. Later, Klinger joins the 4077th and cross-dresses in an attempt to convince psychiatrists that he is unfit for service.

These patterns continue through sitcom production, where disability is rarely an ongoing concern but shows up to move the plot along or just create a new site of humor. Almost every popular sitcom has an episode about a disabled guest character. *Becker* is unique in that it features a continuous character who is blind (played by a sighted actor).

## ANIMATION

Disability plays an at times troubling role in a series of late 1990s and early 2000s adult animation television programs that are not only removed from the conventions of realism but also deliberately created in bad taste. *Family Guy* offers an easily duped ex-cop who is in a wheelchair. *South Park*'s Timmy, a young boy with cerebral palsy, is the butt of jokes because of his tendency to say his own name repeatedly. He propels plots that present disability themes, including a satire on Christopher Reeve as "fake disabled," but mostly he is even more ridiculous than other *South Park* characters because of his cerebral palsy. *Quads* focuses entirely on disability but does not forward any particular critique or expression of disability identity in doing so.

## DISABLED ACTORS

The most well-known disabled television actors are Marlee Matlin, who has been on 19 television shows, including *ER, Seinfeld, Spin City, Gideon's Crossing, Law and Order,* and *The West Wing;* Jim Byrnes, who has been on more than 20 television shows, including *Sliders, The Outer Limits, Highlander,* and *X-Men: Evolution;* and the late Christopher Reeve, who started his career on a small-screen soap opera, played a disabled war veteran on stage, and then returned to television after he became disabled himself.

Chris Burke, an actor with Down syndrome, played Corky Thatcher on *Life Goes On,* a 1980s family drama that features Corky being mainstreamed and fighting his own battles at school. Burke has also appeared on *ER, Touched by an Angel, Promised Land,* and *The Commish.*

While their status as actors may remain in question, a number of people with disabilities have appeared on reality television shows. One show, *The Littlest Groom,* made disability its central device by having a short-statured groom choose among average-sized and little women as his future bride. *The Amazing Race* included a short-statured competitor whose size was a distinct advantage in competition. *Survivor* has included one deaf competitor, who received some negative publicity from her friends at Gallaudet University for not signing during the show, and one character with a partially amputated leg. As with most television formats, reality television reflects both an increasing representativeness by including these characters with disabilities and also an exploitative thirst for the spectacle they produce.

## ADVERTISING

As Ganahl and Arbuckle together with Haller and Ralph demonstrate, people with disabilities do not have adequate representation in television advertisements, though it is increasing. The rise in prominence is not resulting in more positive images, however. The most troubling examples include Christopher Reeve, in the prime Super Bowl advertising spot, depicted as cured and able to walk again. Similarly, Mothers Against Drunk Driving sponsored an ad with a young walking man purchasing a wheelchair. The implication is that he plans to drink and drive, and this will have the apparently horrifying effect of landing him in a wheelchair. These advertisements together signal the white, male physically disabled figure as the disability representative most likely to appear in advertisements that play on the general public's desire not to become disabled. The lack of televised coverage of the Paralympics as compared with the inordinate attention to athletic achievements of Olympians reinforces this imbalance.

*—Sally Chivers and*
*Tiffany Potter*

***See also*** Advertising; Drama and Performance; Paralympics; Telethon.

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## TEMPORAL LOBE EPILEPSIES

*See* Epilepsies, Temporal Lobe.

## TENBROEK, JACOBUS

### (1911–1968)

*American Advocate for the Blind*

Dr. Jacobus tenBroek, called "Chick" by friends and family, blinded at the age of seven in a hunting accident, was a charter member and the first president of the National Federation of the Blind (NFB), founded in 1940 in Wilkes-Barre, Pennsylvania. The NFB grew to become the largest advocacy group of blind people in the United States. TenBroek was a constitutional scholar who wrote academic monographs on the 14th Amendment, public policy (particularly as it pertained to welfare programs), and the nascent Social Security Administration and its impact on the blind. TenBroek waged a relentless war of words against publicly financed programs that purported to assist the blind but that were in fact, he asserted, institutions rife with paternalistic attitudes and designed to perpetuate the inferior status and indigency of the blind. TenBroek argued in favor of a pension for the blind that would not require means testing as did social security. After earning a law degree and a doctorate in public policy, tenBroek taught speech and political science at the University of California at Berkeley for 25 years.

As a boy, tenBroek studied with Newell Perry at the California School for the Blind in Oakland, California. Perry mentored a generation of leaders that would found the California Council for the Blind in the 1930s, along with a handful of other state advocacy groups that would coalesce into a nationwide movement of blind activists. TenBroek would galvanize this generation of activists and draw them into the NFB under his leadership.

TenBroek served as president of the NFB from 1940 to 1961, when he resigned at the NFB national convention in Kansas City amidst a firestorm of dissension among a number of NFB state affiliates. By resigning, tenBroek managed to quell this dissent and put in place the next generation of leaders who he felt best represented his vision for the organization and the broader movement.

*—Brian R. Miller*

***See also*** Advocacy; Blind, History of the; Blindness and Visual Impairment.

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## TERATOLOGY

In the twenty-first century, freak shows are more about performance than somatic oddity. Suspension of disbelief must accompany the exhibit that purports to be a cross between species, and even the most naïve person knows that unusual physical features such as extra limbs or variant statures do not result from supernatural forces. In the ancient world, people were not equipped to understand physical configurations as we do in the modern world, and ancient scientific thought provided no reason to disbelieve the combination of a horse and a man or the existence of a human with a hundred hands. Monstrous beings—*terata,* in Greek—usually inhabited lands around the edge of the earth and the mythological past. Monstrous beings also inhabited the Roman imagination: Historians of the Roman world frequently reported monstrous births as portents.

A distinction must be drawn between people with disabilities and monsters. People with disabilities comprised a significant proportion of the ancient landscape, and an ordinary community member who had some sort of disfigurement would not have been considered to be a monster; indeed, the unknown characterizes the monster. In the ancient world as today, physical configuration alone does not make a monster; rather, a confluence of social forces defines what lies within the bounds of human normality and what lies outside it. Plutarch, the first century AD biographer, refers to a Roman "monster market," where one could buy human oddities such as people with three eyes. This may have been a market in which people with variant bodies were sold and may have doubled as a sort of freak show; it must have had as much to do with salesmanship and showmanship as with somatic variation.

Monsters lend order to the world by defining the boundary of normal human parameters. The ancient world was not guided by the statistical bell curve of the eighteenth century; instead, the monster delineated physical normalcy by reflecting its antithesis. In the fourth century BC, in *Generation of Animals,* Aristotle described *monstrosity* as the failure to resemble a human being at all. Monstrosities, in Aristotle's view, included aberrations such as animal heads on human bodies or humans with extra heads.

In addition to defining physical normalcy, monsters also reflect social and moral bounds of their culture. Robert Garland (1995), in *The Eye of the Beholder,* argues that the Roman emperors, often reported to have people with physical anomalies amongst their courtiers, were themselves in the category of the monstrous. Sexual ambivalence, too, was seen as a monstrosity, as argued by Luc Brisson (2002).

A collection of essays on monstrosity in the Graeco-Roman world (the majority on the Greek world) can be found in Catherine Atherton's (2002) *Monsters and Monstrosity in Greek and Roman Culture.*

*—M. Lynn Rose*

***See also*** Monsters.

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## THALAB THE GRAMMARIAN

**(ca. 845–904)**

*Iraqi grammarian and philologist*

Abu 'l-Abbas Ahmad ibn Yahya ibn Zaid ibn Saiyar, more briefly known as Thalab, became the foremost grammarian and philologist at Kufa in Iraq. Even in his youth, reference was made to him as a reliable source of accurate knowledge. In his later years, he lost most of his hearing. One Friday afternoon, he left the mosque and was walking along the street while reading a book "when a horse knocked against him and threw him into a deep pit, out of which he was taken nearly senseless." He died in Baghdad the next day.

*—Kumur B. Selim*

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## TIMUR THE LAME (1336–1405)

*Tatar Warrior*

From 1369 until his death, the Tatar warrior Timur Lang (the Lame) led his army through north India and central and west Asia, enlarging his dominion from Aleppo through Baghdad, Shiraz, and Hormuz in the south, bounded eastward by the Indus, and stretching north to the Aral Sea and much of the Caspian coast. He died while marching on China. Contemporaries mention his lame right leg and arm, from battle wounds or a youthful sheep-stealing incident. Examination of his skeleton in the 1940s confirmed the lameness. Memoirs attributed to Timur include a description of leading troops through snowbound mountains and being lowered down a precipice in a wicker basket attached with long ropes. He experienced rheumatic pain during such campaigns but drove himself on. A story has Timur laughing at Sultan Bayazid, who he had captured. Bayazid reminded Timur that the rise and fall of kingdoms was in God's hands. Timur replied that he was laughing at their mutual ugliness, because God gave kingdoms indifferently to "such ugly Fellows as we are, you a squinting clown, and I a lame Wretch."

*—Kumur B. Selim*

***See also*** The Lame.

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## TOKENISM

In modern industrial societies, people with disabilities have been widely underrepresented publicly and in the workforce, especially within white-collar professional jobs and other high-status positions in the media, government, and business. Within labor markets based on segmentation and hierarchy, very few people with disabilities have been able to break through what feminist discourse has labeled the "glass ceiling," into the upper echelons of leadership and power. Indeed, in most developed societies, a large majority of people with disabilities are denied employment altogether, curtailing their cultural participation as effective and self-determined individuals.

Unfortunately, the underrepresentation of large numbers of people with disabilities inevitably puts tremendous pressure on those in the public eye to embody a type of disability overcoming. From a historical perspective, famous high-achieving individuals with disabilities, such as reformer and writer Helen Keller and U.S. President Franklin Roosevelt, have been represented as inspirational examples of success against great personal obstacles. Similarly, figures such as Vincent van Gogh and Virginia Woolf are appreciated for their tremendous genius, while their experience of mental illness is separated out as a tragic fate. In such cases, disability is understood as an impediment to be overcome, rather than as an intrinsic component of one's individual work, art, or social perspective. Of course, while overcoming narratives are misleading and destructive in their own right, social interpretations of the vast majority of people with disabilities revolve around discourses of dependency, tragedy, and victimization.

Within this framework, contemporary public figures with recognized disabilities tend to be positioned within a binary construct—as either an extraordinary role model or an embodiment of the tragic nature of disability. Stephen Hawking's scientific genius seems to "transcend" his disability. On the other hand, Jerry Lewis's telethons, which feature the tragic stories of "poster children" with muscular dystrophy, perpetuate a belief system that invalidates the agency of people with disabilities. These reductive perspectives are indicative of the way disability tokenism functions. Out of this socially manufactured binary, individuals with disabilities who do gain power and influence are represented within public discourse as the "truth" of disability. Within this framework, they are living in a problematic double bind: If they succeed, the media may broadcast false expectations of other people with similar or dissimilar impairments; if they fail, they can be used as a rationalization for further broad-based discrimination.

Feminist scholars have described gender tokenism as a process of granting power and privilege to a few while withholding it from the vast majority of women. In this way, it appears that if one is truly qualified, that person can achieve any position she desires. The tokenized person is used by the establishment as (faulty) evidence that a system of justice based on personal merit is intact. The visible success of very few people is used to displace the social reality that the vast majority of people with disabilities lack the resources, opportunities, and support to experience the kind of success promised by this gesture of tokenism.

In effect, without support from a community of allies and other people with disabilities, people who are put in positions and expected to represent disability are set up to fail themselves and their community, because either outcome distorts any real relationship to the diverse and complex heterogeneity that disability represents.

*—Michelle Jarman*

***See also*** Employment; Feminism; Helen Keller; Franklin Delano Roosevelt; Vincent van Gogh; Virginia Woolf.

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## TRAINING SCHOOLS

In the United States, training schools were institutions erected to house some of the children designated as feebleminded. They appeared mainly during the later part of the nineteenth century and the early decades of the twentieth century. Historically, they emerged as in-between sites, formalizing generally after the earlier East Coast asylums and religious-based charity institutions and before the special education classes funded under the auspices of public school authorities. By the early 1900s, scholars such as Henry Goddard of the Vineland Institute of New Jersey on the East Coast and Lewis Terman of Stanford University on the West Coast were arguing that 2–3 percent of the U.S. population were classifiable as feebleminded.

Training schools were initially institutions to which parents, for the most part, had to be persuaded to send their children. For most social groups in the United States at that point, voluntary segregation of the young from immediate family was generally not a preferred cultural experience. As such, welfare experts, religious workers, and concerned donors established rigorous programs of persuasion to segregate feebleminded children and place them in the new institutions.

The overt nature of this effort indicated a refiguration of the relationships that constituted the state. The shift in relationship structures, especially within families, was often commented on in two key sites where the successes and failures of training schools were reported. Two national conferences held annually in the United States documented these efforts across states and are important to note (published proceedings are available): the National Conference of Charities and Corrections and the National Conference on the Education of Backward, Truant, Delinquent, Dependent, and Defective Children. In addition, journals focused specifically on feeblemindedness, such as the *Training School Journal* and the *Journal of Psycho-aesthenics,* stood alongside more broadly conceived journals concerned with education in general, such as G. Stanley Hall's *Journal of Genetic Psychology* and *Pedagogical Seminary,* both of which frequently contained articles on feeblemindedness and degeneracy. (G. Stanley Hall was a founder of the *American Psychological Association* and a leading exponent of the child study movement.)

The new relationship of children to statehood was borne out in such documentary sites. These sites of information exchange are particularly significant for understanding how feebleminded children were constructed and imagined in relation to training schools and, in turn, nationhood. Under discourses of scientifically managed citizenship and a competitive eugenic philosophy, the routes through which human bonding could proceed and the methods for getting things done had changed. The child-adult binary had been refigured through the establishment of a variety of institutions that separated the young from each other and their elders, such as children's hospitals, schools of different kinds, and youth clubs, all of which were often further segregated by race in their establishment or operation. While all the young were now to be thought of as vulnerable, ignorant, segregable, and delayed from responsibility, children designated as feebleminded were made to embody the perpetuity of these features symbolically and to represent an apparent threat to the strength of the nation.

The variety of training schools that existed indicated an uncertainty over the minutiae of this logic but reflected a common dedication to segregation. Different schools had different functions. In a 40-year period around the turn of the twentieth century, training schools were one of several sites to which children labeled feebleminded could be allocated, depending on local laws and availability. For example, children could be assigned to (1) publicly funded training schools, some of which taught manual labor tasks; (2) privately endowed training schools; (3) philanthropic institutions more overtly concerned with segregation and medicalization; (4) state-care medical institutions that did not assume themselves to have pedagogical functions, including asylums; or (5) special classes either attached to a public school or centralized in a separate building within a given school district. In regard to training schools specifically, some had more of a "warehousing" function, while others placed an emphasis on manual training designed to "mitigate" the effects of feebleminded children on the larger group of citizens. Training schools were thus also "in-between" institutions, not only in terms of when they emerged, but insofar as the children sent to them were sometimes considered to be liminal—trainable but not educable, with manual or vocational labor being the only kind offered, if at all.

Because training schools emerged as part of a proliferation of formal segregating institutions, their role has been viewed in ways that go beyond their specific or intended internal functions. Earlier forms of segregation, such as reservation systems and slavery, were followed by other forms, such as asylums, prisons, orphanages, schools for Deaf and Blind, industrial schools, centers for juvenile delinquents, and training schools. Historians of education such as John Richardson (1999) have suggested that compulsory attendance legislation would not have been possible without this prior experience of confinement. By 1918, all existing U.S. states had compulsory attendance legislation, which was less about a commitment to elementary public schooling and more about who was *not* allowed to attend. In sum, training schools, alongside other prior institutions, had several kinds of purification purposes: (1) reforming state relations: they were believed to purify the child of familial influence by removing them and opening them to expert governance; (2) production and reproduction: to purify the wider population from "having to see" feebleminded children, with the hope of ending the reproduction of feebleminded people while simultaneously molding cheap, productive laborers; and (3) defining the citizen and the public: to purify state-funded "regular" or mainstream schooling by offering segregated spaces that made possible a more narrow definition of who the public was in public schooling.

*—Bernadette Baker*

***See also*** Education and Disability; *Feeblemindedness*; Henry Herbert Goddard; Special Education.

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## TRANSGRESSION

Transgression is a form of resistance involving the crossing of limits or boundaries. It is not antagonistic or aggressive, nor does it involve a contest in which there is a victor; rather, transgression is playful and creative. Among disabled people, transgression has been a significant means of challenging limits and disabling barriers. Disability activists have been involved in a long campaign of direct action against disabling barriers, whereas transgression has been a more indirect and subtle form of challenge by disabled people.

The concept of transgression has been elaborated extensively by Michel Foucault, who was interested in Kant's critique of limits but wished to pursue more practical (and political) forms of engagement. Foucault saw transgression as distinctively different from transcendence or transformation: He did not envisage individuals as gaining absolute freedom from limits, as transcending, or as finding a new self. Instead, he suggested that individuals, in crossing limits or boundaries, might find moments of freedom or of otherness. Foucault's account of where transgression takes place is somewhat complex. In his "Preface to Transgression" (1963), written as an introduction to the work of Georges Bataille, he argues that "it is likely that transgression has its entire space in the line it crosses" (Foucault, 1963/1984, p. 73). This implies a boundary that can only exist if it is crossed. The limit and transgression depend on each other, but the relationship is not a simple one; rather, Foucault explains the relationship as being like a spiral, with moments of crossing of the limit appearing as flashes of lightning in the night that give a darkening intensity to the night they obscure. He also describes the interplay of limits and transgression as being regulated by a simple obstinacy. The act of crossing the limit does not violate it, but simultaneously affirms and weakens it. Foucault regards this as a form of nonpositive affirmation, which has to be constantly repeated, and likens it to Blanchôt's notion of contestation, which does not imply a generalized negation, but an affirmation that affirms nothing. A more positive version of transgression was developed by Foucault in the shape of practices of the self, whereby individuals set about changing their own selves.

Derrida sees transgression as being achieved in deconstructive readings of texts, which cross the protective limit given by traditional readings. It involves going beyond the first reading of a text and examining its ambivalences, contradictions, and slippages. Deconstruction transgresses against the protection that a traditional reading affords, by reading against the grain, exploring alternative meanings, and considering how the text itself *performs.* The playful nature of deconstruction and the transgressive forms of writing that are often adopted has provoked some criticism about its acceptability as a form of scholarship and has even led to the publication in *Social Theory* of a hoax article by Alan Sokal entitled "Transgressing the Boundaries: Toward a Transformative Hermeneutic of Quantum Gravity." However, those practicing deconstruction maintain that the transgressive strategies may be playful, but their intent—to challenge assumptions, orthodoxy, and dogma—is deadly serious.

Foucault uses sexuality to illustrate transgression, arguing that since the writings of Sade and, more recently, Bataille, sexuality has been a fissure that marks the limit within us and designates us as a limit. Foucault has been criticized extensively for failing to provide empirical examples of his concepts, and indeed, his discussion of sexuality provides little guidance into the practical pursuit of transgression. It has been suggested by one of Foucault's biographers, however, that sexuality is one area in which he did in fact experiment, and his own testing of the limits of homosexuality involved promiscuous behavior that led to his premature death from an AIDS-related illness.

Nevertheless, transgression has been viewed as an attractive construct in relation to marginalized and oppressed groups, as Foucault points out, not least of all because "it serves as a glorification of what it excludes" and forces recognition of exclusion. For those who transgress, according to Boyne (1990), "otherness lies ahead" (p. 82), and this allows individuals to shape their own identities by subverting the norms that compel them to perform repeatedly as gendered or disabled subjects. They are not required to—and indeed could not—reject these identities entirely, but they can vary the way in which they have to repeat these performances. Researchers studying transgression have uncovered strategies in which new mothers have avoided both breast feeding and the wrath of the health visitors checking on them. Within disability, it has been suggested that self-help groups for "ME sufferers" (those with myalgic encephalomyelitis/chronic fatigue syndrome) enable them to transgress against the regulatory norms that inscribe their bodies differently. Research with disabled students by Allan in 1999 documented the ways in which they transgressed both in and out of disability. Transgressive strategies that moved the students away from a disabled identity included using humor to put peers at ease, pretending to be "blind drunk" rather than drunk, or avoiding going to the toilet; acts of transgression toward disability included claiming a more disabled label and requiring peers to provide help. Teachers were generally unsympathetic to, and critical of, the students' transgressive practices, tending to read these as evidence of students' failure to accept the "fact" that they were disabled. There appeared to be a clash of discourses within the school, between, on one hand, the students' discourse of desire, within which they practiced transgression, and, on the other hand, the teachers' discourse of special educational needs, within which they provided support.

Disability arts represent a particularly creative and innovative form of transgression. They celebrate difference but also seek to subvert the normality genre by using the body as a weapon to subvert and undermine disabling barriers. Disability arts deploy difference strategically and involve individuals portraying themselves as aesthetic objects, through dance, photography, art, and other cultural forms. One powerful example comes from Cheryl Marie Wade, who, in her poem "I Am Not One of the," reverses beauty and ugliness, portrays herself both as a sexual object, with lace panties, and as deformed, with a stub, and demands a presence that has hitherto been denied. In "Crip Pride," Jessie Aaron presents herself and her "family" of disabled people as subjects with sexualities. She offers solidarity and difference as a response to the rejection she and others have experienced. Both writers assert their sexual and gendered identities in playful ways that challenge the desexing discourses of disability. Their transgression, therefore, has an impact on their own identities, but also on those who read the poems and who are forced to examine their own normalizing and disabling knowledge and actions.

Foucault acknowledges a "difficulty with words" that hampers philosophy and sees the absence of a language with which to talk about transgression as inhibiting its practice. Nevertheless, he expresses his hope that one day transgression will be as much a part of our culture as contradiction was for dialectical thought. Bataille also looks forward to the normalization of transgression whereby silent contemplation would be substituted with language (Foucault 1984). It could be said that transgression is indeed part of everyday culture, albeit denoting some marginal activities: A web search suggests that transgression has become synonymous with forms of eroticism and "deviant" sex. Transgression is also prevalent in the arts: Anton Chekhov's short story, Kate Jordan's play, and a film written and directed by Michael diPaulo all have the title *Transgression,* and Joyce Carol Oates's collection of short stories is entitled *Faithless: Tales of Transgression.*

Transgression appears to provide an important way for disabled people to engage playfully with limits imposed on them by a disabling society. It seems to provide scope for challenging the very existence of some of these limits and for self-transformation. Transgression operates within a discourse of desire, and this discourse has to be extremely powerful to speak against the needs-based discourses that dominate disability services.

*—Julie Allan*

***See also*** Dance; Disability Arts; Drama and Performance; Film; Michel Foucault; Poetry.

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## TRANSITIONS IN EDUCATION AND EMPLOYMENT

*Transition* generally refers to any process that characterizes an evolution resulting in something new or different from that which was before. It may express the process of change in form, as in the shape or structure of the human body as it grows or ages, or it may refer to the process of changing emotional states, as in the swing from a normal to a depressed emotional state. In any case, *transition* is the term we use to label the process of change, reflecting the movement from one set of identifiable characteristics of something or someone to a new set of identifiable characteristics.

In the past two decades, *transition* has been the term used in education, particularly vocational education, to refer to the process of helping secondary education students become "work ready." In this context, transition includes all of the efforts of schools to modify and improve their vocationally oriented practices that more directly and effectively prepare students for the world of work. It refers to system-level efforts, including curriculum reform, changes or additions to course offerings, and enhanced work experiences. It quite literally refers to any effort by schools to influence and improve the potential for their students to achieve positive vocational outcomes. Transition from school to work, as it is often called, is the application of those practices referring to the transformation process of being school oriented to being work oriented.

The term *transition* has a more specific and formal meaning in special education. In this context, transition not only refers to the general school-based process of preparing students for the world of work, but also denotes a component of the individualized education plan (IEP) of students aged 14 and older. Thus, transition refers to improvements in "system" practices as well as to the application of those practices to individual students. Students with disabilities (who have an IEP) are required to have a formal transition plan as part of their education plan. The purpose and focus of the transition plan are to ensure that appropriate steps are in place that will lead to successful integration of students with disabilities into adult living environments, with special emphasis on work and post–secondary education settings.

## TRANSITION AND STUDENTS WITH DISABILITIES

The concept of transition in special education has its roots in the early 1980s, when parents and advocates of students with disabilities began to voice concerns about the employment prospects for their children. The U.S. Education for All Handicapped Children Act (P.L. 94–142), which called for a free and appropriate education for students with disabilities, had been in place for nearly a decade. Evaluation data regarding its lack of effectiveness in stimulating the schools to adequately prepare students with disabilities for adult living and the world of work were beginning to mount and raised serious concerns among parents and advocacy groups. The facts that schools were now required to provide appropriate education to students with disabilities together with the accumulating data revealing the apparent lack of preparation for work and adult living led to sustained advocacy efforts to get the schools to include school-to-work transition planning as part of the educational plan for every secondary-age student. That advocacy effort culminated in the Individuals with Disabilities Education Act (IDEA) of 1990, which also mandated schools to incorporate into each student's IEP an outcome-oriented statement about transition services.

IDEA describes a transition plan as an outcome-oriented process that leads the student to successful linkages with the adult community. Successful linkages include postsecondary education; vocational training, integrated employment, or continuing adult education; adult services; or independent living and community participation. The entire emphasis of transition planning is to ensure that when the student exits the school setting—thus absolving the school of any further IEP responsibility—he or she has a direction and is effectively engaged in the adult environment. Practically, given individual interests and abilities, that could mean the student is working (has a job), is engaged in vocational rehabilitation services, is enrolled at a college or university, or is doing all three. Equally important, transition planning is intended to convey that students are linked with the community and community services in such a way that they have as much control over their lives and daily living as possible or are moving toward self-directed independence and independent living.

## THE FOCUS OF TRANSITION PLANS

Transition plans embody a comprehensive and often complex strategy for bringing about the successful movement of students with disabilities from school to work and adult living. Comprehensive plans consider the wide range of programs in the workforce development system (including the school) that should play a role in bringing individual student success. In doing so, successful transition plans are characterized by four common elements: They are student centered, incorporate input from and identify critical stakeholders in the transition process, reflect interagency collaboration in meeting student needs, and address the broad range of student needs that will lead to successful transition.

The foundation of a successful transition plan is a genuine student-centered planning process. Successful transition plans reflect a clear and strong commitment to the goals, interests, and dreams of the student. Schools are obliged to work with the student through testing and assessment to determine his or her strengths and interests in order to articulate the intent, focus, and chief outcomes of the plan. The more closely the plan is tied to the goals of the student, the more likely its success will be. As plans are developed and modified over time, the student's goals and interests remain the centerpiece in the planning process. Successful transition plans take on appropriate detail depending on the interests, abilities, and needs of the student. No two plans are alike.

Stakeholder input and participation in plan execution are key characteristics of successful transition plans. Stakeholders can include the student, family members, teachers and other relevant educators, adult service providers, and relevant community members (e.g., advocacy groups) as appropriate and needed. The challenging aspects of stakeholder involvement are identifying the individuals who can play a key role in the development and execution of the plan and the timing of their involvement.

The third characteristic of successful transition plans is interagency collaboration. Involving the schools alone in the transition planning process is considered to be shortsighted and ineffective when adult service providers can supply key insight and services that can offer the student real-world experiences. Thus, it is imperative that schools involve agency representatives in planning both content and timing. In addition, plans should describe the details of how students will be linked to adult and community service agencies. At a minimum, the plan should include representatives from vocational rehabilitation services and the local workforce development system. In the United States, these are now called the "one-stop" employment development agencies. Other agencies that may play a role in transition planning and execution include mental health services, developmental disabilities, local centers for independent living, and the myriad of community-based services.

The fourth characteristic of successful transition plans is the focus on the broad range of student development needs. All students, whether bound for college or sheltered employment, will need assistance to meet the broad range of adult living requirements. Thus, transition plans should reflect the activities that are needed to meet those requirements, including consideration of life skills instruction, career and vocational exploration, structured work experiences, and support services.

## THE TRANSITION PLANNING PROCESS

Transition planning typically begins when the student reaches high school age. IDEA mandates the development of a transition plan at age 14. The general idea is that the plan is first articulated early in the student's high school experience and is refined over time to reflect new information, changing demands, and refined interests. Successful plans result from planning activities that are open and participatory, ongoing, and centered on the goals and interests of the student. The process is open in that it involves individuals who have and feel a stake in the success of the resulting plan. The planning process is controlled by interested stakeholders, including the student for whom the plan is designed. All stakeholders provide input to the plan and share in the responsibilities for carrying out the plan.

Successful transition plans are dynamic and undergo periodic review to assess progress. They rarely remain static from initiation to completion, as opportunities and environments change over time. To take advantage of new opportunities, stakeholders should periodically assess progress of the plan toward the intended goals, review activities and supports, and revise as appropriate.

*—William D. Frey*

***See also*** Education, College and University; Education, Primary and Secondary; Education and Disability; Employment; Individualized Education Plan; Individuals with Disabilities Education Act of 1990 (United States); Sheltered Employment; Special Education.

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# TRANSLATING THEORY AND RESEARCH INTO PRACTICE

The issue of translating theory and research into practice is ultimately one of disseminating and utilizing research findings. Through the dissemination and utilization of theories, practical programs implement and test new theories on varieties of populations and situations. The iterative nature of this process requires a constant dialogue between researchers and practitioners. While so-called pure research may be valued in the quest for knowledge in and of itself, applied research on disability, for example, presumes that individuals with disabilities, their family members, researchers, policy makers, and activists will be able to utilize those theories and findings in their own lives or professional work. To those ends, translating theory into practice is an important issue for many applied fields that work with and serve members of disability communities.

This entry has three objectives. First, five dimensions of dissemination that influence the utilization of new knowledge will be explored to suggest factors that should be considered during the dissemination process. Second, two models of information integration will be detailed to explore how practitioners incorporate new knowledge and processes. Finally, the implications of these components for integrating research findings into practice will be briefly discussed.

## DIMENSIONS OF DISSEMINATION

Based on a literature review, the National Center for the Dissemination of Disability Research (NCDDR) identified four key dimensions that affect the acceptance of new theories and knowledge. The first dimension is the source of new knowledge: Where is the information coming from? This dimension speaks to the information source's credibility. If the information is from a reputable institution or researcher, the findings may be more readily accepted and integrated into the daily activities of an individual or agency. However, if the information originates from unknown or dubious sources, the information consumer may quickly disregard the findings. Indeed, the source of information is often more important than the actual information presented.

Second, the content of the disseminated message impacts whether it is incorporated into practice. While the previous dimension focuses on the quality of the information provider, this dimension focuses specifically on the message. To gauge the quality of the information, an individual must weigh the content against existing knowledge to see whether their experience confirms the theory. As consumers of information, people are constantly weighing new theories and messages against preexisting knowledge. As these messages cohere with previous knowledge and experience, the information will be accepted and implemented.

Third, the medium through which the theory is conveyed can affect its utilization. This dimension concerns how the material is disseminated. Perhaps the largest breakdown in theory implementation occurs in this dimension. For researchers based at colleges and universities, their positions often require them to present research findings at academic conferences or in scholarly journals. These venues may not be appropriate locations or formats for members of disability communities, practitioners, or agency staff. Research findings must be presented and conveyed in accessible formats and locations to assist in broader practice implementation. During the past several years, the Internet has made knowledge dissemination much faster and more accessible through web pages and an increasing number of online journals. However, with so much information coming from so many sources, people are forced to critically evaluate the credibility of information now more than ever.

Fourth, the users receiving the knowledge affect how the theories are translated into practice. As the

NCDDR suggests, facilitating a user's utilization of knowledge can be accomplished in two primary ways. First, the materials need to be relevant to the user's daily life. Second, the user must be ready to accept the information. Thus, from the information receiver's point of view, knowledge is more likely to be implemented as its utility increases. Within some academic fields, researchers have addressed issues of utility through participatory action research that incorporates the potential users of the information not only in selecting research questions, but also in developing theories and methods to answer those questions. Research suggests that through this collaboration, users and agencies are more likely to utilize the research findings.

A fifth dimension to the implementation of information that the NCDDR did not mention is the speed at which the information arrives to practitioners. The time lag between the research project and the dissemination of research findings can make the information out-of-date by the time practitioners and agencies receive it. This time lag occurs at numerous stages of the research and dissemination process. For example, when looking at possible racial and ethnic discrimination in vocational rehabilitation (VR) services in the United States, many of the articles that were published in 2002 and 2003 relied on information from the 1996 and 1997 Rehabilitation Services Administration's database, RSA-911. This lag of approximately six years could make the findings useless to VR practitioners and agencies as policies and administrations remain in flux.

## MODELS OF INFORMATION INTEGRATION

The literature suggests two primary models to explain how theory is adopted into practice. First, the agricultural extension model suggests that people adopt new models for pragmatic reasons. If the theory produces a more efficient and efficacious means of getting outcomes, then it should be utilized. Second, the constructivist model indicates that people will adapt new methods only when their old methods fail and the new method reflects their experiences. Therefore, the first model can be seen as more of an objective approach and the second model as more of a subjective approach.

### *Agricultural Extension Model*

The agricultural extension model developed as a model of translating theory into practice following patterns established in agriculture. This model focuses primarily on spreading the word of successful interventions. For example, in pharmacology, Viagra initially began as a treatment for high blood pressure and was used on young, male medical students. While the drug was successful at reducing high blood pressure, it also had an adverse side effect of an erection. Now the drug not only is used generally for men with impotence but also is used for men with spinal cord injuries to enhance their sexual functioning. Through that process, the use of Viagra spread from people with high blood pressure to older men with erectile dysfunction to men with paraplegia and tetraplegia.

This agricultural extension model also establishes "best practices" paradigms in fields such as public health and medicine. However, this model presents a narrow notion of knowledge dissemination. For example, the agricultural extension model assumes that the environmental and individual factors will be the same despite any differences that may exist between the initial study site and future sites where the knowledge may be applied. For this reason, some researchers in the literature have called for "best practices" to be considered "best processes" so that environmental and individual variables can be better considered in utilization. Indeed, this transition contextualizes the processes within the specific situations and reminds users to consider that context when adapting those processes.

### *Constructivist Model*

The constructivist model is primarily concerned with how dissemination fits into the process of learning. This model considers how individuals and groups assimilate knowledge based on how well it blends with previous experience. Essentially, learners accept knowledge if it meshes with their personal experience and reject knowledge if it does not mesh with their experience. As a consequence of this model, people are likely to maintain the status quo unless faced with a problem. This stagnancy further detracts from possible innovations that may develop during process improvements. A possible way to counteract this stagnancy and push for innovations is to maintain cross-disciplinary teams to introduce theories from different fields when considering new practices.

## CONCLUSIONS AND SUGGESTIONS

This entry has examined important factors in the research dissemination process and models to explain why practitioners and agencies may utilize research findings. At least three suggestions can be made based on the dissemination literature. First, researchers need to make new information accessible to all levels of users (e.g., researchers, individuals with disabilities, families, activists, policy makers). Accessibility may mean publishing and presenting the materials differently to different groups. This implication follows one of the primary rules of writing: Always consider your audience.

Second, researchers need to ground their research in communities that may implement their findings. This activity accomplishes several goals. Not only does the researcher gain credibility in the community, but also the community will be more likely to utilize the research findings. Participatory action research has provided a useful model to assist with this process. By incorporating community members in all phases of research and maintaining this connection throughout the project, researchers may be able to disseminate their findings more quickly to the people who are most likely to utilize them.

Finally, researchers need to understand models that lead people to utilize research findings so their dissemination efforts can target those models. For example, if individuals only accept new theories when old theories fail them, then researchers disseminating new findings need to show why old theories no longer apply. This concentration on dissemination packaging is vital to increase the likelihood of translating theory into practice.

—*R. Noam Ostrander*

***See also*** Research; Vocational Rehabilitation.

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## TRAUMATIC BRAIN INJURY

Traumatic brain injury (TBI) is defined as any damage to the brain from an applied force. The forces involved can be from direct contact, as in blunt or penetrating head injury, from a gravitational source such as fierce shaking, or from rotational energy, as in shaken baby syndrome. Often, a combination of these forces is involved (a motor vehicle collision can cause both direct blunt trauma and rotational and rapid velocity changes). These events cause a deformation of the brain tissue that results in several types of pathology. In addition to the *primary injury* (caused at the moment the force is applied), a series of events is set in motion that continue to cause cellular damage over the next days to weeks, or even longer. These *secondary injury* events include a complex set of biochemical reactions and molecular changes that extend cellular damage, brain edema, and inflammation in a self-perpetuating cycle that rapidly increases the extent of the brain damage.

### PRIMARY INJURY

Direct contact with the skull or brain is classified as *blunt trauma* (caused by, for example, a baseball bat or windshield) or *penetrating trauma* (from gunshot wounds, shrapnel, and knives). Blunt contact causes injury directly below the contact point. The impact can also cause the brain to move or shift back and forth inside the skull, damaging the opposite side of the brain, in a "contracoup" injury. The base of the skull is bony and rough and can cause tearing and bruising to brain tissue when it bounces back and forth. The extent of the damage varies depending on the intensity of force applied. The primary injuries that result are contusions (bruising of the brain tissue), tearing of the tissue and blood vessels, bleeding, tissue shearing, and disruption of neuronal networks. There are multiple types of contusions. Blunt head injury may be *open,* if the skull has been compromised to the point that brain tissue is open to the environment, or *closed.*

In addition to the direct blow, blunt trauma to the head causes the transmission of forces throughout the brain tissue. If strong enough, they can cause shearing and disruption of tissue and neural networks deep within the brain. This type of damage tends to be diffuse and can result in axonal damage (*diffuse axonal injury* [DAI]), diffuse edema, and extensive neuronal death and can extend the toxic secondary injury throughout the brain to areas far from the point of original contact. The same acceleration forces that cause DAI can also cause stretching and tearing of blood vessels leading to subcortical hemorrhages, additional neuronal damage, and disrupted functional activity in otherwise intact neurons.

Penetrating injury results in different injury patterns from blunt injury. The biggest factors in the degree of damage from a penetrating injury are the velocity and mass of the projectile. Shells from high-powered rifles and other high-velocity projectiles can cause an enormous pressure wave that damages the brain tissue in predictable patterns and can be massive and devastating. Lower-velocity projectiles cause less pressure-wave damage and less direct shrapnel path damage. As with blunt TBI, penetrating injury sets off a secondary injury cascade.

## SECONDARY INJURY

The initial trauma to the brain that kills or damages nerve cells is only the first step in a drawn-out and complex cascade of events that cause further cell death. Immediately after a TBI, some cells are mortally wounded, while others farther away from the injury insult receive lesser wounds. However, within hours to days after the injury, if the metabolic and cellular machinery in the nerves (*homeostasis*) is too perturbed, these cells swell and die (*necrosis*). Necrosis can be caused by inflammatory factors produced in the brain, by free radicals entering into the brain, or by the excessive release of excitatory neurotransmitters such as glutamate. Some cells that survive the initial injury may die days, weeks, or months later, when mechanisms inside the nucleus of the cell trigger a breakdown of its DNA. This process is known as *apoptosis,* or programmed cell death, because it is triggered by genes within the cell nucleus responding to external signals caused by the TBI.

Components of the secondary injury cascade include *anoxia* (absence of oxygen), *hypoxemia* (low oxygen content in the blood), *hypotension* (low blood pressure) and *anemia* (low blood count), *hemorrhages* (bleeding in the brain), *edema* (swelling), and increased intracranial pressure. Edema is a common component of TBI that occurs when disruption of the blood-brain barrier allows fluid to leak into the brain, or cellular swelling follows cell membrane damage and ion transport dysfunction. Edema increases intracranial pressure and can result in further damage to brain tissue. If intracranial pressure continues to increase, it leads to compression of the brain tissue and eventual herniation of tissue through the brain stem, resulting in death. In addition to edema any new lesion or mass that occupies space causes increased intracranial pressure after TBI, and if these masses continue to grow, permanent brain damage ensues.

## OUTCOMES

Traumatic brain injury is broadly defined in terms of three categories of severity: mild, moderate, and severe, based on the Glasgow Coma Scale, a 15-point scale designed to measure the patient's ability to respond to environmental stimulus (visual, verbal, motor) after TBI. The degree of impairment depends on the extent of damage to critical brain areas. In the United States, approximately 80 percent of TBIs are mild, 10 percent are moderate, and 10 percent are severe. Outcome after TBI can vary widely depending on the locus and extent of damage, age and sex of the patient, prior medical conditions, socioeconomic and educational status, early treatment interventions, and subsequent extent of rehabilitation and medical therapy. An equally broad range of symptoms—loss of consciousness and coma, persistent vegetative state, seizures, disrupted motor functions, visual defects, dizziness, disordered language, executive functions and communication skills, lack of emotional control, diminished (or enhanced) sex drive, depression, changes in personality, inability to focus and loss of attention, and impaired memory, especially short-term processing of information—can occur in the successive stages after TBI.

There are currently no clinically effective treatments than can directly repair the damaged brain. Basic research in this area focuses either on developing drugs that can prevent swelling, necrosis, and apoptosis (neuroprotection), or on agents or physiological techniques that encourage intact nerve cells to grow new branches, or to increase or even change their activity to replace the neurons that have been lost (enhancing neuroplasticity). A third category of research, using stem cells or other genetically modified cells (glial cells) that are transplanted into the zone of injury, seeks to replace damaged cells with substitute neurons or other cells that can restore function.

In the current absence of treatments, symptoms can persist indefinitely, although there may be gradual amelioration that can sometimes be improved with rehabilitation therapy. Many patients diagnosed with mild TBI develop behavioral problems and symptoms that prevent them from returning fully to their preinjury lifestyles or work, and in about 30 percent of cases, they are accused of malingering, although this condition is not easy to verify. There is now accumulating evidence that even mild but repeated head injuries (e.g., those associated with sports such as boxing or football) occurring over time can result in cumulative impairments that can be very disabling or even fatal.

According to the Centers for Disease Control, each year in the United States, 1.5 million people sustain some form of TBI—8 times the number of people diagnosed with breast cancer and 34 times the number of new cases of HIV/AIDS. TBI is the leading cause of death in males aged younger than 35 years. Fifty thousand people die from TBI each year, and these account for one-third of all injury-related deaths. Eighty to ninety thousand people each year "will experience the onset of long-term or lifelong disability associated with TBI" (Thurman et al. 1999:612). TBI is a leading cause of death and disability in people aged older than 75 years, mostly from falls and related accidents.

*—Donald Stein*

***See also*** Medicine.

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## TRAVEL

Travel can narrow or widen gaps among people with disabilities (PWDs) and gaps between disabled and nondisabled people. As with the political, economic, and social development that often fosters it, travel can (but sometimes does not) create an egalitarian civil society. For many of the world's PWDs, economic, social, and political factors compound structural barriers to travel. PWDs are tourists traveling for leisure, "hosts" for the tourist industry, migrant laborers, students in educational exchange, and travelers in search of refuge.

*Travel* has several definitions, with different implications for disabled people. A basic definition is in the *Cambridge English Dictionary:* "to make a journey, usually over a long distance." Especially in Commonwealth countries, reference to travelers is often to migrants who are excluded from many social services.

Many authors looking at globalization, disability, and travel examine the dualisms (e.g., rich and poor, urban and rural) affected by globalization. But for the most part, these analyses have looked at disability only tangentially. Since disability, travel, and globalization are inextricably linked, this is a shame.

## LEISURE AND BUSINESS TRAVEL

On the upper side of the gap between the "haves" and "have-nots" among PWDs are most leisure and business travelers. Travel for leisure or business is most frequent and easiest in the United States, followed by Canada and Western Europe, and most infrequent and difficult in most of Asia and Africa.

Many books and organizations have emphasized the gains that disabled people receive from travel. In the United States, Jillian Magalaner's publication of a travel guide geared toward travelers with disabilities in 1994 (revised in a new edition by Fodor in 1996) was a landmark. The publications acknowledged the importance of legislation, especially the Americans with Disabilities Act (ADA) of 1990, in bringing about change, and acknowledged that laws worked most effectively when people held businesses accountable. In 2002, the American Automobile Association (AAA) published *Guides to Barrier-Free Travel* for New York City, Washington, DC, and other destinations.

Such publications indicate progress, but the need for them reflects the limited access for travelers. They also reflect extensive cooperation between individuals and groups designed to promote accessible travel by PWDs. The AAA publications, for instance, drew on "accessibility appraisers" that included for-profit and nonprofit entities such as Access-Able Travel Source in Colorado, Accessible San Diego, and a Canadian company, Beyond Ability International.

Travel for disabled people has had an impact in the travel industry. This is reflected in growth and development of organizations such as the Society for Accessible Tourism and Hospitality (SATH) and estimates such as one from a 1999 publication of the European Commission: "an unserved potential of 35 million overnight travelers and 630 million nights could be generated (p. 4). Globally, that potential is much greater.

The global travel industry may have negative effects on tourist destinations. High disability expectancy characterizes some parts of the tourist industry. Deborah McLaren (2003) observed that "the general health of people in tourist destinations is declining, and locals are the least likely to be able to afford treatment" (p. 82). She offers specifics, such as the rise of HIV/AIDS in Thailand. Global travel and urbanization affects both the scope and the nature of disability.

## TRANSPORTATION

Air, rail, cruise ship, and highway travel are all impacted by disability. In each, there have been many standards and aspirations for disability access but fewer enforceable rules.

In the United States, air carriers are regulated under the Air Carriers Access Act (ACAA). The ACAA's adoption in 1986 was unevenly implemented, however, and was aided by Department of Transportation's rule-making regarding matters such as service animals, boarding, and seating. That major problems remained was evident in a 1999 report of the U.S. National Council on Disability. In 2000, the ACAA's provisions were extended to foreign carriers landing in the United States. Writing in 2002, Curtis Edmonds suggested the need for a private right of action, allowing for individual lawsuits to bring about the promise of the ACAA.

Cruise lines attract many PWDs. Plaintiffs hoping that a U.S. court would order imposition of ADA standards on foreign-flagged cruise ships were ultimately successful. In *Spector v. Norwegian Cruise Lines,* the appellate court reversed a district court ruling where people faced barriers making access to services and evacuation equipment difficult or impossible. The ship flew the Bahamian flag, so the cruise line argued that it was not bound to comply with the ADA. Then, on June 6, 2005, the U.S. Supreme Court reversed the appellate court's decision and sided with the plaintiffs in their argument that the ADA's guarantees of access were applicable.

The concept of universal design has been applied to transportation systems, with the design of bus, rail, and air facilities intended to accommodate everyone.

Accessible transportation solutions exist but often are not adopted by industries and public authorities alleging budgetary restraints.

## LODGING

Bathrooms, signage, elevators, telephones, transportation, staff training, parking, and other factors may determine how accommodating a hotel or motel will be for travelers with disabilities.

In the United States, lodgings are "public accommodations" covered under Title III of the ADA. Through the Access Board, there are specific requirements that lodgings should meet. Some adaptations have been made voluntarily, and some of the requirements have been enforced through the courts and through settlement agreements. However, requirements such as choice of rooms (e.g., twin, double double, or suite) and access to public areas (e.g., breakfast room, patio) continue to be violated. So do simple and widely known requirements for service dog access and placement of furniture to accommodate travelers with mobility impairments. As evidenced by numerous guides, though, accessible lodging exists, and some establishments have made major improvements.

## ACCESS TO RECREATION

As with lodging, many recreational sites are "public accommodations" and are covered by legislation such as the ADA. Technological developments, such as all-terrain wheelchairs, can make accessible recreational attractions that were not accessible before.

Travelers' access to recreation may be purchased at the expense of high rates of disability in the host community, which becomes a basis for discrimination. In Pakistan, Kenneth MacDonald found that local porters had increasingly short careers aiding outside mountaineers, often because of chronic disability.

## TRAVEL FOR EDUCATION, CIVIC ENGAGEMENT, AND MEDICAL SERVICES

People may travel for study in boarding schools, educational exchanges, study trips, Elderhostels, or other programs. Travel may be within a country or to another country.

Protections for U.S. citizens studying abroad were litigated in *Bird v. Lewis and Clark College,* where the court held that the guarantees of the ADA did not extend to overseas travel programs of U.S. universities.

Travel may catalyze civic engagement. In Zimbabwe, Rosangela Berman Bieler (one of Jim Charlton's [2000] respondents) said that she got involved at her rehabilitation center because she "wanted to travel, do sports, and other social things" (p. 13). Often, travel and involvement are mutually reinforcing. Many travel programs deliberately promote foreign study as equal exchange, rather than as a reflection of global inequalities. They involve PWDs as participating students and in host countries.

People may travel in search of medical services. Differing laws and economic, social, and cultural factors mean that different drugs, services, and barriers to access to care exist in different places. "Suicide tourism" was reported in accounts of physician-assisted suicide—actual in Switzerland and the Netherlands, hypothetical in Oregon. In India, the lure of tourism induced several poor people to sell kidneys. Medicinal marijuana and pharmaceuticals are more available in some jurisdictions than in others. More travel by PWDs is the likely result.

## REFUGEES, ASYLUM, MIGRATION, DISABLED PEOPLE, AND TRAVEL

Millions of people, many of them PWDs, travel because of political, social, or economic conditions that push them away from their homes and pull them voluntarily or involuntarily to new homes. Some of these people are disabled when they leave their old homes; more will become disabled because of conditions during and after their travel.

### *Refugees and Asylum*

Disability may affect an individual's getting asylum or extended departure. To claim refugee status, a person needs to show "well founded fear of persecution" on account of group membership (Convention Relating to the Status of Refugees 1954). Membership in a racial or religious group is more often useful in claiming refugee status than membership in an "other social group" (Convention Relating to the Status of Refugees

1954), which Arlene Kanter and others have persuasively argued should be read as including PWDs. Immigration officials often disagree, however. Disability also influences claims to asylum, which governments often deny on economic grounds.

Nongovernmental organizations (NGOs) and governments distinguish "refugees" from "internally displaced people" according to whether their travel was across national boundaries. In each case, many previously nondisabled people become disabled through travel, and disabled people are disproportionately likely to bear the consequences of unequal access. In Cambodia, Danilo Delfin (another Charlton [2000] respondent) observed that "if you are disabled, you automatically have people after you" (p. 102). The government and Khmer Rouge would each assume that a PWD was the enemy.

### *Migration*

Millions of people each year migrate, often for employment or to follow tradition. The Commission for Racial Equality (2004) in the United Kingdom recently bemoaned that the "last 'respectable' form of racism" (para. 4) was against Gypsies (Rom) and travelers. Consequences include a life expectancy of 11 years less than average, diminished access to education, and poorer access to health care, all issues that disproportionately impact PWDs.

Several observers have noted a significant connection between the classification of mental disability and the immigration or refugee experience. In addition to the impairments that accompany migration, professionals may attach the "disability" label to the range of reasons why immigrants might not "fit in."

## REGULATION OF TRAVEL

Many changes easing PWD travel result from pressure exerted by PWDs and allies in the disability rights movement. Kanter (2003a) described encouraging legislative developments as the "globalization of disability rights law." A common focus is access to buildings and transportation, which sometimes (not always) includes explicit mention of PWDs' right to travel.

### *National Governments*

National governmental laws, such as the ADA in the United States, are mentioned above. Many countries have legislation acknowledging disability rights; in most cases, travel is indirectly implicated in provisions on transportation and access to public and, in some cases, private facilities.

### *The United Nations*

Within the United Nations (UN), PWDs have participated in the development of rules, hoping to move them from aspiration to binding law. The 1982 World Programme of Action Concerning Disabled Persons included a section on recreation. It linked PWDs' having equal opportunities for recreation to use of hotels, beaches, restaurants, travel agencies, holiday resorts, and other facilities.

In 1993, the UN General Assembly adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The Rules are not compulsory but provide goals, including Rule 11 on Recreation and Sports. This Rule mandates that travel services and hotels should offer their services and opportunities to all.

Despite the lofty objectives agreed to by national governments, achievements do not match aspirations. Arlene Kanter (2003a) noted that "disability remains invisible and marginalized as a human rights issue, even among human rights organizations and NGO's" (p. 266). With a Convention (treaty), parties would be legally bound to comply, and the public would be in a stronger position to pressure nonparties.

The Convention was the subject of a Mexican United Nations General Assembly resolution and ad hoc conferences on a "Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities." Adoption of a Convention with provisions related to (although not necessarily explicitly mentioning) travel is probable; as with other human rights conventions, implementation will be uneven.

### *Regional Organizations*

Regional organizations, especially the European Union and the Organization of American States (OAS), also are arenas where disability and travel are discussed. The first intergovernmental disability rights convention was a regional one, the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, adopted by the OAS in 1999. Parties agree to promote integration "by public authorities and/or private entities" and eliminate discrimination "gradually" in transportation, recreation, services, and other areas (Inter-American Convention 1999). Mexico and Costa Rica are among the countries bound by this treaty; Canada and the United States are not.

## NONGOVERNMENTAL ORGANIZATIONS AND TRAVEL

Prominent NGOs include organizations devoted to the travel industry, seeking to entice PWD travelers; organizations promoting the well-being of displaced people, many of whom are PWDs; and organizations devoted to participation by disabled people in all sectors of life, including travel.

### *Society for Accessible Tourism and Hospitality*

SATH was founded in 1976 as the Society for Advancement of Travel for the Handicapped. Its mission is "to raise awareness of the needs of all travelers with disabilities, remove physical and attitudinal barriers to free access and expand travel opportunities in the United States and abroad" (Society for Accessible Tourism and Hospitality n.d., para. 1). SATH members include PWD consumers, but the organization's primary appeal is to travel professionals.

### *Independent Living Institute*

The Independent Living Institute (ILI) was founded in Sweden in 1993 as the Institute on Independent Living. Since its inception, the ILI has worked across borders in Europe and disseminated information worldwide. It deals with a full range of independent living issues. Some, such as personal assistance, are unrelated to travel. The ILI website has a useful Recreation & Travel heading in its online library, recently added a section on Study and Work Abroad for All, and has long had an international Vacation Home Exchange.

### *Mobility International USA*

Mobility International USA (MIUSA) was cofounded in 1981 by Susan Sygall (currently the executive director) and Barbara Williams. Its programs and services include the National Clearinghouse on Disability and Exchange (NCDE); International Development and Disability; International Exchange and Leadership Development; and Loud, Proud and Passionate!—International Women with Disabilities Leadership and Networking Projects. It promotes travel as empowering, particularly for disabled women facing sexism and ableism. MIUSA promotes a central role for PWDs in the development process. Travel is both an effect of and part of that process.

### *Other Nongovernmental Organizations*

Travel and PWDs are touched upon by many NGOs, including the International Organization for Migration and Disabled Peoples' International. Travel is central to the mission of other NGOs, such as Access Exchange International. Together they influence perceptions of the connection between disability and travel. As NGOs become stronger, more PWDs should be participating in travel for leisure or business and fewer because of the "push" and "pull" factors generated by economic inequality.

*—Arthur Blaser*

***See also*** Air Carrier Access; Americans with Disabilities Act of 1990 (United States); Public Transportation; United Nations; United Nations Standard Rules.

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## TREDGOLD, ALFRED F.

**(1870–1952)**

*British physician and eugenicist*

Alfred F. Tredgold was an influential writer and medical expert in the early decades of the twentieth century, both in Great Britain and—through his influential textbook—throughout the English-speaking world. His book, *Mental Deficiency (Amentia),* first published in 1908, went through some eight editions before Tredgold's death in 1952, continuing to be revised by new editors through 1979.

In the Edwardian era in England, Tredgold was also a prominent eugenicist, writing and testifying on the social importance of dealing with the "problem of the feeble-minded" (Tredgold 1911) and arguing that "morbid heredity . . . is present in 80 percent of cases [of amentia]" (Tredgold 1908:38). During this period, Tredgold testified for the Royal Commission on the Care and Control of the Feeble-Minded and served as consulting physician to the Littleton Home for Defective Children and the National Association for Promoting the Welfare of the Feeble-Minded. Along with other British eugenicists of the era, Tredgold warned the government to act aggressively to counter the burgeoning birth rates of intellectually disabled mothers. Only through segregation and sterilization, Tredgold argued, could Britain successfully arrest the "manner in which feeble-mindedness is permeating the country and swamping the mental and moral vigour of the community" (Jackson 2000:140).

*—Philip M. Ferguson*

***See also*** Eugenics; *Feeblemindedness;* Sterilization.

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## TROPICAL DISEASES

The nosological category of tropical diseases grew out of the colonial expansion of European nations and the United States at the end of the nineteenth century. In less than a hundred years, *tropical medicine* became a term increasingly devoid of meaning, as scientific research, deteriorating public health infrastructures, and rapid, large-scale human displacement (among other reasons) produced the identification of new vector-borne infections in temperate climates and the reemergence of others long gone. In addition, the largest proportion of diseases found today in tropical countries are not due to parasites or vector-borne agents but to globally distributed causes such as tuberculosis, HIV, and smoking, whose prevalence and severity are increased by the conjunction of poverty, hunger, and lack of medical care.

The list of infections with a primary locus of transmission in tropical areas is vast, so this entry will comment only on the most important causes of disability (short- or long-term incapacitation on a mass scale). Those selected by Murray and Lopez in their analysis of the global burden of disease include four diseases transmitted by the bite of a mosquito (malaria, dengue hemorrhagic fever, Japanese encephalitis, and lymphatic filariasis); four transmitted by other arthropods (onchocerciasis, trypanosomiasis, Chagas disease, and leishmaniasis); two acquired by contact with a contaminated environment—soil (intestinal nematode infections) or water with infected snails (schistosomiasis); one acquired through contact with contaminated secretions or by flies (trachoma); and leprosy, for which close, prolonged personal contact is the suspected mode of transmission. A succinct exposition of the natural history, preventive measures, and drug therapy for these diseases can be found elsewhere. In all of these diseases, treatment (if available) to cure the infection will partially or not at all reverse the long-term disability produced by the disease. In almost all of these diseases, the initial infection usually produces a short, undifferentiated febrile illness or may be asymptomatic. Only malaria, dengue, and Japanese encephalitis are likely to produce life-threatening syndromes on first infection, and the resulting long-term disability (other than the incapacitation due to malarial relapses) mostly depends on the severity of the initial episode and sequelae from shock or respiratory compromise. Among all these diseases, the major producers of days of illness and early death according to Murray and Lopez are malaria (by far the most common), filariasis, leishmaniasis, and intestinal nematodes, so they are considered in the short space allowed by this entry. It must be emphasized, though, that the true illness burden is underestimated because of the lack of local resources, even for data collection.

Malaria is caused by any of four protozoan *Plasmodium* species (*falciparum, malariae, ovale,* and *vivax*) and produces fever, chills, sweats, and headache for a week to a month or longer, with relapses at irregular intervals for years thereafter, unless the proper antibiotic is provided. Falciparum malaria may progress to jaundice, shock, renal and liver failure, encephalopathy, and coma, with case-fatality ratios of 10–40 percent if untreated. Cases of cerebral malaria may recover with significant neuromotor deficits.

In contrast, the severe manifestations of lymphatic filariasis are usually the result of repeated infections that are active for years. *Wuchereria bancrofti, Brugia malayi,* and *Brugia timori* larvae, transmitted by mosquitoes, lodge in the lymph tissue and the lungs and may produce paroxysmal nocturnal asthma, chronic lung disease, renal disease, arthritis, adenitis, lymphangitis, chyluria, and elephantiasis of the genitalia or limbs. Drug treatment clears most microfilariae from the blood but may not destroy all adult worms, so it must usually be repeated at yearly intervals. The principal goal in the treatment of these patients is to prevent secondary bacterial infections in areas swollen with lymph, which can be accomplished through good hygiene, prevention and cure of skin lesions, exercise, elevation of affected limbs, and wearing of appropriate shoes. Hydrocele (collection of fluid inside the scrotal sac) can be treated with surgery. A very useful guide for management of areas with lymph swelling (lymphedema) has been recently published (Dreyer et al. 2002).

Onchocerciasis (river blindness) is also produced by filarial worms (*Onchocerca volvulus*) but transmitted by the bite of infected *Simulium* (black) flies. The microfilariae migrate through the skin and produce a chronic systemic illness with skin edema and atrophy, subcutaneous or periosteal fibrous nodules, and, if they reach the eye, visual disturbances or blindness. The introduction of ivermectin for onchocerciasis in 1987 was a milestone of disease treatment in less developed countries because of the efficacy and safety of the drug and because the manufacturer (Merck) decided to donate it without charge. This gift provided the incentive for establishing community-based distribution networks in affected areas (even if they had no established public health systems), stimulated similar donations by other pharmaceutical companies, and is seen as an example of what could potentially be accomplished for AIDS therapy.

Leishmaniasis, caused by a number of species of the protozoan genus *Leishmania,* is transmitted by the bite of sandflies and produces cutaneous and mucosal lesions that may last weeks or months and then heal spontaneously, only to recur even years later with dissemination and nasopharyngeal tissue destruction. Visceral leishmaniasis (kala-azar), characterized by fever, diarrhea, abdominal pain, hepatosplenomegaly, pancytopenia, and progressive emaciation, is usually fatal within 3–20 months if untreated.

The principal intestinal nematode infections are hookworm disease (uncinariasis, by *Ancylostoma duodenale, Ancylostoma ceylanicum,* and *Necator americanus*), roundworm disease (*Ascaris lumbricoides*), and trichuriasis (*Trichuris trichiura*). Hookworm eggs passed with feces hatch in the ground. Larvae penetrate human skin (usually the bare feet) and migrate through lymphatics and blood to the lungs, up the trachea, and then down the esophagus to the small intestine, where they attach to the wall, feed off the patient's blood, and produce thousands of eggs each day. This process may result in pulmonary infiltrates, cough, and tracheitis, but the major cause of disability in heavy infections is iron deficiency, with hypochromic microcytic anemia, hypoproteinemia, and retarded mental and physical development of children. *Ascaris* and *Trichuris* are acquired by the ingestion of eggs through pica or contaminated vegetables. The larvae attach to the mucosa of the intestine, and heavy infections may produce bowel obstruction, bloody stools, diarrhea, nutritional deficiency, and growth retardation in children.

The principal specialized medical care required by the long-term sequelae of these "tropical" infections can be grouped as follows: neurological and physical rehabilitation for cerebral malaria, encephalitis due to dengue or Japanese encephalitis virus, lymphatic filariasis, and leprosy; skin care and reconstructive surgery for lymphatic filariasis, leprosy, leishmaniasis, and onchocerciasis; ophthalmologic treatment for onchocerciasis, trachoma, and leprosy; gastroenterological expertise in hepatic schistosomiasis and Chagasic megacolon; and cardiological, urological, and pulmonary care for Chagasic cardiomyopathy, urinary schistosomiasis, and filarial interstitial lung disease, respectively. Unfortunately, these services are required by populations with other highly endemic severe diseases, such as HIV, that have little access to education and medical attention and are also burdened by poverty and malnutrition.

*—José G. Rigau*

***See also*** Disease; HIV/AIDS; Infectious Diseases; Leprosy; Medicine.

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## TUBERCULOSIS

*Tuberculosis* is a communicable disease caused by a mycobacterium. Its most common form is pulmonary tuberculosis, what used to be called *consumption*. A chronic disease, tuberculosis was endemic in Western countries until the post–World War II period. It is now endemic in developing countries, with the World Health Organization declaring a global emergency in 1992. Without antibiotic treatment, in the past in the West, and currently elsewhere, individuals have been disabled for many years by this long-term illness. In countries such as Germany, the United Kingdom, and Australia, the massive problem of tuberculosis prompted some of the earliest experiments in government welfare in the late nineteenth and early twentieth centuries. These early disability allowances, insurance programs, and pensions were often the basis on which later sickness, welfare, and disability support programs developed.

Tuberculosis has not always been understood as a communicable disease. In the nineteenth century and earlier, it was sometimes thought to be hereditary and at other times thought to be an effect of environment or constitutional weakness or a combination of these factors. Indeed, although the tuberculosis pathogen was identified by Robert Koch in 1882, the question "Is consumption contagious?" continued to be asked well into the twentieth century. In Victorian literature and visual culture, the aestheticized, chronically weak and bed-ridden consumptive was a stock figure. Partly but not wholly as a response to the identification of the causative organism, comprehension of the disease shifted from this individualized understanding to being an issue of public health. It became a disease associated with poverty and urbanization, disproportionately affecting minority groups, especially in cities.

Toward the end of the nineteenth century, a therapeutic regimen known as "open-air treatment" was developed. Typically, this involved several months' stay in an isolated institutional environment. The first British institutions opened in Edinburgh in 1889, modelled on German private institutions for open-air treatment. In the United States, similar institutions began about 1884. There was a phenomenal proliferation of tuberculosis sanatoria over the next few decades and well into the interwar period. Still understood within climatic theories of health and ill health, sanatoria for open-air treatment of tuberculosis were often built in carefully selected rural, mountain, or seaside locations. Following the basic principle that fresh air was itself curative, people were enjoined to undertake as much of their daily activity as possible outside: school, rest, sleep, exercise. At the height of its popularity, sanatorium treatment involved a radical, sometimes coerced and tightly controlled regimen of rest and incremental exercise. A person might be brought to the sanatorium and forced into total bedrest and, in some systems, total silence. Gradually, and sometimes over a period of six months, the patient was permitted to sit, move, and exercise in controlled ways, from small walks, to inclines, to long walks. Progress was measured by the person's temperature at specified times during the day, by appetite, and by capacity for exercise.

The idea of open-air treatment was to control rather than to cure the disease, but in doing so, the therapy temporarily "disabled" patients sometimes more than the disease itself. The major twentieth-century sociologist Erving Goffman's classic study on segregation and institutionalization, *Asylum,* was based on his time and observations in a tuberculosis sanatorium. The nature of these sanatoria ranged from versions of health resorts to versions of government workhouses, according to the social position of patients, usually depending on their class or race. The correlation of tuberculosis with urbanization and poverty meant that many indigent people were disabled by the disease and were institutionalized in sanatoria. In these instances, the tuberculosis sanatorium was also a place of detention, of unwilling institutionalization and segregation. In the United States, there is a particular history of the institutionalization of indigent African Americans on the grounds of their infection with tuberculosis.

Tuberculosis is arguably the most significant illness in the history of the development of welfare and health insurance programs over the twentieth century. At a population level, tuberculosis mattered greatly, because it typically disabled men and women in the middle years of life; it was not usually a disease of old age. Thus, as was noted over and over again until the antibiotic era, tuberculosis struck men and women in their "prime" productive and reproductive years. These people were usually, though not always, chronically disabled. This made the disease an economically significant one and prompted major new experiments in welfare, insurance, and disability allowance programs.

Because tuberculosis was so endemic in Western countries, the idea and sometimes the legal concept of disability itself were constructed specifically in relation to it. In Germany, novel programs for work-related insurance were developed in the late nineteenth century. In the United Kingdom in the early twentieth century, governments took financial responsibility for treatment of this disease in an unprecedented way. Often, "disability," and therefore eligibility for a pension, free treatment, or insurance payment, was determined by a person's capacity or incapacity to work. To qualify for the invalid pension in Australia, for example, an individual had to be deemed "totally and permanently incapacitated": disabled and, as it was then seen, unfit for work. These employment-oriented systems of insurance and welfare were problematically devised around the idea of a male breadwinner and a female dependent.

Over the twentieth century, the treatment for tuberculosis changed dramatically. Following the principle of rest to arrest the disease, physicians in the 1930s and 1940s sometimes surgically collapsed one lung for long periods. From late 1940s, chemotherapy began to replace previous therapies, dramatically changing the incidence of the disease in countries where the drugs were available: streptomycin in the 1940s, isoniazid and para-aminosalicylic acid (PAS) in the early 1950s, and rifampicin from the late 1960s. Once considered powerful enough to eradicate tuberculosis, chemotherapies have proven effective for populations with access to them. However, for nations and subpopulations without access to antibiotics, the tuberculosis problem escalates. This has been compounded by the emergence of multidrug-resistant strains. In countries such as Russia, the problem of coinfection with HIV and multidrug-resistant tuberculosis is an extremely serious one. Elsewhere, the issue of tuberculosis and global migration have become intertwined: For many nations, a central aspect of global movement and border control has been the strict screening of migrants, asylum seekers, and travelers for tuberculosis.

*—Alison Bashford*

***See also*** Disease; HIV/AIDS; Infectious Diseases; Institutionalization and Segregation; Medicine.

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## TUBMAN, ARAMINTA ROSS (HARRIET) (1820–1913)

*American abolitionist*

Born into slavery in Dorchester County, Maryland, Harriet was said to be of purely African ancestry. Raised under harsh conditions, she was subjected to whippings and heavy labor at an early age. At the age of 12, a blow to the head by her master resulted in constant blackouts and periods of narcolepsy throughout her lifetime. At the age of 25, she married John Tubman, a free black man, but when her master's slaves were put up for sale five years later, she escaped, and, with the help of white antislavery sympathizers, Harriet made her way to Philadelphia. There, she became acquainted with William Still, founder and Philadelphia stationmaster of the Underground Railroad. With the assistance of Still and other members of the Philadelphia Anti-Slavery Society, she learned about the workings of the Underground Railroad. She remained in Philadelphia for two years, working and saving money to return to Maryland for her husband, but when she reached him, she found that he had taken another wife and had no interest in returning north. At this juncture, Harriet dedicated herself to a life as a "conductor" on the Underground Railroad.

As the "Black Moses," Tubman "delivered" 300 slaves safely to the Free States or to Canada. Every time she traveled south, the dangers increased. This was partially due to her habit of falling into deep sleeplike states during the journey. Throughout her life, Tubman was subject to periods of seizures and periods of falling into a deep sleep. The slaves (and later soldiers) who traveled with her to freedom came to understand and expect that behavior. It was even rumored that during those sleeplike periods, she was receiving messages from God as to which route was the safest to lead her charges. In 1860, being too well-known and constantly hunted by slave catchers, she went into the South for the last time to bring back slaves.

During the Civil War, Tubman was a soldier, a spy, and a nurse, serving for a time at Fortress Monroe, which would later become the prison of Jefferson Davis. She slipped through enemy lines to bring back valuable information to the Union Army. She led soldiers through the Southern lines, bringing them back as safely as the slaves she had once led to freedom. While guiding a group of black soldiers through South Carolina, Tubman met Nelson Davis, who she would marry after the Civil War. The couple moved to Auburn, New York, where Tubman stayed active in support of the women's rights movement.

In 1908, Harriet Tubman built a house for the aged. It was there that she worked and was cared for in the years before her death in 1913. After her death, she was buried in Fort Hill Cemetery in Auburn, with military honors. She has since received many honors. On June 14, 1914, a large bronze plaque was placed at the Cayuga County Courthouse, and a civic holiday was declared in her honor. Freedom Park, a tribute to the memory of Harriet Tubman, opened in the summer of 1994 at 17 North Street in Auburn, and in 1995, the U.S. Post Office honored Harriet Tubman with a commemorative stamp. Tubman is widely remembered as a trusted spy, "conductor," and activist in the abolition and woman's rights movements.

*—Carlos Clarke Drazen*

***See also*** Feminism; Race and Ethnicity; Racism.

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# U

## "UGLY LAWS"

In May 1881, the Chicago City Council enacted 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." National networks of ministers, charity organizers, city planners, and municipal officials followed Chicago's ordinance with efforts to enact similar laws elsewhere: in Denver and Lincoln in 1889, in Columbus in 1894, in New York (unsuccessfully) in 1895, and in the entire state of Pennsylvania in 1891. The ordinance, wrote one Chicago reporter, would stamp its author, Alderman Peevey, as a public benefactor: "He proposes to abolish . . . the woman with two sick children who was drawn through the carding-machine in a woolen mill and who grinds 'Mollie Darling' incessantly on a hurdy-gurdy on a street corner." Remembering the woman who played "Mollie Darling," contemporary disability activists cite the extremity of "ugly law" as a signal reminder of the sometimes less obvious but still persistent forms of disability oppression today.

Most of these citations derive from a single and partly misleading paragraph in a landmark work of legal scholarship, Marcia Pearce Burgdorf and Robert Burgdorf Jr.'s "A History of Unequal Treatment: The Qualifications of Handicapped Persons as a 'Suspect Class' under the Equal Protection Clause," published in 1975. The Burgdorfs coined the phrase "ugly law" and placed it in "Chicago 1911," the date and place most commonly used when people quote it now. "Ugly," it should be noted, appears nowhere in the wording of the actual ordinances. "Unsightly beggar" ordinance is more accurate historically, since some of these laws, though not all, appear under that heading in the code books. Inventing "ugly" law, the Burgdorfs performed an act of advocacy probably inspired by the title of a newspaper article they footnoted concerning the last known arrest (in Omaha in 1974), "Begging Law Punishes Only the Ugly."

Unsightly beggar laws were enforced unevenly and perhaps rarely, as historian Brad Byrom has argued. Nonetheless, they had both concrete and chilling effects. A 1916 report by the "Committee on Cripples of the Welfare Federation of Cleveland" records the story of an unnamed man who sold newspapers until "the enforcement of a statute which prevented cripples from exposing their deformity by selling on street corners abolished [his] job. . . . Although it seemed rather hard," the Cleveland Cripple Survey reports, "he appreciated the meaning of it, but considered it ill-advised unless some step went with it for providing other opportunity for work for cripples." Understanding the meaning that this man, in his guarded, strategic protest, is said to appreciate requires placing the "ugly laws" within a complex set of vectors. These include the "tramp scare" and fears of vagrancy; the influence of the charity organization movement; new conditions of visibility in modern urbanity; labor unrest; social Darwinist theories and the rise of eugenics; and, not least, the concurrent development of institutions for the blind, deaf, feebleminded, and generally "dependent and defective classes."

—*Susan Schweik*

***See also*** Begging; Deformity; Normality.

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# UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION (UPIAS)

The initiative to form the Union of the Physically Impaired against Segregation (UPIAS) was taken by Paul Hunt in 1972 when he called for a consumer group to promote the views of actual and potential residents of institutional homes for disabled people in the United Kingdom. The aim was to formulate and publicize plans for alternative forms of support in the community.

Exploring what support was needed to enable the most severely impaired people to live in the community encouraged UPIAS to completely rethink the prevailing interpretation of *disability*. In 1974, UPIAS published its detailed policies. This proposed the examination of "ways of *changing our conditions of life*, and thus *overcoming* the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us."

This interpretation of *disability* was taken a step further in 1975 when it published "Fundamental Principles of Disability" and set out its radical definitions:

> *Impairment*—lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body.
>
> *Disability*—the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

This interpretation of *disability* came to be known as the social model of disability. It radically transformed the way disabled people came to see themselves and their place in society.

—*Vic Finkelstein*

***See also*** Disability Studies; Paul Hunt; Models.

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# UNITED NATIONS

The United Nations was established on October 24, 1945, by 51 countries. Today, UN membership totals 191 countries. The United Nations has four purposes: to maintain international peace and security; to develop friendly relations among nations; to cooperate in solving international problems and in promoting respect for human rights; and to be a center for harmonizing the actions of nations for peace and development based on the fundamental principles of human rights for justice, human dignity, and well-being of all people. The United Nations affords the opportunity for countries to balance global interdependence and national interests when addressing international problems to pursue these goals. The current 191 members of the United Nations meet in the General Assembly, the highest decision-making organ within the UN system, in which each country, large or small, rich or poor, has a vote and voice in this process; however, the decisions taken by the assembly are not legally binding. There are six main organs of the United Nations: the General Assembly, the Security Council, the Economic and Social Council, the Trusteeship Council, the Secretariat, and the International Court of Justice (The Hague in the Netherlands). Six official languages are used at the United Nations: Arabic, Chinese, English, French, Russian, and Spanish.

The UN global Programme on Disability is the lead program concerning disability—the focal point within the UN system. It is housed in the Division for Social Policy and Development at the Department of Economic and Social Affairs of the UN Secretariat. The mandate of the UN global Programme on Disability emanates from the 1982 World Programme of Action Concerning Disabled Persons and the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities as well as other relevant international instruments, such as the UN Charter, the Universal Declaration of Human Rights (UDHR), the International Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights.

The major objectives of the World Programme are (1) to support the full and effective participation of persons with disabilities in social life and development, (2) to advance the rights and protect the dignity of persons with disabilities, and (3) to promote equal access to employment, education, information, goods, and services. Since 2001, the UN global Programme on Disability also serves as the substantive secretariat for the General Assembly Ad Hoc Committee on a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities.

In its early period, the United Nations focused on improvement of the well-being of persons with disabilities to meet their needs in the social context.

In the 1960s, initiatives within the disability community and adoption by the United Nations of the international human rights conventions both in civil and political and economic, social, and cultural realms resulted in a fundamental reevaluation of the rights of persons with disabilities within the context of development. In the 1970s, the evolution of thinking on disability issues at the United Nations resulted in a number of initiatives embracing the growing international concept of human rights of persons with disabilities and equalization of opportunities for them. These include the 1971 Declaration on the Rights of Mentally Retarded Persons and the 1975 Declaration on the Rights of Disabled Persons.

These efforts were intensified within the framework of the UN Decade of Disabled Persons (1983–1992). A major outcome of the International Year of Disabled Persons, which preceded the Decade of Disabled Persons, was the World Programme of Action Concerning Disabled Persons, the most comprehensive global strategy, which took "equalization of opportunities" as its guiding principle. The Standard Rules, a major outcome of the Decade of Disabled Persons, provide an instrument for policy making and a basis for technical and economic cooperation. The international frameworks to promote the rights of persons with disabilities were further advanced by a series of 1990s UN development conferences and their respective five-year reviews, such as the 1993 Vienna Declaration and Programme of Action for human rights, the 1995 Copenhagen Declaration and Programme of Action for social development, the 1995 Beijing Declaration and Platform for Action, the Millennium Development Goals, and other relevant international commitments.

To implement the World Programme and the Standard Rules, the United Nations' global comparative studies suggest that disability is a quintessential cross-cutting development issue. The international community is witnessing a significant expansion of constituencies concerned with disability and the situation of persons with disabilities. In part, this can be attributed to the aging of the world's populations and the increased number of persons surviving diseases or conflicts with a disability. Disability issues and the situation of persons with disabilities within the context of overall national development need to be addressed. Examining these issues contributes to a growing awareness of universal design concepts globally and to recognition of the importance of incorporating universal design principles in international policies and programs for social infrastructure, social services, and promotion and development of accessible environments and institutions. While universal approaches to policy design and program planning represent a somewhat new trend, they reflect the concern of the United Nations not only with social and economic development but also with fundamental human rights.

While the means chosen to promote full realization of economic, social, and cultural rights of persons with disabilities will differ from one country to another, there is no country in which a major policy or program effort is not required. The commitment of member states to realization of the fundamental human rights of all persons would require governments to take all possible measures to make further progress in protection and promotion of the rights of persons with disabilities.

More recently, the initiative on a comprehensive and integral convention to promote and protect the rights of disabled persons resulted from a proposal made by Mexico during the 56th session of the UN General Assembly, which called on the international community to combat poverty and social exclusion. The importance was highlighted to involve all citizens as stakeholders and that a just world must be inclusive of all groups. For that reason, Mexico proposed the establishment of a special committee to study the elaboration of an international convention on promoting the rights and dignity of persons with disabilities, which was endorsed by General Assembly resolution 56/168.

The Ad Hoc Committee of the General Assembly on a comprehensive and integral convention on the rights of persons with disabilities was established in 2001 by assembly resolution 56/168. It was established in the context of addressing poverty and promoting social integration so as to create just and equitable societies based on participation of all citizens as stakeholders. The elaboration of a convention and its future adoption and implementation are expected to provide for a normative basis not only for implementation of the rights of persons with disabilities within the existing legal frameworks but also for formulating strategic options for policies and programs and evaluating measures to promote full and equal participation of persons with disabilities in society and development. National, regional, and international consultations concerning the potential convention are resulting in the emergence of new disability- sensitive networks of policy makers, program specialists, academics, and advocates.

*—Akiko Ito*

***See also*** Developing World; Economic and Social Development; United Nations Declaration on the Rights of Disabled Persons; United Nations Disability Convention; United Nations Disability Statistics; United Nations Standard Rules.

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## UNITED NATIONS DECLARATION ON THE RIGHTS OF DISABLED PERSONS

In December 1975, the United Nations (UN) General Assembly adopted the Declaration on the Rights of Disabled Persons, which states that all persons with disabilities have the same rights as other persons. Provisions of the declaration include (1) defining a “disabled person” as anyone who cannot ensure the necessities of a normal individual and/or social life, as a result of a deficiency in physical or mental capabilities; (2) a nondiscrimination clause applying the rights to all disabled persons regardless of race, color, sex, language, religion, political or other opinions, national or social origin, state of wealth, or birth situation; (3) a right to respect for human dignity; (4) civil and political rights; (5) the right to measures to enable self-reliance; (6) the right to medical, psychological, and functional treatment; (7) the right to economic and social security and to a decent level of living and, according to capability, to employment; (8) the right to have their special needs taken into consideration at all stages of economic and social planning; (9) the right to live with family and to participate in all social, creative, or recreational activities; (10) the right to be protected against all exploitation/discrimination/abuse/degradation; (11) the right to qualified legal aid; (12) a clause stipulating that organizations of disabled persons may be consulted regarding the rights; and (13) a clause urging that persons with disabilities, their families, and communities be fully informed of the rights contained in the declaration. This act culminated the beginning of a new conceptual approach to disability issues as human rights issues.

Prior to 1970, the United Nations approached disability issues from a social welfare perspective. Little attention was paid to obstacles created by social institutions and society in general. The late 1960s became a time for reevaluation. In 1969, the General Assembly adopted the Declaration on Social Progress and Development, which, in Article 19, advocated the provision of health, social security, and social welfare services for all persons, including the provision of measures to rehabilitate the mentally and physically disabled to facilitate their integration into society. Education, vocational/social guidance, and job training and placement provisions were included. On December 20, 1971, the General Assembly proclaimed the Declaration on the Rights of Mentally Retarded Persons, which stated that the mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings, a right to proper medical care and education, to economic security, to a qualified guardian if required, to protection from exploitation, and to legal procedures. The declaration stressed that mentally retarded persons should live with their families and participate in the community. These declarations led up to the movement to create the Declaration on the Rights of Disabled Persons, which, in some sense, represents an attempt to delineate that the 1948 UN Declaration of Human Rights clearly applies to persons with disabilities.

Though nonbinding, the declaration led to several subsequent UN initiatives, such as the UN Year of Disabled Persons, the World Programme of Action Concerning Disabled Persons, the UN Decade on Disability, and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. These initiatives have comprised policies specifically to address the situation of persons with disabilities.

A parallel movement has occurred related to the incorporation of disability issues in UN policy initiatives designed to address the needs of all persons. For instance, in 1993, the World Conference on Human Rights in Vienna reconsidered universally recognized human rights issues and produced the Vienna Declaration and Programme of Action to guide human rights efforts. The conference declared that all human rights and fundamental freedoms are universal, and, hence, people with disabilities have these rights. Thus, any discrimination, intentional or unintentional against persons with disabilities, is viewed per se as a violation of human rights.

Since this declaration, the UN system has monitored the incorporation of disability issues into broader human rights initiatives. In 1998, the UN Commission on Human Rights adopted resolution 1998/31, which clearly recognizes that any violation of the fundamental principle of equality or any other discrimination or other negative differential treatment of persons with disabilities inconsistent with the United Nations Standard Rules is an infringement of the human rights of persons with disabilities. It encouraged all human rights treaty- monitoring bodies to monitor the compliance of nation-states with their commitments under human rights instruments to ensure the rights of persons with disabilities. Though expectations from this resolution were high, concerns were present when the commission met two years later. As a result, the commission adopted another resolution asking the UN High Commissioner for Human Rights to examine measures to strengthen the protection and monitoring of the human rights of persons with disabilities.

The incorporation of disability-specific policies within broader human rights instruments, combined with instruments specifically targeting persons with disabilities, has led to the creation of the UN Ad Hoc Committee to consider a Convention on the Rights of Disabled Persons. This represents a movement toward a legally binding human rights instrument for states that ratify it, as opposed to the Declaration on the Rights of Disabled Persons, which was not legally binding.

Nevertheless, the movement toward such a convention can be attributed in part to the original declaration.

*—Scott Brown*

***See also*** United Nations; United Nations Disability Convention; United Nations Standard Rules.

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## UNITED NATIONS DISABILITY CONVENTION

Human rights are basic rights to which every human being is entitled irrespective of age, merit, sex, race, disability, or any other status. Human rights cannot be given or taken away by governments or other entities. They cannot be gained through status or merit nor can they be lost through "inhuman," "deviant," or criminal behavior. Human rights contain the moral values on which modern societies that believe in peace are founded. This is why we often find them in the constitution or some other fundamental legal source of a country. While the history of human rights is much longer, the most affluent period of human rights policy and law began after World War II with the establishment of the United Nations (UN). Human rights are one of the core values mentioned in the Charter of the United Nations and are the topic of one of the first legal instruments adopted by the United Nations, the Universal Declaration of Human Rights of 1948.

The development of UN human rights policy and law is a direct answer to the atrocities of German national socialism during World War II. Since disabled persons were one of the groups victimized by Nazi elimination programs, human rights are an important subject to disability for historical reasons. However, during the first three decades of international human rights law and policy disabled persons were invisible citizens. None of the core UN human rights instruments that were adopted during this time address the situation of disabled persons. Despite the fact that more than 600 million people, or approximately 10 percent of the world's population, have a disability, UN human rights discourse neglected and ignored persons with disabilities. Vice versa, in disability policy human rights were not an issue for a long time. Disability was treated as an issue of medical rehabilitation and welfare policy, issues that also were not regarded as human rights issues during the first decades. Similarly, it was ignored that two-thirds of disabled persons live in developing countries and that the link between poverty and disability is direct and strong. And while many disabled persons live in institutions under conditions that are overt examples of cruel, inhuman, and degrading treatment, they were not seen as victims of human rights violations but as victims of their own personal tragedy caused by their impairments. Neither was the situation of disabled women, who are at a much higher risk of sexual violence and exploitation, dealt with in a human rights context.

A dramatic shift in perspective has taken place over the past two decades from an approach motivated by charity toward the disabled to one based on rights. This shift can be described as a paradigm shift from the medical/individual model of disability to a human rights model. Thus, the issue of human rights has become important to the subject of disability rather recently as a milestone of perspective change. In essence, it means viewing disabled persons not as objects but as subjects. It entails moving away from seeing disabled persons as problems to viewing them as right holders. Importantly, it means locating problems outside the disabled person and looking at the manner in which economic, social, civil, and political processes are structured and whether they accommodate differences, such as disability. With the paradigm shift, a whole set of values that have not yet been applied to disability policy and law become available. Those are the values that underpin human rights: the inestimable dignity of each and every human being, the concept of autonomy and self-determination that demands that the person be placed at the center of all decisions affecting him or her, the inherent equality of all regardless of difference, and the concept of solidarity that requires society to sustain freedom of the person with appropriate social supports.

The shift from a medical/individual model of disability to a human rights perspective is a slow process, but it takes place at every level of modern society. The human rights model of disability has been authoritatively endorsed at the level of the United Nations over the past two decades. The process has led to the current drafting process of a UN treaty on human rights of persons with disabilities. Governments are clearly moving in the direction of the human rights perspective on disability. Recent research shows that more than 40 nation-states in all regions of the world have adopted nondiscrimination or equal opportunity legislation for their disabled citizens. National institutions for the promotion and protection of human rights in many countries take an active interest in disability issues. This helps to bridge the international human rights debate on disability to domestic discourses on disability law and policy reform. Finally, civil society is taking part in the change process. Disability organizations at international and national levels have come to characterize themselves as human rights organizations and have started to use human rights law and human rights mechanisms to foster their cause. Within a short time, disability organizations have become experts in the field, presenting hard facts on human rights violations against disabled persons all over the world, monitoring projects, and becoming actively involved in the drafting process. Disability organizations also have started to involve nongovernmental organizations (NGOs), which are mainstream human rights organizations that have in the past neglected disabled persons.

New human rights laws for disabled persons have emerged at the national as well as at the supranational and international levels. Today, we have binding and nonbinding instruments of international human rights explicitly for disabled persons that have been adopted by the General Assembly of the United Nations as well as by some of the specialized UN organizations, notable among them the International Labour Organization. At the regional level, the Organization of American States (OAS) and the European Union (EU) have passed strong equality legislation on disability. The OAS is the first intergovernmental organization that has a binding human rights treaty on disability. In 1999, the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities (IACPWD) was adopted.

Most of these human rights laws on disability have been adopted during the past two decades. Developments within the main bodies of the United Nations had a strong impact. These started with two resolutions adopted by the General Assembly in the 1970s. These were the 1971 Declaration on the Rights of Mentally Retarded Persons and the 1975 Declaration on the Rights of Disabled Persons. They are the first signs of a shift from a “caring” to a “rights-based” approach. The International Year of Disabled Persons (1981) was followed by the Decade of Disabled Persons (1983–1992), and the guiding policy instrument was the landmark World Programme of Action Concerning Disabled Persons (WPA), adopted in 1982 by the General Assembly. While the first two aims of the WPA reflect a more traditional approach to disability in that they focus on rehabilitation and prevention, the third aim—“equalization of opportunities”—is sign of a slow but sure shift to a human rights–based approach. The WPA has been prolonged and is still the guiding policy instrument on disability within the United Nations today. It is reviewed every five years (1987, 1992, 1997, 2002). The next review is due in 2007. During the Decade of Disabled Persons, two significant studies on human rights and disability were carried out under the auspice of the UN Commission on Human Rights and its subcommission. The first was a report prepared by Erica-Irene A. Daes, who was appointed special rapporteur by the Sub-Commission on Prevention of Discrimination and Protection of Minorities. It was titled *Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder* (1986). The report led to a 1991 resolution titled *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*. These principles have been hailed as a new departure in the perception of the role of law in this area. In recent years, however, this instrument has been criticized by some NGOs.

The second report was prepared by Leandro Despouy, who was also appointed a special rapporteur by the subcommission in 1984. His thoughtful and comprehensive report was titled *Human Rights and Disabled Persons* (1993). The Despouy report chronicles widespread human rights abuses in the area of disability and cites a number of such abuses as causes of disability.

The UN Disability Decade also led to the first efforts to adopt a human rights convention on disability. Such a recommendation was made by a global experts meeting in Stockholm in 1987, which had the mandate to review the WPA. Similarly, the Despouy report emphasized the need for a convention in order to put disabled persons on an equal footing with women, children, or migrant workers. Unlike these groups, who have their own thematic convention, disabled persons were left with what is called soft law. Unlike conventions, which are binding treaties to those member states that have signed and ratified them, declarations and resolutions adopted by the General Assembly have no binding legal effect.

Following these recommendations, Italy in 1987 and Sweden in 1989 proposed the drafting of a convention to the General Assembly, but did not succeed. As an alternative, a different kind of instrument was adopted by the General Assembly. The 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities (StRE) are unbinding soft law, but they have become the guiding principles for disability policy within the United Nations and its member states. They mark a clear shift from the rehabilitation and prevention paradigm to the human rights perspective on disability. Unlike the aforementioned instruments, the StRE have their own monitoring mechanism. A special rapporteur who is supported by a panel of experts, composed of representatives of the main international disability organizations, is assigned the task of monitoring implementation of the StRE. The special rapporteur reports to the Commission on Social Development. The first special rapporteur of the StRE was a disabled person. Bengt Lindqvist of Sweden held office from 1994 to 2002. In 2003, Sheika Hissa K.A. Al-Thani from Qatar was appointed second special rapporteur.

With respect to hard human rights law, disability has been an issue to some extent during the past decade. There are currently seven human rights treaties, which also apply to disabled persons. The two core treaties are the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), both of which were adopted in 1966. Another treaty, adopted in 1984, deals with torture, the Convention against Torture and Other Forms of Cruel, Inhuman or Degrading Treatment and Punishment, whereas the other four treaties deal with specific groups: the 1965 Convention on the Elimination of All Forms of Racial Discrimination (CERD), the 1979 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the 1989 Convention on the Rights of the Child (CRC), and the 1990 International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (CMW). While only the CRC addresses disabled children in the text of the treaty, some of these treaties have been officially interpreted with respect to disabled persons. Such an official interpretation takes place when “General Comments” or “General Recommendations” to these treaties are adopted by their monitoring bodies. Thus, the Comm ittee on CESCR adopted in 1994 General Comment No. 5 on disabled persons. Similarly, the CEDAW Committee mentioned disabled women in two of its general recommendations.

Despite these efforts to include disability into the monitoring process of hard human rights law, disabled persons have remained marginalized. The study *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (Degener and

Quinn 2002a) has shown that treaty-monitoring bodies do not have the resources or the expertise to deal with disability comprehensively and on a general basis. The study, which was commissioned by the High Commissioner for Human Rights, entails a number of recommendations on how to improve the current human rights system with respect to disability. In addition, the need for a new disability rights convention is emphasized.

The idea of a thematic convention has been taken up by many NGOs in recent years again. On the initiative of Mexico, the issue was put on the General Assembly agenda again in 2001. GA Resolution 56/168 of December 19, 2001, established an Ad Hoc Committee

> to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination.

The Ad Hoc Committee, which is open to all UN member states and observers, met twice (2002 and 2003) before it established a working group with the aim of preparing a draft text of a convention, which would be the basis for negotiation by the Ad Hoc Committee. The working group would take into account all previous contributions submitted to the Ad Hoc Committee by states; observers; regional meetings; relevant UN bodies, entities, and agencies; regional commissions and intergovernmental organizations; and civil society including NGOs, national disability and human rights institutions, and independent experts. The working group met in January 2004 for 10 working days and was composed of representatives of 27 member states, 12 NGOs, and 1 National Institute on Human Rights. For the first time in the history of UN law, NGOs had an equal status to member states in the drafting process of a treaty.

The drafting process revealed many yet unresolved issues that have to be negotiated by the member states in future Ad Hoc Committee meetings. How to define disability and disability-based discrimination are examples of these issues. Today, there is no universal definition of disability. The debate about the medical versus social model of disability has raised concern about medically oriented definitions. The well-known World Health Organization (WHO) definition of disability, the ICF (formerly ICIDH), is not seen as appropriate for a legal text by many experts.

The question on how to define disability-based discrimination is closely linked to the equality concept at stake. A more formal equality concept does not tackle all forms of discrimination, that is, not those caused by structural barriers. A more material equality concept would, however, include that governments need to actively take steps to build an inclusive society that accommodates differences. The key words are “reasonable accommodation” (or “effective adjustment”).

Other controversial issues are whether the treaty should include third-generation rights (i.e., the right to development and the duty of international cooperation) or new human rights that are not enumerated in the two core human rights treaties (ICCPR and ICESCR) or others. An example for a new right would be the right to be different. Since disability is closely linked to poverty and two-thirds of all disabled persons live in developing countries, the right to development is endorsed by many member states from developing regions as well as by NGOs. Not surprisingly, member states from richer regions are reluctant to include such a right in a human rights treaty that is not supposed to protect governments but people. Similarly, “new” human rights will not easily find consensus among member states, in times when international politics are in turmoil.

Finally, the implementation and monitoring mechanism of the treaty will cause much debate in the Ad Hoc Committee. The current UN treaty-monitoring system is in the process of reform for various reasons, such as overload of state reporting obligations and lack of resources. Some member states are reluctant to accept yet another treaty-monitoring body. Others prefer the StRE monitoring mechanism with a special rapporteur and a panel of experts. Another, related question is which role national human rights institutions shall play. These institutions are a rather modern development of human rights promotion and implementation, and there are vast differences between countries regarding mandate, independence, and competency of these institutes. There is some likelihood that the issue of monitoring and implementation will be postponed to a later drafting stage, to await the outcome of the reform process.

While many controversial issues remain to be resolved, the fact that a human rights convention for disabled persons is now finally being drafted is a tremendous progress in human rights and disability policy.

*—Theresia Degener and Gerard Quinn*

***See also*** United Nations; United Nations Declaration on the Rights of Disabled Persons; United Nations Standard Rules.

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## UNITED NATIONS DISABILITY STATISTICS

The collection and dissemination of disability statistics, by the United Nations Statistics Division (UNSD), started in the early 1980s in response to an increasing international interest in issues pertaining to disability. For example, 1981 was declared the International Year of Disabled Persons and the period 1983 to 1992 the Decade of Disabled Persons. The World Programme of Action Concerning Disabled Persons was adopted as an international guide for use in monitoring the situation of persons with disabilities. This Programme of Action called on the United Nations to develop, on a continuous basis, suitable systems for the collection and dissemination of information on disability necessary for program evaluation at all levels. UNSD therefore has been collecting and disseminating national disability statistics based on censuses and sample survey results, including administrative records. This has involved a worldwide review of published reports and direct communication with national statistics offices and relevant government ministries.

### FRAMEWORK FOR DATA COLLECTION AND CLASSIFICATION

The United Nations encourages countries to use the conceptual framework of the International Classification of Functioning, Disability, and Health (ICF) for collection and classification of data on disability. The use of the common framework will facilitate the comparability of data at both the national and international levels, which is currently lacking within and among many countries.

In view of the problems of comparability of disability statistics, the international community is currently working to standardize and harmonize concepts and measures, for use in collecting and reporting disability data based on the ICF conceptual framework. The ICF provides a framework that describes health and health-related domains as body functions and structures, activities, and participation. The domains are classified from body, individual, and societal perspectives. The use of the ICF would result in better measures of disability compared to the use of strictly a severe impairment model. The ICF is multidimensional and has multiple domains and as such presents a framework to collect and present data on impairments, activity limitations, and participation restrictions as well as on the role of the environment. It places disability on a continuum of health with established thresholds for defining decrements of health that constitute disability. It also recognizes the impact of the environment on levels of functioning.

In the "Guidelines and Principles for the Development of Disability Statistics" (United Nations 2001), it is recommended that the ICF be the basis for defining the population with disabilities, developing questions, and classifying the data resulting from such measurements. Before the ICF was developed, the framework and terminology of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) were recommended so as to harmonize concepts used in disability measurement and classification.

## THE UNITED NATIONS DISABILITY DATABASE

The United Nations Disability Database (DISTAT) is meant to promote wider dissemination and use of disability statistics. This database apart from providing statistical data and prevalence rates gives textual information or metadata from surveys and censuses conducted in a number of countries, such as questions used in studies, coverage, and sources of data. Metadata are particularly important in the area of disability statistics because currently different studies use different definitions and concepts of disability as well as conceptually different questions to identify the population with disabilities.

DISTAT-1, which was published in 1988, presents statistics from 63 national studies covering 55 countries. This information is published in the "Disability Statistics Compendium." The database contains national statistics on disability status of the population as well as socioeconomic characteristics of the population with and without disability such as marital status, education, and economic status.

DISTAT-2 shows a relative increase in the number of countries collecting and disseminating data on disability. The 2001 publication has 111 national studies from 78 countries worldwide. Common sources of disability data are censuses and surveys. The majority of countries in Africa and Asia collected disability data through censuses. Only a few countries in the database have statistics on disability that were compiled from administrative records.

## ISSUES OF COMPARABILITY

The major problems in comparing disability prevalence rates among countries and within countries, over time, are the absence of internationally standardized definitions, concepts, classifications, and measures of disability. For example, some countries, which collected disability statistics through surveys, have included relatively detailed questions in the survey instruments that focus on activity limitations and participation restrictions. On the other hand, most countries, which collected data on disability through censuses, focused on persons with severe impairments, such as blindness, deafness, and mental retardation. Prevalence rates calculated on the basis of the two different approaches result in wide variation. Countries using questions based on the latter approach have relatively lower rates compared to countries using the former approach.

This wide disparity among prevalence rates has initiated a debate in the field of disability statistics where some people argue that there is no point in maintaining a database with seemingly incomparable prevalence rates. Others argue that the data serve their purpose by showing how prevalence rates are affected by concepts used and questions asked in various studies. The metadata included in the database therefore help readers to discern the inherent conceptual differences underlying the prevalence rates.

Statistics in DISTAT show wide variations among estimates of the prevalence of disability based on various studies and for different countries because of the use of different concepts and definitions among countries and studies. For example, the disability prevalence rate for Zambia based on the 1990 census was 0.9 compared to 20 percent for the 1996 survey in New Zealand. Methodological differences in the measurement of disability therefore constrain the straightforward comparisons of disability prevalence rates among studies and countries.

## DEVELOPING STANDARD MEASURES OF DISABILITY

Efforts are under way to identify minimum common questions that can be used, by countries, in censuses and sample surveys. In June 2001, the United Nations hosted an international seminar on disability measurement. The purpose of this seminar was to review and assess methods used in data collection activities related to the measurement of disability in national statistical systems and to develop recommendations and priorities. The seminar recommended establishment of a forum called the Washington Group on disability measurement. The objectives of the group are (1) to guide the development of a small set of general disability measures suitable for censuses, national sample surveys, or any other source that will provide basic necessary information on disability worldwide; (2) to recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population censuses or as modules to specialized surveys; and (3) to address the methodological issues associated with the measurement of disability as identified by the group.

The first meeting of the group covered various methodological issues related to disability measurement including purposes of measurement. The group also reviewed the ICF model, disability tables in the United Nations census recommendations, global measures of disability, relationship of global measures to the ICF, the confounding function of assistive device use, cultural practices that influence the nature of the environment or proscribe participation, cultural issues that act as barriers to collecting data, and cross-national comparability of information.

The second meeting discussed a matrix that linked the characteristics of questions on disability to purposes for collecting the data and results of methodological testing of general measures of disability. At the third meeting, it was agreed that disability was multidimensional, therefore it was not possible to ascertain the single “true” disabled person, and therefore different purposes were related to different dimensions of disability. The fourth meeting agreed on a draft set of questions on disability for use in population censuses.

## TRAINING WORKSHOPS

To encourage countries to use the ICF and improve data collection methodologies, UNSD has conducted regional/subregional workshops on disability statistics, one in Africa and the other for the countries in the Economic and Social Council for Western Asia (ESCWA). Apart from covering the sources and uses of disability statistics, the workshops covered the elements and concepts of the ICF as a basis for statistical measurement of disability. This approach encourages the use of common definitions and concepts, which would eventually generate internationally comparable data. In the Economic and Social Commission for Asia and the Pacific (ESCAP) region, they conducted a similar workshop on improving disability data for policy use. The next workshop, on improving disability statistics and measurement, was held in Bangkok, September 2004.

## REGULARIZING INTERNATIONAL DATA COLLECTION

In October 2005, the UNSD will initiate a systematic and regular national collection of basic disability statistics as part of the Demographic Yearbook data collection system.

*—Jeremiah Banda*

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

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## UNITED NATIONS STANDARD RULES

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities have their origin in the passage by the United Nations General Assembly of the World Programme of Action Concerning Disabled Persons on December 3, 1982. The World Programme outlined three goals: the prevention of disability, rehabilitation for persons with disabilities, and the equalization of opportunities for disabled persons. While not abandoning the more traditional efforts regarding disability, its inclusion in the World Programme placed equalization of opportunities on a par with the more traditional concerns. Care was taken to define equality as a parity of opportunities with those of the whole population. This parity was viewed not as a static phenomenon but one that would be fostered and maintained as countries engaged in economic and social development. Thus, the concepts would apply equally to both developing and developed countries.

In December 1992, the General Assembly wanted to continue implementing the World Programme and passed a resolution urging expedited elaboration of standard rules on the equalization of opportunity for persons with disabilities. The Standard Rules were adopted on December 20, 1993. Their purpose was "to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others" (United Nations General Assembly 1993, Resolution 48/96, paragraph 15, p. 8). The Standard Rules, although not compulsory, offered an instrument for policy making and action to persons with disabilities and their organizations, while providing a basis for technical and economic cooperation.

The Standard Rules delineated UN member states' responsibilities in three areas. The first area, preconditions for equal participation, included member state responsibilities to (1) raise awareness, (2) provide effective medical care to persons with disabilities, (3) provide rehabilitation services, and (4) ensure the development and supply of support services, including assistive devices. The next area, target areas for equal participation, comprised the following rules: (5) accessibility, (6) education, (7) employment, (8) income maintenance and social security, (9) family life and personal integrity, (10) culture, (11) recreation and sports, and (12) religion. Rule 7 for employment, for example, stipulated that persons with disabilities must have equal opportunities for productive and gainful employment in the labor market in both rural and urban areas. The final group provided implementation measures for member states on (13) information and research, (14) policy making and planning, (15) legislation, (16) economic policies, (17) coordination of work, (18) organizations of persons with disabilities, (19) personnel training, (20) national monitoring and evaluation of disability programmers in the implementation of the Standard Rules, (21) technical and economic cooperation, and (22) international cooperation.

Member states were urged to establish national coordinating committees to monitor the Standard Rules and to coordinate implementation efforts with organizations of people with disabilities. The rules recommended the establishment of a special rapporteur to monitor the rules at the international level and this feature was implemented. A panel of experts established by nongovernmental organizations (NGOs) consults with the special rapporteur to monitor implementation of the rules.

*—Scott Brown*

***See also*** Developing World; Economic and Social Development; United Nations.

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## UNITED WAY OF AMERICA

The United Way of America (UWA) traces its beginnings back to 1887, when the Charity Organization Society began in Denver, Colorado. While this organization did not provide any direct human service provisions, it did conduct regular fund-raising campaigns for 22 local social service agencies and served as an intermediary between philanthropists and human service agencies. This sort of fund-raising role became the hallmark of what would become the UWA as it continued to develop throughout the twentieth century. By 1974, the UWA raised more than $1 billion in the United States and Canada, becoming the first charity to raise that much money.

In recent years, UWA has sought to evolve from strictly a fund-raising organization to a community empowerment organization. Three factors may have contributed to this evolution. First, widely publicized embezzlement scandals in not-for-profit organizations, including the UWA, have led contributors to demand greater transparency from these organizations. The UWA, however, provides no aggregate information about how much of the total money raised by United Way organizations across the United States goes to programs versus overhead costs. Second, following the terrorist attacks of September 11, 2001, on New York City, individuals and foundations donated large amounts of money to relief organizations such as Red Cross International and the Salvation Army. These contributions were targeted specifically for the victims of September 11 and left little money for other human services and other not-for-profit organizations in America. Finally, as a consequence of the first two factors, new philanthropists wanted to be more involved with agencies and wanted see how these agencies spent their donations.

To this day, as UWA transitions into a community empowerment agency, it maintains its identity as a fund-raising organization. For example, in 2002–2003, the United Way organizations across the United States raised $4.44 billion to target broad-impact areas such as strengthening families, building safe communities, supporting self-sufficiency, supporting vulnerable populations (e.g., people with disabilities and the elderly), and helping youths succeed. During its current transition period, UWA began referring to "member agencies" (i.e., agencies receiving money from the UWA) as "partner agencies." UWA's change in nomenclature from "member agencies" to "partner agencies" hints at the initial actualization of the organization's community empowerment vision.

This vision emerged further through UWA's greater emphasis on program evaluation among partner agencies. Now agencies must demonstrate both a need for program funding through a needs assessment and the program's effectiveness through formative and summative evaluations. To assist with these increased reporting requirements, the agency has created an innovative and informational web page, as well as developed numerous trainings concentrating on empowering social service agencies with greater program evaluation skills. These evaluation skills and the requirements the UWA developed necessitate greater transparency among agencies. Furthermore, once agencies develop the capacity for formal evaluation, they can use those skills to find grants outside the UWA. Indeed, UWA has shown that social service agencies now not only need to do good work, but they must also prove they do good work to remain viable.

*—R. Noam Ostrander*

***See also*** Charity.

**Websites**

United Way of America, http://national.unitedway.org/

## UNIVERSAL DESIGN

*See* Accessibility; Aids for Activities of Daily Living; Assistive Technology; Visitability

## UNIVERSALISM

The word *universalism* is sometimes not found in dictionaries, yet it is in current use. In the sphere of disability, it stands in opposition to an overly specialized perspective that would leave some people as exceptions and in marginalized status. But the term also has a more general meaning, derived from the word *universal*. Here it refers to the totality of reality, to that which extends to the entire collectivity.

The term is employed in the domain of disability to focus attention on the fact that we must above all make social spaces accessible—physical space, educational space, and mental space. As a consequence, it is a matter of reforming society so that it is receptive to the greatest possible number of disabled persons. The phrase "universal design" sums up this vision. The term is then in opposition to a particularist conception that would authorize intervention in social spaces only in the event of this or that specific deficiency. For example, instead of planning for maximum accessibility in the construction of an apartment building—for the entire building (universalism)—provision is made for one or two apartments outfitted for people in wheelchairs (particularism). It is quite clear that it will never be possible to foresee everyone's needs in every case and circumstance. But the very fact of setting accessibility as a goal for the majority of cases lowers the level of difficulty for a very great number of people and precludes handicap, or at least surplus handicap. This is one of the meanings of the word universal, as a synonym for general: what extends to the greatest number. Striving for universalism dictates working on and with the common everyday environment to avoid detours through specialist institutions or social stigmatization. Everything that enables disabled citizens to participate without obstacle in the life of the community must be attempted.

The limitation that has been recognized, that total accessibility cannot be achieved, will assist us in better understanding what *universal* and the doctrine of *universalism* really mean. Universal designates that which extends to the entire universe, to the total reality of the world or of the human collectivity. Apart from the laws of physics (an apple falls in the same way in Beijing as in New York), we may ask whether there are rules that are valid for humanity in its entirety. One could doubtless assert, for example, that some fundamental proscriptions seem common to all societies (the ban against killing, in particular one's kin; the ban against incest; the ban against generalized lying). But we must immediately add that the modalities, boundaries, and sanctions affecting these forbidden areas are extremely diverse. We more often encounter resistant particularisms, deeply anchored in culture, than common norms, customs, and conceptions. This is why it is perhaps better to view universalism in the narrow sense of logicians. They speak of a "universal term," that is, a term understood in its fullest extension, encompassing all the individuals in the category of individuals under consideration. The universal deals with a human group—a set—but not with the whole of humanity.

Philosophy has not always understood the universal in this sense. We should recall the celebrated "Dispute over Universals" that raged in the Middle Ages. Behind the diversity of beings, is there something that can be called "being"? Behind our ideas and the varied forms of what we call beauty, goodness, truth, is there a heaven where ideas of the beautiful, the good, the truthful exist? More recent is the question whether behind the diversity of languages there are laws that apply without exception to the totality of languages. This was the debate between linguists such as Sapir, on the one hand, and Chomsky, on the other, to cite but these two names. The universal, be it ontological, formal, or linguistic, is still being debated. Perhaps the most telling "last word" in the medieval debate was that of the fourteenth-century philosopher William of Ockham, who said, "The universal is an intention of the mind, susceptible of being attributed to a great number of subjects" (*Ordinatio sive scriptum in librum primum Sententiarum*, distinction II, question 6).

In this quick review of meanings of the words *universal* and *universalism*, we should also note the religious signification, Christian in particular, that makes universalism the doctrine of those who believe that all human beings are saved, whatever their religious views and thus without the mediation of Jesus Christ, while mainstream theology affirms that no one is saved without that mediation. Here universalism has a pejorative shading, even though the Christian religion lays claim to a universal calling, addressing all people of all times, to teach them of the promise of universal salvation through Christ. This, it may be noted in passing, is a neat reconciliation between the universal and the particular: Salvation is available to everyone but is mediated by the singular person of Christ.

Last, a more sociological signification for the word *universalism* should be noted. Social or cosmic reality is a whole on which individuals are dependent. In this context, the word emphasizes the social totality that precedes and determines individuals. The universal is primary with respect to the particular; it proceeds as a deduction and is not the result of a kind of induction from particulars toward a general level. Societies that have been called holistic operate on the basis of this primacy of the totality, of what dominates individuals and constitutes the common law to which they must submit. This sense of the word does not characterize modern societies, in which the point of departure is always individuals, their rights and their claims. Yet, on the other hand, our contemporary societies are borne along by the movement called globalization. Here we cannot analyze the different meanings and different levels of globalization. It will suffice to note that one of its aspects is the forcible application, often initiated by the countries most powerful in terms of demography and economy, of canons, standards, styles, technologies, which tend to be imposed on everyone, everywhere. The English language, to take a single example, is progressively becoming the universal language, the one in which the inhabitants of the culturally most remote countries will communicate, the one that will serve as the medium of exchange in all four corners of the world. This globalization is realized, by the very coercive nature of things, to the detriment, greater or lesser, of distinctive collective identities and ancestral traditions.

To summarize, the word *universalism* can have many meanings (religion claiming to address all humans; a doctrine that views reality as a totality, preceding all individuals; a philosophy in search of universals; a science that seeks laws without exception; a culture that imposes itself on other, earlier cultures), but it always comes back to the question of knowing whether we should focus on singularities in order to move to a higher level or posit a universal that subsumes these singularities. The problem of the universal will always be that of the relationship between the particular, always certifiable, and a superior level that transcends it, one established by the mind but not empirical.

In this general, abstract question, it is important to distinguish among a multitude of concepts. What is constant is not fully universal, because a constant is not susceptible, at a given time, to exceptions, although it does not rule out surprises. The general is not a synonym for the universal, because generality is the product of a statistical, probabilistic perspective and cannot claim to be valid for the whole of reality or society. Nor is global a synonym for universal, since globalization refers to the international without our being able to predict its universality.

This discursive tour of semantics, in the context of an encyclopedia devoted to disability, is not intended to make a full exposition of the problems of the universal. What stands out is that the universal has never been realized and never will. Its role is to establish, as some philosophers put it, a "horizon," that is, a kind of ideal in front of us that we must not drop from sight, one with which we must constantly concern ourselves without getting lost in the restrictive, sequestering detail of particularist views and special interests. The status of the universal, and consequently that which must sustain universalism, stems from a double necessity: to refuse to believe that the universal is something that has already been achieved, and to refuse to renounce attaining it. This only appears to be paradoxical. In fact, anyone who claimed to have realized the universal would only have imposed his or her particularism on others. We have seen this in colonialism; we see it now in the standards of various technologies. It was seen in the Marxist ideology that sought to subject the world; it is seen now in the pretentions of the cultures of developed countries to regulate, and thus to reduce, other cultures (under the cover of universal human rights, nonetheless indispensable, or under the cover of democracy on the American, French, or British model). On the other hand, anyone who renounces the universal as goal opens the way to all kinds of excess, all kinds of cowardly tolerance and imprisonment in archaism. This is evident when no one speaks to the exploitation of women by certain religions, or when one accords this or that fanaticism the same respect and rights as the defense of human dignity, or when one fails to affirm that there are rights to be recognized for all humans, in their simple capacity as human beings.

To return, in conclusion, to the specific problem of disabled people, it seems important to claim that all of society be open to them and that the same real rights and responsibilities be recognized for them. At the same time, it is equally important not to neglect to insist that certain specific measures be taken, in particular for certain onerous or rare deficiencies, for instance. Aiming for universality in these measures and arrangements prevents us from siding with any one category of disadvantaged citizens, but believing that generalized accessibility is in itself sufficient would leave us the victims of illusion, since this would also entail abandoning certain people. Universalism remains a horizon, a perspective, a stimulating goal. The worst that could happen to it would be to believe that it is no longer worth pursuing.

*—Henri-Jacques Stiker*

***See also*** Globalization; Inclusion and Exclusion; Values.

## UNIVERSITY AND COLLEGE EDUCATION

*See* Education, College and University

## UPIAS

*See* Union of the Physically Impaired against Segregation

## URBANIZATION

Most people in the Western world live in cities, and increasingly people living in developing countries are moving to urban areas. In this urbanizing world, the majority of job opportunities, access to goods and services, entertainment, and other functions are found in cities. Since the late nineteenth century, the city has been viewed as a source of social alienation and anomie, characterized by fragmentation and the dissolution of traditional (often rural) social networks. Urbanization over the course of the twentieth century has witnessed, some commentators suggest, the emergence of unsustainable cities and modes of living. In this view, the city is conceived of as dystopia, increasingly plagued by environmental pollution, poor health for its inhabitants, social polarization between rich and poor neighborhoods, land degradation, and crime.

Such observations resonate with many disabled people whose experiences of urban environments are far from positive and are conditioned, in part, by their difficulties in moving about and getting access to places in the city. From sidewalks cluttered with street furniture such as benches and other physical obstacles to the absence of clear signage, urban areas are constructed in ways that do not contribute to the mobility of disabled people. In this respect, urban areas may be regarded as reproducing inequalities between disabled and nondisabled people (see Allen, Milner, and Price 2002; Imrie 1996, 2005; Imrie and Hall 2001). For some, urbanization is characterized by a design "apartheid" in which the design of the built environment actively disables disabled people, which, in turn, prevents them from accessing facilities such as shops, parks, transport, and dwellings without help.

For instance, common experiences of the effects of urbanization for disabled people who use wheelchairs include the following: ramps that are installed but prove to be too steep to be used safely, dropped curbs that are present but are badly placed; a government office on the second floor of a building but with no elevator; a shopping center without a disabled person's toilet; streets without clear signage or tactile walkways or means of way finding; a "wheelchair friendly" restaurant that has two steps at the entrance; a museum that has ramps and a disabled person's toilet but no elevator, so that wheelchair users can visit only the ground floor; and a municipal building with a ramp that is so steep that most wheelchair users prefer to go down it backwards. Such features are commonplace, so much so that they are broadly accepted by the population as a whole as normal and inevitable parts of everyday life.

An important theme in the study of the city and disability is that the disabling nature of the urban built environment is, in part, related to the purposive plans and policies of urban planners who have the responsibility for the production of cities. Urbanization, as product and process, takes shape through the context of the values of and actions by professionals, who, in Western societies, have rarely acknowledged disabled people and their needs. Rather, the urban subject—those whom planners seek to plan for—is conceived of as an abstract generalization and is rarely thought of in terms of differences in relation to the body, ethnicity, gender, or sexuality. Disability, as a descriptor or category of social reality, has rarely figured in architectural or planning education, and, as Greed (1999:270) suggested, the subcultures of design, property, and construction professionals are resistant to change in not permitting "much space for wider strategic and holistic approaches to . . . social factors."

While building regulators and officials have some scope to influence the form of the urban environment, the physical shape of urbanization is largely determined by the values and practices of property developers and builders. The values of property professionals are usually impervious to disability, and they tend to perpetuate problematical, and erroneous, assumptions about disabled people in relation to the design of their buildings. Professionals in the building industry continue to argue that there is insufficient demand by disabled people for an accessible built environment and that the provision of accessible buildings is prohibitively expensive. While both assumptions have been shown to be false, they persist as blocks to a progressive urbanism characterized by barrier-free environments.

Disabled people's experiences of urbanization are not just related to the form of the physical environment but are also determined, in part, by what Ellin (1996:252) referred to as the city with "a confluence of meanings rather than functions." Thus, many of the symbols and images of the city do not provide disabled people with the means for self-expression or autonomous behavior, but rather encourage a retreat into private spaces (or out of sight and off the streets). For instance, steps into shops or nightclubs not only prevent a wheelchair user ease of access to the facility but also create a context of dependence on others for assistance while transmitting a sense that those without "able" limbs, or independent use of body parts, are unwelcome. Likewise, for many wheelchair users, "back door treatment" is the norm, in which the entrance to a building is often through side doors, back doors, or everywhere but the front. In this sense, the built environment is marked out by spatial signifiers or symbols of difference that serve, potentially, to separate disabled people from their "normal" counterparts (see Hawkesworth 2001).

What are the possibilities for an urbanization that will facilitate livable places for disabled people? Most forms of urban renewal are characterized by a property-based approach to development, in which people-based issues are sidelined. However, recent debates about the "good city" revolve around principles of new urbanism, in which it is suggested that cities should be constructed as compact spaces with an emphasis on accessible, safe, and inclusive spaces. Its emphasis on small-scale, localized forms of urbanization, based on diverse neighborhoods and human scales of interaction, provides potential for crafting urban spaces based on human need rather than profit. In this respect, the people-centered design philosophy of new urbanism, while not a panacea, gives some hope that urban renewal will be attentive to some of the needs of disabled people (see Talen 1999).

Its translation into the lived realities of urbanization will depend, in part, on shifts in social attitudes and practices in relation to disability and a greater willingness of building professionals and others to recognize and respond to disabled people's intrinsic rights to access and mobility and movement in cities. In the United States and the United Kingdom, legislation is an important part of requiring much more provision of accessibility features than was hitherto the case, and city governments are adopting diversity agendas that require urban renewal policies and plans to incorporate the needs of disabled people. For instance, in the United Kingdom, all new dwellings have to be constructed to minimum levels of accessibility, while in the United States, many state and local governments have adopted ordinances that require developers to provide access in single-family dwellings. While legal measures, in and of themselves, cannot guarantee barrier-free environments, they provide the possibilities for a new era of urbanization characterized by the breakup of social and physical barriers in cities.

*—Rob Imrie*

***See also*** Accessibility; Accessibility Codes and Standards; Fair Housing Act Amendments of 1988 (United States); Health Care and Disability.

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## URINARY TRACT INFECTION IN SPINAL CORD–DISABLED PATIENTS

Urinary tract infection (UTI) refers to infectious diseases of the kidneys (pyelonephritis), ureters, bladder (cystitis), and urethra (urethritis). The most common way for bacteria to enter the urinary tract is through an ascending route from the genitourinary region through the urethra, counter to the usual flow of urine. Thus, the typical causes are bacteria from the gastrointestinal tract and vagina given their close proximity to the urethra.

Patients with disabilities are particularly at risk for UTI. The most notable group includes individuals with spinal cord dysfunction (SCD) including spinal cord injury and multiple sclerosis. Important complications of the urinary tract include kidney failure and infection. They have traditionally been ranked as leading causes of death in those affected with SCD. Prior to the early 1990s, diseases of the urinary tract accounted for two-thirds of deaths in this group of people. While medical care of patients with SCD has dramatically improved over the past one to two decades, UTI still ranks as the second most common medical complication. Increasing disability in patients with SCD increases the risk of UTI whereby 75 percent of patients with paraplegia and over 85 percent with quadriplegia experience UTI. As a result of recurrent UTI among patients with SCD, the medical costs are substantial; rehospitalization for complications can cost in excess of $12,000.

The basis for increased rates of UTI among patients with SCD is principally two-fold: (1) the decreased ability to completely empty urine from the bladder, producing static urine where even small numbers of contaminating bacteria can replicate, and (2) the requirement for either intermittent or indwelling catheterization for drainage of the urine, each of which can provide direct access for bacteria to the urinary tract. The use of catheters has dramatically improved the care of patients with SCD; however, catheters also substantially increase the risk of UTI especially when indwelling catheters are employed. Undoubtedly, antibiotics have had a major impact on treatment of serious UTI in patients with SCD, decreasing morbidity and mortality. Unfortunately, the diagnosis and the appropriate treatment for UTI in people with SCD are exceptionally difficult because individuals can have bacteria persist in their bladders without disease and can have dramatic cases of infection without fever or pain (as a result of their spinal cord injury). Antibiotics given prophylactically decrease the persistence of bacteria in the urine and delay the time until the development of a UTI; however, patients on prophylaxis still experience the same number of bona fide infections. The constant use of antibiotics also increases the occurrence of infections with antibiotic-resistant bacteria, a public health challenge.

In the future, medical advances may produce tests that differentiate true UTI from persistent bacteria in the urine. Examples of preventive therapies include colonization of the bladder with benign bacteria that block the disease-causing agents from gaining a foothold and vaccination against the most important causes of UTI. Improvements in rehabilitation may improve patients' sensation and thus their ability to appreciate pain and other symptoms of urinary infection while improving bladder function, decreasing their dependence on catheterization.

*—Patrick C. Seed*

***See also*** Bladder Control; Multiple Sclerosis; Spinal Cord Injury.

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# V

## VALLATHOL (1878–1958)

*Indian poet, essayist, and cultural architect*

Vallathol Narayan Menon was a South Indian poet, essayist, and major contributor to the renaissance of the Malayalam language and culture. He lost much of his hearing as a young man. In his early 30s, he wrote *Badhira Vilapam* (*Lament of a Deaf Person*) expressing a sense of loss and deprivation as he became deaf. Vallathol had earlier translated Valmiki's *Ramayana* into Malayalam, and in his 70s he completed a translation of the *Rig Veda*. His eight-volume "Bouquet of Books" appeared successively from 1917 to 1970, after his death.

The dream of his mature years was to initiate the revival of Kathakali dance drama. He opened the Kerala *Kalamandalam* in 1930 to teach all the classical arts of Kerala, and his cultural crusade was recognized and honored after India's independence. The American danseuse La Meri (1941:27) studied gestural communication in Kerala in the 1930s and noted that "Vallathol, the great poet who has revived the Kathakali form in Malabar, is deaf and so converses entirely by means of the beautiful gesture-language of India."

*—Kumur B. Selim*

***See also*** Dance; Experience of Disability: India; Poetry; Sign Poetry.

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## VALUES

Any discussion of disability as a social phenomenon must also include the issue of values. Values are a set of principles or standards concerning the relative worth, utility, or importance of things and experiences. Often values appear in everyday life as judgments or points of view on behaviors and social problems. Disability as a category or a label is not value neutral. The term itself—*dis*-ability—implies a value judgment. All individuals vary in the skills and abilities they possess. Yet for a whole class of individuals, society considers their physical limitations to be a defining characteristic. Therefore, discussions of disability must be mindful of how values shape our attitudes and actions toward those with disability in society.

Social values are significant for how we, as a society, interact with, think of, and provide services for individuals with disabilities. However, the experience of disability is highly variable. The ways that individuals value (or devalue) their experience of disability is dependent on a wide range of factors. These factors include the age at onset of disability, the cause of their limitation, its visibility to others, and the degree to which it poses functional challenges or impediments in their daily lives. Each factor influences the value one places on his or her own life as well as the value of his or her life to others. Beyond individual values, society also values (or devalues) disability. Society's values are reflected in public policy initiatives and in the physical and social environments. This entry highlights the importance of values, as they influence behaviors and actions at both an individual and social level.

A person may experience disability at any point in life. The point of onset of disability may have a profound effect on how individuals think about and value their lives and their disability. Individuals who experience the onset of disability later in life must address their loss of physical function. Even more, they may perceive a loss of self. People who experience the onset of disability during adulthood often grapple with the loss of physical function and reconcile their current abilities with their ideas about who they were and the role they served. The ability to perform social roles such as wife, father, or employee might be limited by the physical experience of disability. This inability to fulfill their familiar roles may lead people not only to resent their disability but also to regard themselves as less valuable members of society.

Those who experience the onset of disability at an early age are faced with another set of social and personal challenges. Children may be unaware of their disability and how others perceive them. Many children without disability are not taught how to talk about disability. Rather than acknowledging children's curiosity, many parents hush them when they inquire about another child's disability in public, furthering the stigma that disability is something to be devalued. Furthermore, because children do not know what/how to talk about disability and difference, it makes social interactions all the more awkward for children with disabilities. As children age, they may realize that they do some things differently from their peers or cannot participate in some activities. As a result, they may see themselves as less socially valued. Alternatively, children may be able to incorporate their disability into their self-concept or identity from the start, thus avoiding the difficult transition experienced by many adults.

The visibility of one's disability could also play a role in how individuals think about and value their disability. Those with more visible disabilities—paralysis, amputeeism, severe forms of mental retardation—may experience more prejudice than do those whose disabilities are hidden, such as chronic pain. Alternatively, those with hidden disabilities may experience insensitive treatment from individuals who, unaware of their disability, do not anticipate the need for accommodation. More visible disabling conditions create an opportunity for the general public to pass judgment on and label those who experience disability. These judgments and associated labels indicate how society values disability.

Our discussion here focuses on the American experience of disability; however, how disability is valued is context dependent. The experience of disability depends on the social, cultural, economic, and political context in which a person lives, as well as the norms and beliefs associated with these dimensions. For example, some Middle-Eastern Muslim societies view those with mental retardation as "saints." Likewise, the economic circumstances of an area can influence social perceptions of disability. In a hunter-gatherer society, physical disabilities may be seen as exceptionally detrimental to the well-being of the tribe. Overall, there are very different cultural reactions toward those with disability. These cultural reactions shape the values of a society and thus influence the way those with disability are labeled and cared for in society.

The words that we use to talk about a phenomenon not only describe it but also shape the nature of the phenomenon itself. Language reflects the social values of the times. Today, many use *disability* and *impairment* interchangeably, yet they have profoundly different indications for how we are to think about the very nature of the state itself. The World Health Organization (WHO) has tried to reconcile these definitions in its International Classification of Impairments, Disabilities, and Handicaps (1980) and more recently in its International Classification of Functioning (2001). *Impairment* refers to problems in physical function, loss, or abnormality. *Disability* occurs when there is a mismatch between the physical capabilities of a person and the demands of the environment. In other words, the environment does not accommodate the limitation or inability of the person to perform such tasks as boarding a public bus or entering some buildings, creating "disability." Therefore, the WHO definition suggests that disability should not be viewed as a problem located solely within the individual, but rather as a problem in how society and the physical environment are structured.

Disability rights activists have long argued this point. They suggest that disability is a condition created by society and how it is arranged. They reject that disability is a personal inability to perform tasks because of a physical or mental deviation from "normal." These activists see disability as the result of an environment that is not accepting or accessible to people with abilities that stray from "normal." The concept of universal design taps into this notion. Universal design refers to an architectural approach that is accepting of all variants of physical ability. Stairs are replaced by gradual inclines; floors are neither so smooth to make it difficult to walk nor so coarse that it impedes mobility in a wheelchair. Disability activists' social model of disability favors environmental change rather than personal change. That is, environments should be accessible to all people, regardless of their physical and mental levels of function. This principle views disability as value neutral or even value added. Overall, this type of environment would better the lives of those with disability as well as those without disability.

Along with shifting the responsibility of disability away from the individual and toward society by altering the physical environment, changing language is also important in valuing disability. To say an individual "suffers" from deafness or mental retardation is to make a judgment about the worth and value of these experiences, and of those individuals who have such conditions. The importance of language in shaping the meaning and worth of disability has been emphasized by the "person first" campaign within the disability rights movement. This movement has argued that the term *disabled person* should be replaced by *person with a disability.* That is, the former term emphasizes disability as a master status—as the most salient and defining characteristic of an individual—whereas the latter stresses that people with disability are first and foremost *people* and that their disability is only one aspect of their personhood. This person-first campaign has empowered those with disability while at the same time raising their value in society. However, disability rights activists have launched a backlash against the person-first language that has come to permeate the field of disability studies on the basis that it undermines the importance of their disabilities to their lives. This movement argues that person-first language is a politically correct approach instituted by individuals who claim to speak for those with disability. Both sides of this debate, however, provide evidence that increased social value has been placed on disability. In turn, this is reflected in current public policy initiatives.

At a societal level, we may infer social values by analyzing public policy about disability. A glance at disability policy in the United States, as well as in other developed countries, depicts a formidable change in the way people with disability have been valued in society over the past century. In the past hundred years, we have moved from a society that promoted the principles of eugenics to one that incorporates people with disabilities more fully in social life. Again, this discussion emphasizes the American experience; however, it is, in many ways, typical of most developed Western countries' experience.

Public policy is strongly shaped by social values, and disability policy is no exception. In the United States, we can trace the evolution of social policy and social values regarding those with disabilities. Disability has been a stigmatizing characteristic throughout history, and people with disability have experienced oppression to various degrees. This oppression has resulted from and been legitimized by social policy and has ranged from eugenically driven attempts to eliminate those with disability from our society to extremely paternalistic attempts to protect those with disabilities from the larger society.

Disability was strongly devalued by society in the late nineteenth and early twentieth centuries. Individuals with disabilities were viewed as deviants to be kept away from society at best, as a fatal flaw in society that required elimination at the worst. We have moved past this phase in our history. Beginning in the 1950s but coming to a head in the early 1970s, parents, professionals, and disability rights activists began to demand policy changes. In the 1950s, parents began to form organizations around the specific disability categories that affected their children. These groups soon became instrumental in advocating for disability rights, most particularly for quality schooling for children with disabilities.

Throughout the 1960s, Congress expanded programs to fund education, rehabilitation, and social services for those with disabilities. During 1975, two crucial pieces of legislation were passed: the Education for All Handicapped Children Act (EHCA) and the Developmentally Disabled Assistance and Bill of Rights Act (DD Act). The EHCA guaranteed all school-age children with disabling conditions the right to a free and appropriate public education.

Though these policy advancements indicated a dramatic shift in our social conception of disability, the most significant legislative event was the 1990 passage of the Americans with Disabilities Act (ADA). This act formally outlawed all discrimination on the basis of disability, including discrimination in the workplace, in businesses, schools, transportation, and the like. Furthermore, it mandated, when economically feasible, that public spaces be made accessible to those with mental and physical disabilities. This sweeping legislation was the most profound indication that our society no longer found it appropriate to marginalize those individuals with disabilities. At the heart of the ADA was the aim of making all dimensions of public life available to those individuals with disability and to allow them to participate fully in society.

This is not to imply that the ADA has alleviated all forms of discrimination, nor does it suggest that, as a society, we have eliminated all stigma associated with disability. The ADA is worded so as to allow significant discretion in its interpretation. Still, a trend toward inclusion permeates current policy. This legislative shift is a further indication that society has become more accepting of disability. Rather than deliberately excluding individuals with disabilities from the public sphere of everyday life, the ADA protects the rights of people with disabilities to live their lives fully without environmentally imposed limitation.

Values, then, are clearly significant for how we, as a society, interact with, think about, and provide services for individuals with disabilities. Moreover, these social values play an important role in shaping the ways that individuals value (or devalue) their experience of disability. Culture also influences the social valuation of disability, and the ways in which these values translate into public policy and environmental change. During the past century, society has undergone a notable shift in the ways we value disability. We have moved from a society that has oppressed and hidden those with disabilities to a society that is more accepting of the disability experience. This shift in values has been reflected by a shift in public policy. Moreover, the personal experience and valuation of disability have likely changed as well over this period. People with disabilities are able to accept their disabilities and live in the public sphere in a way that earlier generations of people with disabilities were not. People with disabilities are now legally afforded educational and employment opportunities that were, in earlier times, systematically denied to them. Changes in policy and social values, in turn, have altered how individuals evaluate their bodies and their mental or physical abilities. More accommodating environments and a social awareness of the diversity of human abilities has begun to reduce the stigma associated with the disability experience for many. In the future, these social values may continue to provide those with physical or mental disabilities the ability to live life fully.

*—Maryhelen D'Ottavi and*
*Carrie E. Spearin*

***See also*** Empowerment and Emancipation; Disability Policy: United States; People First.®

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## VAN GOGH, VINCENT (1853–1890)

*Dutch artist*

Vincent van Gogh was born in Zundert, the Netherlands. At age 27, after years spent in various failed professions, he decided to become an artist with the help of his brother Theo. In 1886, he moved to Paris to live with Theo, and there he met the Impressionist group. His palette lightened, and in 1888 he left Paris for Arles, a small, picturesque town in the south of France where he achieved full maturity as an artist. In 1888, he had the first of several epileptic seizures and mutilated his ear by severing an artery. In 1889, he voluntarily stayed at St. Remy, a mental hospital, where he was treated for seizures. In the last months of his life, he stayed at Auvers-sur-Oise near Paris and was treated by Dr. Gachet, who was willing to be paid in paintings. Also diagnosed with chronic sunstroke and intoxication from turpentine and absinthe, van Gogh died at age 37 by his own hand. He sold only one painting during his lifetime, yet left behind 1,600 paintings and drawings. His letters to Theo reveal the depression and elation of Vincent's life as a painter as well as his gentleness, love of humanity, and clarity of thought about his art.

*—Katherine Sherwood*

## VAN LANDEGHEM, HYPPOLITE (fl. 1865)

*European disability activist*

The blind polemicist Hyppolite (sometimes given as Hippolyte) Van Landeghem published ca. 1863 a long denunciation of the "exile system" that "immured" blind youths in segregated schools (he had spent 12 years in one), wasting huge sums on buildings and "salaries of sighted officials, who are totally unfit to educate the blind" while the number of blind people thus (mis)educated was tiny compared with those for whom nothing was available. Van Landeghem keenly advocated home education, yet he was severely critical of William Moon's Society for Teaching the Blind at their own homes and of other evangelistic organizations using embossed books: "Restore to a blind man his social rights, give him an opportunity of achieving his own support," and only then expect him to attend to religion (Van Landeghem 1863). He railed against fund-raising to teach blind people in Asia, when 27,000 blind people in the United Kingdom lacked education or employment. Van Landeghem advised blind people to dispense with guides and walk the streets by themselves, after trying this himself for two years in London. A book by Mrs. Hippolyte Van Landeghem (1865) reinforced the message with life histories of notable blind people from Europe and America.

*—Kumur B. Selim*

***See also*** Blind, History of the.

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## VEECK, BILL (1914–1986)

*American businessman*

Bill Veeck was one of the greatest innovators of baseball management while serving as owner and/or manager of four different major league baseball teams. The son of a sportswriter turned president of the Chicago Cubs, Veeck began working in baseball at age 11 as a ticket seller, vendor, and groundskeeper. He was famous for introducing gimmicks and marketing stunts including the exploding scoreboard, giving away live animals, scheduling morning games for late-shift workers, having marriage ceremonies on home plate, and his famous Grandstand Managers Day where he asked fans holding placards with a "yes" or "no" to vote on whether to hit, bunt, steal, or other managerial choices. He once presented his manager with a huge birthday cake, out of which popped a much-needed left-handed pitcher. In 1952, Veeck arranged for midget Eddie Gaedel to bat for the St. Louis Browns. Veeck also introduced innovations that became part of baseball management; shortly after taking over the Chicago White Sox he created a media event by setting up an office in a hotel lobby and purchasing contracts from players from other clubs, introducing free agency into major league baseball.

While still part owner of the Brewers, Veeck served three years in World War II in the U.S. Marines. An accident cost him his right foot and, despite 36 operations over the rest of his life, he lost his leg as well. Veeck never let the loss limit his work, and in one of his most creative stunts, in 1976 Veeck staged a bicentennial-inspired Spirit of '76 parade on Opening Day—with himself as the peg-legged fifer.

Veeck is also credited for being a major management force toward integrating major league sports. Before entering the military, Veeck secured backing to buy the Philadelphia Phillies and had a plan to stock the club with stars from the Negro leagues, a plan rejected by the baseball commissioner. However, after the war, in 1947, Veeck integrated the American League by hiring Larry Doby, weeks after Jackie Robinson joined the Brooklyn Dodgers of the National League.

*—Joseph A. Flaherty*

***See also*** Sports and Disability.

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## VESTIBULAR DISORDERS

Vestibular disorders refer to a group of problems affecting an individual's sense of balance. Dizziness, vertigo, unsteadiness, light-headedness, and disequilibrium are some of the words people may use to describe a feeling of imbalance. Most vestibular disorders are transient and improve with observation and occasional symptomatic treatment. However, in rare instances, imbalance can be a sign of a potentially serious disorder.

The vestibular system is composed of a set of balance organs within each inner ear (collectively referred to as the *labyrinth*), nerves connecting the labyrinth to the brain, and various nuclei within the brainstem, cerebellum, and cerebral cortex that interconnect at multiple levels. The brain uses the input from both labyrinths to help determine one's position in space. If there is a disturbance in input from one side, the asymmetry may be perceived as imbalance. Vision, *proprioception* (the ability to sense one's position in space with the eyes closed), and *central integration* (the processing by the brain of input from the eyes, ears, head, trunk, and extremities into a meaningful whole) also significantly influence balance and are considered part of the vestibular system.

In addressing complaints of dizziness, physicians must first consider whether symptoms arise from true vestibular dysfunction or from a more general medical cause. Diabetes, cardiac arrhythmia, and hypotension are some of the many disorders that can cause dizziness or exacerbate a true vestibular disorder. Complaints of frank *vertigo* (the illusion of a turning motion) or the presence of *nystagmus* (an involuntary linear or rotary movement of the eye) on physical exam denote a vestibular problem. Once a vestibular lesion is suspected, a distinction is then made as to whether the site of the lesion is inside the brain or brainstem (*central*) or outside (*peripheral*). The pattern of onset (acute, subacute, progressive, intermittent), the duration of dizziness (seconds, minutes, hours, days), and associated signs and symptoms (hearing loss, tinnitus, head trauma) can further help to localize the lesion.

The diagnosis of most vestibular disorders is through a careful history and physical exam. A neurological exam is essential to identify disturbances in gait and balance and to uncover the presence of cranial nerve neuropathies, which may help to localize a lesion. The head-and-neck exam is focused on identifying the presence and direction of nystagmus and ruling out evidence of otologic pathology (a draining ear, mass, membrane perforation), which may suggest the cause of the problem. Once a differential diagnosis is established, additional testing such as an electronystagmogram (ENG) can then help to rule in or out a specific diagnosis.

Vestibular dysfunction can be caused by vascular events (migraine, stroke, hypotension), infections (labyrinthitis, otitis, mastoiditis), trauma to the temporal bone, autoimmune disorders (Cogan syndrome), metabolic derangements (diabetes, hypothyroidism), or neoplasms (vestibular schwannomas). Some diseases are idiopathic, such as benign positional vertigo (BPV) and Meniere's disease. Common peripheral vestibular disorders include BPV, Meniere's disease, vestibular neuronitis, acoustic neuromas, and labyrinthitis. Central vestibular disorders include migraine, multiple sclerosis, vascular insufficiency, cerebellar dysfunction, and Arnold-Chiari malformation, among others.

*—John Damrose and*
*Hamid R. Djalilian*

***See also*** Diabetes; Gait Analysis; Multiple Sclerosis; Neurological Impairments and Nervous Disorders; Stroke.

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## VETERANS

War has been credited as an impetus for change. Within many fields, war has been responsible for new methods, materials, and organizations. Clearly, war has been responsible for a mass of injuries that result in numbers of disabled people but has also acted as a catalyst to improve medical knowledge and techniques in the treatment of disability. During war, many different types of therapy have been developed that have primarily ensured the survival of those injured and also have produced innovative methods of treatment that have ensured a better quality of life for disabled people.

While wars in the previous centuries produced disabled men, World War I is the one noted for creating enormous numbers of disabled men. Estimates suggest that at least 1.5 million people were left with some sort of disability. Physical and sensory disabilities were augmented by those suffering from neurasthenia or shell shock. Innovations in medicine such as orthopedic surgery ensured that permanent disability was lessened, and often servicemen were made well enough to return to the battlefield and risk being killed once more.

Those who returned home with a disability became the government's responsibility; the Ministry of Pensions was established in 1917. In the United States after the war, three different agencies administered veteran's benefits: the Veterans Bureau, the Bureau of Pensions of the Interior Department, and the National Home for Disabled Volunteer Soldiers. Programs included compensation, insurance, and vocational rehabilitation. Advocate agencies in the United Kingdom such as the British Legion and the Returned Sailors and Soldiers Imperial League of Australia were established in 1921 and 1916, respectively, to look after the interests of disabled ex-servicemen. There were constant disagreements over pensions for disabled ex-servicemen, and the British government was criticized by organizations such as the British Legion for their lack of fiscal support. The United States established its own Veterans Administration in 1930, although there had been provision for disabled veterans since 1776 when, to increase enlistment for the Revolutionary War, pensions were offered to anyone who was disabled in the fighting.

Although World War II was not as devastating in terms of numbers killed as World War I, numbers of people were disabled as a result of the war. As the fighting line was more fluid, civilians were drawn into the field of battle and became disabled as a result of enemy action. New regimes were established to ensure that those who had been permanently disabled were able to be employed elsewhere to assist the war effort. Termed *rehabilitation*, its purpose was to ensure that the effect of the manpower shortage due to mass mobilization was lessened. The Disabled Person's Employment Act of 1944 in Britain established guidelines for the employment of disabled people after the war.

As well as being workers, disabled people were viewed as heroic. Douglas Bader, the famous double amputee, was feted for his bravery flying Spitfires for the Royal Air Force. Some of the most important work on disability was that of neurosurgeon Sir Ludwig Guttmann, at Stoke Mandeville in Aylesbury, England, who worked with servicemen and servicewomen who had incurred spinal injury with resultant paralysis. His efforts to prevent them from sinking into depression and work toward building a stronger body with compensatory muscles through sports had far-reaching implications, as these early competitions evolved into the contemporary Paralympic Games.

In the second half of the twentieth century, wars were conducted on a smaller scale, but numbers of people were disabled as a result of the conflicts. About 75,000 Americans were severely disabled in the Vietnam War. Later conflicts saw complicated disabling conditions such as Gulf War syndrome, which was reported to be caused by exposure to a cocktail of chemical agents. While there were fewer battle casualties in the latter decades of the twentieth century due to advances in technology that distanced the warring parties, the disabling effects of war continue.

*—Julie Anderson*

***See also*** Disabled Veterans; Posttraumatic Stress Disorder; War.

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## VICTOR OF AVEYRON

**(ca. 1790–1828)**

*French "feral child"*

Victor is perhaps the best known and most important of the long list of so-called feral children. Often referred to as "the wild boy of Aveyron," Victor is forever associated with the name of his teacher, Jean Marc Gaspard Itard (who also gave Victor his name). For an entire generation of French intellectuals, Victor represented a chance to study what could not ethically be created: a "noble savage" raised in a state of nature uncontaminated by human culture. What could such a child show about the essence of human nature, human capacity? In what some have called the "forbidden experiment," Itard and Victor (and a caretaker, Madame Guerin) spent five intensive years together testing the empiricist notion that the human mind was a blank slate, dependent on the sensory experiences to develop all knowledge and socialization.

Victor was first brought to Paris in 1800 after being captured by townspeople in the region of Aveyron in the south of France. After an initial swirl of public attention and excitement, however, the French *alieniste* Philippe Pinel pronounced his diagnosis that Victor was not the suspected noble savage, normal in faculty but uncontaminated by human society. Pinel declared the child to be an incurable idiot, unimprovable in any way. It was Itard, however, who persisted, obtaining permission to work intensively with Victor, carefully exploring just how much the child could learn and approach normal development.

Itard's account of this five-year experiment, documenting Victor's progress in language, behavior, and other functional skills, is often regarded as one of the earliest attempts at systematic instruction of children with intellectual disabilities. Reminders of the many devices and techniques created by Itard for use in Victor's instruction can still be seen in such settings as Montessori classrooms and in the precise language of behavioral observations.

By 1805, Itard concluded that Victor did, in fact, have unalterable limitations to what he could learn, and Itard abandoned his efforts to document Victor's education. Itard went on to work for several more decades in the education of deaf children. Victor spent his remaining days with his devoted caretaker, Madame Guerin, living an apparently quiet life. Victor died in 1828 of unknown causes.

*—Philip M. Ferguson*

***See also*** Feral Children; Jean Marc Gaspard Itard.

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## VINEYARD DEAFNESS

*See* Deafness, on Martha's Vineyard

## VIOLENCE

No country or generation has been unscathed by violence. It is a phenomenon that has been continuously a part of human history. The universality and pervasiveness of violence are evident in our homes, playgrounds, schools, neighborhoods, worksites, places of public gathering, and nations. More than 1.6 million people die each year worldwide because of violence. Approximately half of these deaths are suicides, one-third are homicides, and one-fifth are related to armed conflict. Many more people are injured as a result of violence. For instance, it is estimated that for every death due to gun violence, three more people sustain gun-related injuries. In 1996, the World Health Assembly adopted a resolution declaring violence a leading worldwide public health problem requiring immediate attention from the professional community. *Violence* is defined by the World Health Organization (WHO) as "The intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation." With this far-reaching definition, the WHO recognizes that violence may manifest in a variety of ways. According to the WHO, violence can be categorized as

1. Self-directed violence (self-destructive and suicidal behavior)
2. Interpersonal violence (family/intimate partner violence and community violence that occurs among acquaintances and strangers)
3. Collective violence (violence by a group of individuals against another group)

Given the magnitude of violence, it is not surprising that there is a direct relationship between violent behavior and disability. Violence has affected the field of disability in four distinct ways. First, there are individuals who have acquired a disability as a result of violence. Typically, these acts have been related to warfare, civil unrest, street violence, and interpersonal disputes. Second, people with disabilities are at an increased risk of being targets of violence and abuse both inside and outside of their homes. Third, there is a belief among the general public that people with certain disabilities (i.e., severe psychiatric disabilities such as schizophrenia and bipolar disorder) are likely to exhibit physically aggressive behavior. However, this belief is not entirely accurate. Individuals who are taking medication for a psychiatric disability are not at an increased risk to exhibit violent acts. Fourth, suicide (self-directed violence) is closely linked to psychiatric disabilities, particularly mood disorders. According to the National Institute on Mental Health, approximately 60 percent of individuals who commit suicide have had a mood disorder (such as major depression, bipolar disorder, or dysthymia). In addition, the field of disability has been embroiled in the controversial debate of physician-assisted suicide, whereby physicians provide individuals who are diagnosed with terminal illnesses or severe/incurable physical pain with the means to end their lives.

### ACQUIRING A DISABILITY THROUGH VIOLENCE

Violence is related to disability when one considers the disablement of individuals because of violent acts. Although mortality is commonly used to indicate the magnitude of intentional violence, many more individuals sustain injuries that require medical attention, and a significant proportion become permanently disabled. Prevalence and incidence rates are difficult to determine due to a lack of systematic reporting procedures. Nonetheless, the relationship between violence and disability has been evident throughout human history. Violence-related disabilities occur under a wide range of circumstances, including self-injurious behaviors, suicides, domestic disputes, crime, community violence, civil unrest, political upheaval, and warfare.

War, violence, and disability have a long-standing relationship. One obvious consequence of war is death; another is injury and disability. The outcome of war-related disability was particularly evident during World War I, where an estimated 1.5 million people became disabled. Types of disabilities that were acquired included loss of limbs, blindness, deafness, traumatic brain injuries, and emotional traumas.

War holds a unique position in the disability rights movement because it helped transform attitudes toward those who are disabled. Prior to World War I, individuals with disabilities were often isolated and viewed with pity or apathy. After the war, these attitudes changed as many soldiers acquired their disability while serving their country. Upon their return from military duty, these soldiers were treated with respect by the general public. These changing norms began to influence how people with disabilities were treated in general. Disabled soldiers also brought to their home country a sense of responsibility to assist those with disabilities. In the United States, the Soldier's Rehabilitation Act and Smith-Fess Act were passed in 1918 and 1920, respectively. The Soldier's Rehabilitation Act provided vocational rehabilitation for military personnel, whereas the Smith-Fess Act did the equivalent for civilians.

In addition to warfare, civilians have acquired disabilities as a result of civil unrest and political upheaval. Such circumstances are evident throughout the world (e.g., Afghanistan, Angola, Cambodia, Ethiopia, Kosovo, Rwanda, and Vietnam). These countries have experienced years of internal political conflict, which have led to acts of violence and the disablement of thousands of civilians, including children and women. Given that these individuals typically reside in third world countries, their disabilities are often complicated by conditions of poverty and a lack of assistance and social services. During recent periods of political conflict, land mines have been used with high frequency. These weapons continue to pose a threat even after conflicts have been resolved. For example, as a result of three decades of violence related to political unrest, wars, and international border disputes, Cambodia has more than 30,000 people who have lost limbs following land mine detonation.

Spinal cord injuries as a result of violence have also risen in countries experiencing sociopolitical conflict. In the Republic of South Africa, a recent review of records from a spinal cord injury rehabilitation program indicated that gunshot wounds accounted for 36 percent of spinal cord injuries, a dramatic increase from the past. Similarly, during the 1990s, the United States experienced an extraordinarily high rate of violence-related spinal cord injuries. By 1994, violence accounted for 30 percent of new spinal cord injury cases. The United States has also experienced a rise in youth violence, with shooting sprees occurring across a variety of settings including homes, schools, and city streets.

## VIOLENCE AGAINST PEOPLE WITH DISABILITIES

People with disabilities are also at a greater risk of being victims of violence and abuse compared to those without disabilities. This is particularly true for disabled women, children, and elderly persons. Historically, these three groups have been targets for abuse even when the disability status is not considered. In addition, those with disabilities that are considered severe (e.g., intellectual disabilities) are more likely to be abused than those with nonsevere disabilities. Severe disabilities can affect the person's ability to comprehend and/or report the abuse.

Prevalence and incidence rates of violence toward people with disabilities are difficult to determine because of underreporting and varying definitions for violence. Some definitions focus solely on the physical force that is exerted for the purpose of violating, damaging, or abusing. Other definitions extend beyond physical force to include verbal aggression, neglect, and financial exploitation. For the nondisabled population, 10 to 69 percent of women around the world have reported physical abuse by an intimate male partner, approximately 20 percent of women and 5 to 10 percent of men have experienced sexual abuse as children, and 4 to 6 percent of elderly individuals have experienced some form of abuse in their homes. For the disabled population, these abuse figures are even higher. For example, studies of women with intellectual disabilities have reported rates of sexual abuse from 30 to 90 percent.

A number of factors have been associated with violence, abuse, and disability. First, negative attitudes toward people with disabilities may contribute to abusive behavior. For instance, if people with disabilities are judged to be nonintelligent or weak, such beliefs may be used to justify abusive behavior. Second, when abuse occurs, social isolation among people with disabilities may affect their ability to report and/or identify the situation as abusive. Third, the nature of one's disability may pose barriers to reporting (e.g., people with speech disabilities may have difficulty reporting the abuse by telephone). Fourth, people with disabilities may be hesitant to report abuse if they depend on the abuser for care, fear retaliation from the abuser, and/or experience personal shame over the abuse.

The relationship between violence and disability is further complicated when one considers that people with disabilities can be abused in a number of settings, including their homes, schools, hospitals, residential centers, and social service agencies. Thus, potential perpetrators may include spouses, family members, friends, teachers, personal assistance providers, transportation employees, and health care workers. Such abuse is difficult to comprehend because the very individuals who are expected to provide protection and care pose a threat to those who are disabled.

Last, responses to reports of violence and abuse may vary by setting. For example, within social service settings, there may be ineffective procedures to investigate reports of violence. As a result, responses to violence and abuse may be affected by prejudiced attitudes, ignorance of proper protocol, and inadequate investigative skills. Within legal settings, police may harbor prejudiced attitudes toward persons with disabilities, which in turn may affect their investigations. In addition, the rights of people with disabilities may be impinged upon due to inaccessible courtrooms and courtroom proceedings (e.g., the lack of sign language interpreters for those with hearing disabilities during a trial; judges' reluctance to accept testimony of persons with intellectual disabilities). Because of these variables, people with disabilities may have difficulty obtaining justice, support, and other constructive organizational responses when they are violently victimized. Thus, they may be less likely to seek assistance to address instances of abuse.

## PERPETUATORS OF VIOLENCE?

A third connection between violence and disability centers on how society views people with psychiatric disabilities. Historically, the general public has harbored the belief that individuals with severe psychiatric disabilities are dangerous and violent. Such perceptions are stronger today than they have been in the past and have been perpetuated by sensationalized headlines and popular media. However, such perceptions are misguided. There are three primary predictors of violence: past history of violence, drug and alcohol abuse, and a serious psychiatric disability *combined* with a failure to take medication. Individuals with severe mental illness who *are* taking their medication are no more dangerous than the general population.

Of the three predictors of violence, a past history of violence is the single most critical piece of information to examine regardless of disability status. The second important predictor is drug and alcohol abuse, and this is also true whether the person does or does not have a psychiatric disability. The third important predictor is the failure to take medication. Individuals who do not take prescribed medication for a psychiatric disability are more likely to commit violent acts than those who take their medication. Specifically, individuals with untreated schizophrenia and bipolar disorder are at risk to exhibit violent behavior.

Another possible predictor of violence is the type of delusion (or irrational belief) a person with a severe psychiatric disability is experiencing. Mental health professionals have long viewed paranoid delusions as a potential precursor of violence. However, the relationship between paranoid delusions and violence is not straightforward. For example, persons may experience delusions that they are famous. Yet this delusion is unlikely to lead to violent acts. Instead, a stronger predictor of violence is the feeling that others are out to cause physical harm, coupled with a feeling that one's mind is dominated by forces beyond one's control. An additional factor that may predict violence is *command auditory hallucinations*. Command auditory hallucinations involve voices telling an individual what to do; such voices may encourage violent behavior. In sum, the relationship between psychiatric disabilities and violence is complex, with a number of factors affecting the potential to act aggressively.

## SUICIDE AND DISABILITY

The final link between violence and disability relates to suicide. The relationship between suicide (self-directed violence) and disability is twofold. First, each year approximately 800,000 people die by suicide worldwide, with the highest rates occurring in Eastern European countries and the lowest rates in Latin American countries and a few countries in Asia. Approximately, 30,000 suicides occur in the United States. Although determining the definitive causes of suicides have proven difficult, suicides in many nations are associated with mood disorders. For example, over 90 percent of suicides in the United States are associated with psychiatric disabilities (including depressive disorders, bipolar disorder, schizophrenia, personality disorders, and substance abuse disorders). Advances within psychopharmacology have helped with the treatment of psychiatric disabilities, which in turn help curb suicide ideation and behavior. However, despite medical advances, suicide remains a worldwide problem. In India and China, psychiatric disabilities are less important risk factors. For instance, cross-cultural research indicates that humiliation, shame, economic hardship, examination failure at school, and family disputes were the greatest risk factors for suicide in India.

Second, the fields of disability, medicine, and law have been divided by the issue of physician-assisted suicide. In 2001, the Netherlands became the first country to legalize such a procedure. The law allows individuals who are "suffering unbearably" with "no prospect of improvement" to end their lives, with the assistance of doctors. In the United States, Dr. Jack Kevorkian was the most vocal advocate of assisted suicide. Kevorkian assisted at least 130 individuals with ending their lives, despite legislation prohibiting such action. After much debate and controversy in the United States, physician-assisted suicide was legalized in the state of Oregon by a slim margin, with the passage of the Death with Dignity Act in 1994.

The medical and legal communities remain divided on the issue of physician-assisted suicide. Some medical and legal professionals argue that people should have the option to end severe and incurable physical pain and suffering, highlighting respect for individual autonomy. Others argue that such a legal option perpetuates the erroneous notion that people with untreatable medical conditions lead lives that are not worth living. From the start, prominent disability rights groups have opposed legalization of assisted suicide. They argue that providing such a legal option to individuals with terminal illnesses may generalize to others with treatable conditions (and people with disabilities) who are leading productive and fulfilling lives.

## CONCLUSION

Violence has a clear connection to disability. This connection is evident when one considers (a) acquiring a disability through violent acts, (b) abuse and violence against people with disabilities, (c) the misguided belief that people with disabilities are perpetuators of violent behavior, and (d) self-directed violence and suicide. Given the history and extent of violence worldwide, these unfortunate trends are unlikely to dissipate in the near future. However, with the recent recognition of violence as a global public health problem by the World Health Assembly, the professional community worldwide is being urged to discuss and design prevention and intervention efforts to tackle these significant issues.

*—Brigida Hernandez and*
*Erin Hayes*

***See also*** Abuse and Hate Crimes; Child Abuse; Crime and Delinquency; Physician-Assisted Suicide; Suicide; War.

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# VISIBILITY AND INVISIBILITY

Some physical and mental impairments are clearly visible in the bodies and behavior of people with disabilities, while others are not. The latter are often referred to as "invisible disabilities." The equally common expression "hidden disabilities" has been criticized for its implication that the disabled person is actively choosing to conceal his or her impairment. Within contemporary disability studies and political movements, *invisible disability* is sometimes used as an umbrella term meant to include all those who have not been represented by the first wave of activism and scholarship: people with mental illnesses, cognitive and learning disabilities, developmental disabilities, and/or chronic physical illnesses. Yet not all of those disabilities are invisible, and not all disabilities traditionally recognized as such are visible. Some of the most compelling accounts of passing as nondisabled, for example, have been written by blind people—yet blindness is not included in the "invisible" umbrella because of a long history of cultural recognition of blindness as disability. Thus, the phrase "invisible disability" carries both a literal and metaphoric meaning—literally referring to impairments that are not visible on a person's body or behavior, and metaphorically referring to impairments that have not been well represented or recognized in the disability rights movement or scholarship. Some have advocated severing these meanings by referring to literally invisible disabilities as "nonvisible." However, in current usage, there continues to be considerable overlap and inconsistency in the use of these terms.

People with highly visible impairments, such as amputees, wheelchair users, people with facial markings, and people of short stature, tend to share a common experience of being stared at, often in the context of being pointed out, mocked, touched without permission, or asked intrusive questions. Disability theory, thus, has been deeply concerned with analyzing and counteracting "the stare," while disability activism has often sought to subvert or reverse this dynamic, as in the title of the 1997 anthology *Staring Back: The Disability Experience from the Inside Out.* The "hypervisibility" experienced by many people with disabilities, which continues to have a significant impact on everyday experience, employment, and relationships, has also been creatively adapted and challenged by many artists and performers with disabilities.

Many other people with disabilities exist in a fluid state of intermittent *invisibility*—as when using a prosthesis, when sitting down, when not communicating, or when taking medication that temporarily conceals an impairment, and *visibility*—as when using a cane, brace, or splint; when speaking in sign language; when asking for assistance with a specific task or activity; or when fluctuating symptoms such as a limp or tic temporarily appear. Even a person traditionally defined as visibly disabled, such as a full-time wheelchair user, can transfer to a sofa, fold her chair away, and join the ranks of the invisibly disabled for a time.

## HISTORICAL BACKGROUND

Both social and medical models of disability have traditionally emphasized visible disability, while the status of invisible disability remains contested on many fronts. This emphasis on visibility is part of the overall focus on visualizing the body within Western medicine beginning in the late eighteenth century. The focus of diagnosis and treatment shifted at this time from listening to a patient's descriptions of symptoms to examining the patient's body for visible signs of disease. This shift has been translated into contemporary medicine through the distinction between "subjective" symptoms and "objective" signs, with objective signs taking precedence in determining diagnosis, treatment, accommodations, and benefits.

Historians of medicine and disability have noted that this emphasis on objectivity meant that patients were increasingly treated like objects on display. For example, by the late nineteenth century, many surgical operations in England took place in theaters observed not only by doctors but also by an audience of curious laypeople. The bodies of people with visible disabilities were of particular interest to this audience, and such institutions as the freak show and the "cabinet of oddities" became popular in both Europe and the United States. "Human curiosities" such as amputees, conjoined twins, people of small or large stature, and people with microcephaly were displayed in these settings to audiences whose sense of their own "normality" was produced and reflected through the freakishness projected on people with visible disabilities.

During the same period, Freudian psychoanalysis, with its theories of hysteria and psychosomatism, was gaining credence among a broad group of professionals, including physicians, authors, and crafters of social policy. These theories eventually produced a new explanation of invisible impairments as "all in your head," thus categorizing these impairments as both less exotic than visible ones, and also somehow less "real." In addition, the experience of invisible impairment became highly feminized at this time (such that even men with such impairments were seen as effeminate), and women's reports of their bodily experiences became subjugated to the expertise of the male medical professional. This dynamic continues in the experiences of contemporary women with invisible disabilities, as both studies and anecdotal evidence indicate that women's physical symptoms are taken less seriously and treated less aggressively than those of men and that women are much more likely than men to be referred for psychological evaluation when reporting an invisible physical symptom such as pain or fatigue.

The binary understanding of visible and invisible impairment has influenced even the contemporary social model of disability, which explicitly seeks to refute medical models. Social scientists have suggested that individuals with visible disabilities are more likely to develop a positive disability identity than are invisibly disabled people who can "pass" as normal. Scholars in the humanities have argued that disability itself is defined by a disruption in the visual field. Challenges to these claims have emerged from invisibly disabled scholars who suggest that the dynamics of visibility that oppress some people by "enfreaking" them, oppress others by "invalidating" them. Understandings of disability as "performative" and "rhetorical" are beginning to nuance the emphasis on visible disability prevalent in the first wave of British and American disability studies.

## FORM VERSUS FUNCTION

Much of the cultural tension that exists around the questions of visible and invisible disabilities is based on the assumption that form reflects function. In other words, modern society has developed around the ideal that each of its citizens is able to perform in a "normal" capacity unless he or she looks somehow "abnormal." A woman who walks up to an airline counter to request a wheelchair, for example, will usually receive curious glances directed at her legs. The idea that a person can walk ten feet but not a hundred is just as foreign to modern conceptions of disability as the idea that a person can have limbs that look "normal" but do not function normally.

In contemporary systems of entitlements and access, immense suspicion exists that unethical or lazy citizens will take advantage of those systems. Thus, accusations of faking, malingering, or cheating are reported frequently by people with invisible disabilities across a broad range of impairments, including chronic physical illnesses, blindness and low vision, deafness, mental illnesses, and learning disabilities. In many cases, benefits and accommodations are denied to such people, resulting in significant social and economic disadvantage. For this reason, people with invisible impairments tend to remain more closely tied to the medical community, since they must often rely on doctor's certificates to obtain benefits and accommodations. This may be one reason why this population is perceived by some as having a less positive disability identity, according to the social model.

The assumption that form is tied to function also significantly affects people with visible disabilities, as their competence and intelligence may be challenged based on their bodily appearance or assistive devices. Many people with physical impairments that affect only certain functions can be treated as if completely incapacitated. For example, people whose legs are affected by paralysis, cerebral palsy, or multiple sclerosis report being denied driver's licenses in the United States despite their competence with hand controls. People who are nonverbal, communicate through assistive devices, or have speech impairments report being treated as "stupid," "slow," or developmentally delayed due to others' perception of their mental function as tied to their form of communication. This assumption has a serious impact on these individuals' social experience, as well as access to education and employment. Even individuals whose impairment is entirely formal with no effect on function, such as people with facial markings or skin differences, can face discrimination in these areas, thus demonstrating how issues of visibility affect all aspects of disability experience.

*—Ellen Samuels*

***See also*** Attitudes; Drama and Performance; Stigma; Values.

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## VISITABILITY

Unlike home modifications, where supportive features are incorporated to address residents' individual needs, visitability strives to provide a baseline level of accessibility in all new home construction, in hopes of benefiting the entire population. Therefore, *visitability* is an affordable, sustainable, and accessible design approach that targets single-family homes, the only type of housing not covered by the Fair Housing Act or any other federal or state legislation. Originating in Europe, the visitability movement was initiated in the United States in 1986 by Eleanor Smith, a disability rights advocate, and her group Concrete Change. Smith initially used the term *basic home access*, but in 1990 adopted the word *visitability*. Her ultimate goal is to make all new homes not covered by current access regulations "accessible enough" for a visitor with a disability. Thus, a visitable home is not necessarily intended to have a level of accessibility needed by a person with a disability. It is intended to be a residence for *anyone* and to provide access to *everyone*.

### THREE PRINCIPLES OF VISITABILITY

There are three fundamental principles of visitability. First, visitability is based on the idea that inclusion of basic architectural access features in all new homes is a civil right and improves every person's ability to live productively and comfortably. People with disabilities should be able to visit their neighbors for mutual assistance, friendship formation, and child care. In most neighborhoods, however, a major barrier to social participation for individuals with disabilities is the lack of opportunity to visit other homes. When only a few houses have full access, people with mobility impairments are confined to their homes for socialization in the neighborhood and segregated from others; when people develop impairments, they must find new places to live or wait for expensive renovations; and when accessible entrances, in particular, are built as renovations, the results are often awkward solutions that reinforce the stereotypes and stigmas often associated with disabilities and accessibility. In response to these circumstances, visitability strives to create an opportunity for all neighbors in a community to socialize, help each other, and interact more effectively. It attempts to break down attitudinal as well as physical barriers to social integration of people with disabilities.

Second, visitability rests on the notion that, through good design, basic accessibility to single-family housing can be provided in most cases with minimal financial cost. The design philosophy contends that access is cost-effective if planned in advance. Incorporating accessible architecture features into housing designs during the early stages of development and before construction remains affordable. Although only a limited number of studies actually have analyzed the specific costs associated with visitability, these studies agree that introducing visitability through retrofitting results in significantly higher costs.

The third principle of visitability suggests that simplicity promotes implementation. Prioritizing access features ensures that the supply of accessible homes will increase more rapidly. Visitability advocates argue that a long list of demands can create the misconception that all access features are equally urgent and therefore must all be included in a home. Many builders and designers may currently perceive this as too difficult to even attempt. However, visitability advocates argue that not everything is of equal urgency. Some access features are more important than others in helping individuals visit with their neighbors.

## VISITABILITY AS AN INNOVATION

Visitability's simplicity as a means to promote adoption is compatible with lessons learned from the study of innovation and its diffusion. Everett Rodgers (2002) defines *innovation* as "anything perceived to be new." He argues that it is not the reality that matters but the perception. Although visitability may not require new technology or look radically different, if it is *perceived* as something new, individuals will respond to it as if it *were* new. Because visitability is a new concept to most people, they consider it innovative. Therefore, those who wish to promote visitability need to understand the components of the innovation-decision process. According to Rodgers (2002), "The innovation-decision process is the process though which an individual (or other decision-making unit) passes from first knowledge of an innovation, to the formation of an attitude toward the innovation, to a decision to adopt or reject, to implementation and use of the new idea, and to confirmation of this decision" (p. 216). Rodgers proposes that the adoption of an innovation is a cyclical decision-making process with five activities: obtain knowledge, persuasion of the key decision makers, decision to act on the new idea, implementation, and confirmation.

Moreover, Rodgers argues that the pace of innovation adoption varies greatly. According to him, there are five attributes of innovation that enhance its adoption or diffusion rate: *relative advantage,* in which the diffusion rate is enhanced if there is a clear financial or social advantage for the new idea as compared to the idea or product it would supersede; *compatibility,* whereby if the innovation is congruent with current values, experiences, or needs, its rate of adoption will be faster; *trialability,* an innovation will be adopted more rapidly if it can be experimented with at relatively low cost of time, money, and commitment; *observability,* where the more an innovation is visible to others, the higher its rate of adoption will be; and finally, research by Rodgers's and others discovered that the pace of an innovation is affected by its *complexity*—the more an innovation is perceived to be relatively easy to understand and use, the higher the expected adoption rate (Rogers 2002:223–259).

This last characteristic specifically applies to visitability. In keeping with Rodgers's theory that simplicity promotes implementation, a visitable home is one that meets only three conditions: one zero-step entrance, doorways that are 32 inches wide, and basic access to at least a half bath on the main floor. These three features are considered the most essential for a person with mobility impairments to visit or live in a home, at least temporarily. In response to criticism that these three features are insufficient, Eleanor Smith argues, "What I'm after here is radically changing the way all new houses are built . . . and if you're going to do that, you can't have a long list of demands"

(Truesdale and Steinfeld 2002:3). Visitability advocates believe that once builders learn that visitability is easy to achieve and they receive positive confirmation through sales and consumer acceptance, they will be more likely to expand the list of universal design features they include in the next generation of housing.

## VISITABILITY AND NEIGHBORHOODS

Along with individual single-family homes, many advocates and researchers view visitability as a major step toward achieving universal design on a neighborhood level. In acknowledging the valuable role of visitability in developing active communities, Truesdale and Steinfeld (2002) contend that

> visitability, although less than the ideal of a universally designed home, is actually universal design practiced through community and neighborhood planning. It ensures that a basic level of accessibility will be provided in all housing and it opens opportunities for participation in community life. (pp. 7–8)

Visitability provides benefits to a wide range of users, including those with disabilities, their nuclear families, friends, and other relatives who may, from time to time, need to use wheelchairs or other adaptive equipment. Consequently, rather than forcing individuals to remain isolated and confined to their personal surroundings, visitability allows individuals with a variety of abilities to interact with each other and participate in community activities outside of their homes.

## THE VISITABILITY MOVEMENT

Recognizing the benefits and growing need for more accessible housing, many state and local jurisdictions have joined the visitability movement. In fact, several municipalities and states across the country have already formalized and enacted visitability programs. Despite their common goal of increasing the supply of accessible housing, these visitability programs vary significantly. The three primary ways they tend to differ are the geographic regions they cover, the scope of features they include, and the strategy by which they are implemented and enforced. For instance, some visitability programs cover housing within an entire state, while others only have jurisdiction over cities and/or counties. In addition, some programs strictly adhere to the three basic accessible features (stepless entrance, wider doorways and hallways, and a half bathroom on the main floor), while others include additional architectural elements such as lever handles, blocking for grab bars in bathroom walls, and accessible environmental controls.

Visitability programs also vary in how they are enforced. Some visitability initiatives are mandatory, whereby builders and homeowners are required by a law or ordinance to include the three visitable features during new construction, while other programs are voluntary. With voluntary programs, builders and consumers are encouraged to include the visitability features (stepless entrance, wider doorways and hallways, and basic access to a half bath on the ground floor), but they are not obligated to do so. There are additional variations within mandatory and voluntary programs. Although the majority of mandatory initiatives apply only to homes built with public funds, a few of these programs apply to both public and private homes. Moreover, with respect to voluntary programs, some programs offer monetary incentives while others involve certification or public awareness campaigns.

Whereas most visitability initiatives specifically apply to new housing, initiatives in all three types of jurisdictions (state, county, and city) do not preclude coverage of substantial renovations and retrofits in their respective guidelines. Incorporating renovations in visitability programs extends the housing market affected by the program to include existing homes. Although this expands the opportunity to increase the supply of accessible housing, it also could retard the advancement of the visitability movement. Encouraging consumers and builders to incorporate accessibility features after initial construction results in higher costs and ultimately reinforces the common misconception that visitability demands substantial spending.

Besides the more than 40 mandatory and voluntary programs already in place, there are numerous efforts to establish visitability programs in other states, counties, and cities across the country. Recent research identified 12 state and 15 local initiatives currently under way (Maisel 2004). While the final outcomes of these initiatives remain uncertain, their emergence symbolizes a growing interest in incorporating more accessibility elements in both public and private housing.

*—Jordana L. Maisel and*
*Edward Steinfeld*

***See also*** Accessibility; Home Modification.

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## VOCATIONAL REHABILITATION

Vocational rehabilitation (VR) is practiced by rehabilitation counselors employed by the state-federal system, business and industry, insurance companies, and private agencies. The purpose of VR is to enable individuals with disabilities to acquire, resume, or maintain employment, an outcome that is in some way affected by a physical, intellectual, or emotional condition limiting one or more life functions. Rehabilitation counselors assist people in achieving their vocational goals by providing counseling, guidance, and placement services and by arranging for medical, accommodation, and assistive technology services.

Important emphases in the history of VR include vocational training, a civilian program based on eligibility criteria, professionalism, and civil rights. Historians trace the emphasis on vocational training to the industrialization of America. As were all citizens, people with disabilities were poorly prepared for roles in this new industrial society. After considerable political debate, the state-federal VR system emerged as a means for helping people with disabilities become employed following counseling, guidance, and vocational training services.

The state-federal VR system is a major provider of VR services to eligible individuals. Eligibility criteria include the presence of a disability and the presumption of benefit. Although these criteria have not always been applied in an equitable manner, the intention to do so is a strong force motivating the practices of the state-federal VR system.

The commitment to quality services is nowhere more evident than in the growing professionalism in VR. A *qualified provider* of VR services holds both a master's degree in rehabilitation and certification as a rehabilitation counselor (CRC). VR counselors complete a rigorous curriculum, receiving training in medical and psychological aspects of disability, vocational evaluation, independent living, placement, rehabilitation research, counseling, and multicultural/gender issues.

Given the breadth of their training, VR counselors are well prepared to serve individuals with severe disabilities. The theme of severe disability is another important "defining moment" for VR. It is reflected in (a) early legislative commitments to serve people with physical disabilities who wanted to return to work, (b) later legislation that included services for physical restoration and for people with psychiatric and mental retardation diagnoses, (c) emphases in the Rehabilitation Act of 1973 on serving people with severe disabilities, and (d) order of selection priorities in the state-federal system to serve people with the most severe disabilities first.

For a time in VR, the concept of severe disability was viewed primarily from a medical/economic model. The dominant service mode involved medical services to "fix" the person so that he or she could return to a job consistent with residual capacities. Income maintenance via Social Security's disability program represented the only other alternative. Reactions to the medical/economic model and to discriminatory practices eventually gave rise to assertion of civil rights by people with disabilities. Assertion of civil rights in response to paternalistic treatment provided the foundation for the Americans with Disabilities Act (ADA) with its hiring and accommodation protections. It gave rise to a new respect for people with disabilities as individuals with rights to participation and informed choice. It gave rise to consumer protection via Client Assistance Projects (CAPs). It gave rise to an acknowledgment of the importance of multicultural/gender issues and to the need for counselor sensitivity to the impact that these differences have on VR outcomes.

In conclusion, VR is about people and their desires to become and/or remain productive citizens. VR interventions involving vocational evaluation, vocational planning, physical and psychological restoration, and placement have become more comprehensive and professional. They have focused increasingly on meeting the vocational needs of those with the most severe disabilities. Finally, they have become more and more reflective of the agendas of those seeking services, rather than of those providing services.

*—Rick Roessler*

***See also*** Disability and Career Development; Employability; Employment; Job Retention; Rehabilitation Act of 1973 (United States); Vocational Rehabilitation: Law and Policy.

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## VOCATIONAL REHABILITATION: LAW AND POLICY

Vocational rehabilitation (VR) is a process that enables individuals with disabilities to secure, retain, and advance in suitable employment and thereby further their integration or reintegration into society. Services to individuals with disabilities with a vocational or employment emphasis began before the turn of the twentieth century. They were often custodial in nature, and provided in the context of a caretaking role, thereby promoting segregation and exclusion from mainstream activities, including employment. The early perception of people with disabilities as subjects of health, welfare, and charity programs began to be seriously questioned in the early 1900s. Legislatively mandated changes began to occur around the time of World War I. These changes were initially spurred both by the need to train individuals for technical war occupations and replace workers called to fight in World War I, and later the need to return veterans to civilian careers.

Since then, a string of related legislation has added new services and new populations for coverage. A parallel development of services simultaneously occurred in other industrialized countries. Increasingly over the past century, we have moved to a model that highlights independence, equality of opportunity, recognition of unique talents and contribution, environmental and attitudinal barriers to success, and rights-based approaches that contribute to overcoming these barriers, such as workplace accommodation.

Modern VR policies grew out of the feeling that the federal government had an obligation to those who were wounded and became disabled in defense of their country. In 1918, the Veterans Rehabilitation Act (P.L. 65–178) was passed, authorizing VR services for World War I veterans. Services would be provided by the states, supported by federal grant money. Civilians with disabilities were excluded from receiving services under this act, but were provided for in 1920 with the beginnings of the civilian VR program (Smith-Fess Act, P.L. 66–236).

Parallel legislative developments were evolving at this time in other parts of the industrialized world. In Great Britain, the aftercare of disabled soldiers and sailors moved from being one principally of private initiative and financial support pre–World War I to a state matter with the Military and Naval War Pensions Act in 1915. Germany was in a better position than many countries to deal with the issue of VR, although VR was similarly the province of private charity or individual states pre–World War I. Germany was a leader in orthopedic surgery and rehabilitation and therefore had a well-developed network of disability centers, many of which had workshops teaching a variety of trades.

In the United States, the Social Security Act of 1934 (P.L. 74–271) established state-federal VR as a permanent program that could be discontinued only by an act of Congress. This action, however, did not guarantee continuing congressional appropriations. In 1943, the Barden-LaFollette Act (P.L. 78–113) broadened eligibility for rehabilitation services to include people with mental illness and retardation. *Vocational rehabilitation services* were defined as "any services necessary to render a disabled individual fit to engage in a remunerative occupation." This act also brought services for the blind under the umbrella of the state-federal VR support system, where previously they had been handled solely at the state level by state commissions for the blind.

In the post–World War II environment, the growth of VR slowed somewhat. The program was underpublicized and suffered from a lack of finances and of qualified rehabilitation professionals. The Vocational Rehabilitation Act Amendments of 1954 (the Hill-Burton Act, P.L. 83–565) began a new era for rehabilitation. This act provided funding to colleges and universities for the preparation of rehabilitation professionals and expanded services to people with mental illness or mental retardation. It provided funds for the expansion of rehabilitation facilities, extension and improvement of state agencies, and research and demonstration programs. Further amendments during President Lyndon Johnson's War on Poverty in the 1960s expanded programs, provided more federal funding to the states, and allowed states more flexibility in setting up rehabilitation agencies. In a parallel international effort, the International Labour Organization (ILO) Vocational Rehabilitation (Disabled) Recommendation No. 99 was adopted in 1955. This international instrument served as the basis for all national legislation and practice concerning vocational guidance, vocational training, and placement for persons with disabilities.

The next major piece of U.S. legislation affecting rehabilitation was the Rehabilitation Act of 1973 (P.L. 83–112). It introduced the Individualized Written Rehabilitation Program (IWRP) and postemployment services, made provision of services to people with severe handicaps a first priority, and provided special consideration for public safety officers injured in the line of duty. It authorized demonstration projects for independent living, established client assistance pilot projects, and mandated consumer involvement in state agency policy development. It also initiated the first legislation to prohibit discrimination in employment on the basis of disability and to provide access to federally funded programs for persons with disabilities. Subsequent amendments to the Rehabilitation Act have expanded and strengthened services for blindness and deafness and have added support for supported employment as a goal. Consumer empowerment was advanced in 1992 when consumer-controlled State Rehabilitation Advisory Councils were established and clients were given increased choice of employment objectives, providers, and services. In 1983, the ILO adopted the Vocational Rehabilitation and Employment (Disabled Persons) Convention No. 159, requiring member states to formulate national policies on VR.

Most recently, the Workforce Investment Act of 1998 (WIA) (P.L. 105–220) included amendments to the Rehabilitation Act. WIA changed the name of the IWRP to the Individualized Plan for Employment (IPE) and enhanced the collaborative relationship between the consumer and counselor, increased consumer control so customers could develop their own plans, stressed the concept of "presumptive eligibility" for Social Security Disability Insurance (SSDI) beneficiaries and Supplemental Security Insurance (SSI) recipients, expanded access to services promoting linkages with One-Stop Centers and other programs. VR services were expanded to include technical assistance for individuals to pursue self-employment, telecommuting, or small business operation as well.

The evolution in VR legislative and service structure changes over the past century reflects increasing sophistication and advances in medical and technological sciences. Even more profoundly, it represents a change in philosophy toward persons with disabilities. Twenty-first-century models of VR include recognition of the inherent worth of all individuals, including individuals with disabilities, in contributing to society and to the productivity of a national economy. This has changed how we interact with individuals with disabilities in service provision, from a patronizing and caretaking posture to one that is client driven, consumer focused, and personally empowering. This evolution in the way we prepare for, attach to, and advance individuals with disabilities in work has led a push toward quality, integrated, and paid employment. This movement was further supported by other federal laws, policies, and court actions, including the 1999 *Olmstead* decision, the Americans with Disabilities Act of 1990, further reauthorizations of the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act of 1990, and the Ticket to Work and Work Incentives Improvement Act.

As segregated programming options decrease and integrated employment opportunities expand, person-centered planning, self-determination, and consumer-directed services and supports lead the way. As a result of these developments and a paradigm shift in the way we prepare people for work, individuals with disabilities have greater access to competitive and integrated work environments.

Looking forward, there are several significant trends emerging in VR practice. There is increasing recognition that VR services must be provided in a career development context if successful employment outcomes for people with disabilities are to be realized. Therefore, the role of VR counselors must move beyond just initial training and job placement, and include helping people maintain employment and advance in their careers, including home-based small businesses. Populations the VR process is being applied to are also changing, including people with hidden disabling conditions such as mental illness, diabetes, multiple sclerosis, cancer, HIV/AIDS, fibromyalgia, and heart disease, as well as people with age-related conditions such as arthritis and vision, hearing, and orthopedic-related impairments. There also must be an increasing emphasis on providing consultative services to employers and attention to interpersonal and organizational factors that contribute to long-term vocational success.

The contemporary VR process necessitates knowledge and use of workplace supports and accommodations, workplace disability management, and innovative strategies for building partnerships with employers. In addition, VR practitioners must increasingly be aware of the dynamic workplace ecology factors that shape the attitudes and behaviors of coworkers and supervisors toward workers with disabilities.

*—Susanne M. Bruyère*

***See also*** Disabled Veterans; Job Retention; Rehabilitation Act of 1973 (United States); Vocational Rehabilitation.

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## VOCATIONAL REHABILITATION ACT (UNITED STATES)

*See* Rehabilitation Act of 1973 (United States)

## VOTING

People with disabilities have made tremendous political strides over the past few decades, most notably with the passage of the Americans with Disabilities Act (ADA) in 1990. Despite these policy gains, however, recent research suggests that the voice of people with disabilities in American electoral politics is faint. Several studies over the 1992–2000 period showed that voter turnout was 6 to 21 points lower among people with disabilities and was especially low among people with disabilities who are older, nonemployed, or have difficulty in going outside alone.

Voter turnout is the most basic form of political participation in a representative democracy. The turnout of people with disabilities can be important for electoral outcomes and politicians' attention to disability issues. Voting may also have important personal and social effects for individuals with disabilities, affirming their equality as citizens and integration into mainstream society and increasing perceived personal efficacy.

The factors affecting political participation can be divided into three categories: resources ("Are you able to participate?"), psychology ("Do you want to participate?"), and recruitment ("Did anyone ask you to participate?"). Resources include time, money, and civic skills; psychological factors include political interest, civic values,

**Table 1** Studies of Voter Turnout (in percentages)

| *Election Year* | *Disability Sample* | *Disability Turnout* | *Nondisability Turnout* | *Gap* |
|---|---|---|---|---|
| 1. 1992 | People with SCIs | 56 | 71 | 15 |
| 2. 1994 | Nonemployed | 33 | 54 | 21 |
| 3. 1992–1996 | Nonemployed | 57 | 71 | 14 |
| 4. 1996 | Nonemployed | 44 | 65 | 21 |
| 5. 1996 | Disability households | 33 | 49 | 16 |
| 6. 1998 | Broad disability sample | 54 | 60 | 6 |
| 7. 2000 | Broad disability sample | 70 | 82 | 12 |

Note: SCIs = spinal cord injuries.

efficacy, group consciousness, and commitment to specific policies; and political recruitment occurs through formal and informal networks (e.g., work or voluntary organizations). Research on the general population demonstrates that factors in each of these categories strongly influence the likelihood of voting.

Disability can affect voter turnout in a number of ways. Limited resources can depress voter turnout among people with disabilities. They have lower average income and education levels than people without disabilities, and their financial resources are often further constrained by higher expenses for medical care and special equipment. Political recruitment among people with disabilities is limited by their relative isolation. They are more likely than people without disabilities to live alone and face transportation problems, and they are less likely to be involved in community and social activities. Physical isolation can be exacerbated by discriminatory practices such as states' disenfranchisement of some individuals with disabilities, frequent neglect of candidates and parties to recruit people with disabilities, and negative messages about disability conveyed through public policy.

In addition, the psychological effects of living with a disability can be important. The stigma and discrimination faced by many people with disabilities may combine with isolation and diminished resources to decrease feelings of personal efficacy and control, and in turn depress voter turnout. The stigma attached to disability, however, may motivate some individuals to engage in political action, as shown by the growth of the disability rights movement.

## EVIDENCE ON VOTER TURNOUT

Voter turnout is generally lower among people with disabilities, as shown in seven studies summarized in Table 1. These seven data sources use very different samples. The first is based on a survey of New Jersey residents with spinal cord injuries (SCIs); the next three are based on nonemployed respondents to national surveys who answered an employment question by saying they have a disability; the fifth is based on a national survey of respondents who said that someone in the household has a disability (although the respondent may not have had a disability); and the final two are based on broader samples of people with disabilities (identified by questions based on the 2000 U.S. Census).

Despite important differences in the samples and disability measures, the results consistently show lower voter turnout among people with disabilities. The first five indicate gaps in the range of 14 to 21 percentage points, while the final two (using broader samples) show gaps of 6 and 12 percentage points. The smaller gaps in the last two samples, which are more representative of the full disability population, reflect a higher proportion of senior citizens, who are generally more likely to vote. After adjusting for differences in age and other demographic characteristics, people with disabilities were found to be 20 percentage points less likely to have voted in 1998. These estimated gaps are large in a practical sense: Based on the 2000 election study, if people with disabilities had voted at the same rate as those without disabilities, there would have been an additional 3.2 million voters in 2000.

The above studies are based on data from the United States. Electoral participation of people with disabilities has become a salient issue in a number of other countries, where there have been a variety of initiatives to decrease the barriers they face in voting. These efforts indicate that people with disabilities are less likely to vote in many countries, but systematic comparisons of turnout are not available outside of the United States.

Absentee voting can be an attractive alternative for people with mobility impairments or other transportation difficulties. Four of these U.S. voting studies indicate that absentee voting is higher among people with disabilities, particularly for those with mobility impairments. Voters with SCIs in 1992 were five times as likely as voters in the general population to vote by absentee ballot (35 vs. 7 percent), while other samples show that voters with disabilities were about twice as likely as those without disabilities to vote by absentee ballot (13 vs. 7 percent in 1994, 14 vs. 8 percent in 1998, and 20 vs. 11 percent in 2000).

## TURNOUT PATTERNS AND POSSIBLE EXPLANATIONS

Several studies indicate that turnout continues to be lower on average for people with disabilities even after controlling for a variety of demographic and economic characteristics, but the size of the voting gap varies along several dimensions—particularly age. While voter turnout increases strongly with age in the general population, it rises only weakly with age in the disability population. The result is that voter turnout is slightly depressed among young people with disabilities and much more strongly depressed among senior citizens with disabilities (e.g., in 1998 the turnout gap between people with and without disabilities was less than 10 percentage points among people under age 45, but 30 points among people age 65 or older).

In addition, employment appears to be important: The 1992, 1994, and 1998 election studies found lower turnout among nonemployed people with disabilities, but the 1992 and 1998 studies found that turnout was almost identical between employed working-age people with and without disabilities. Employment may raise voter turnout among people with disabilities due to resource effects (such as higher income), recruitment effects (through increased social contacts at work), psychological effects (such as increased identification with mainstream society and an increased sense of efficacy and interest in public issues), and other reasons. The voting gap is reduced but still exists after controlling for several income, recruitment, and psychological variables in the 1998 study, indicating that the role of employment requires further investigation.

Mobility problems also appear to contribute to the low turnout of people with disabilities. Turnout in 1998 and 2000 was lowest among people who reported difficulty going outside their homes alone. Also, the 1992 and 1998 election studies found that 30 percent of people with disabilities were not able to drive, and voter turnout was 15 to 20 percentage points lower among this group (after controlling for other personal characteristics). Voting clearly does not depend on being able to go outside alone (since one can vote by absentee ballot, or be taken to the polling place by others), suggesting that greater ease of mobility may have important social and psychological effects through increased interaction, feelings of efficacy, and identification with mainstream society.

Turnout of people with disabilities may be discouraged by problems in getting to or using polling places. A 2001 study by the General Accounting Office found that only 16 percent of polling places in 2000 had no potential impediments to access by people with disabilities. In the 2000 election survey, 6 percent of people with disabilities who had voted in the past 10 years reported encountering problems in voting at a polling place, while one-third (33 percent) of all others with disabilities said they would expect problems, compared to only 2 percent of people without disabilities. Based on these figures, an estimated 3.0 million citizens with disabilities either encountered or would expect to encounter difficulties in voting at a polling place. Reported problems include difficulty in getting to or inside the polling place, difficulty once inside the polling place, and general mobility limitations. Inaccessible polling places, apart from the practical difficulties they present, may make people with disabilities feel like second-class citizens who are not fully welcome in the political sphere.

Direct measures of recruitment are available in the 1992–1996, 1998, and 2000 election studies, where people were asked whether they had been contacted or otherwise encouraged to vote by a political party or anyone else. While recruitment is a strong predictor of voter turnout in general, and people with disabilities had fewer such contacts, this accounted for little of their lower turnout.

Psychological factors have been directly examined in several studies. One finding from a 1987 Harris poll indicated that interest in politics is a strong predictor of turnout among people with disabilities, similar to the general population. Feelings of political efficacy—that one is qualified to participate in politics and that the political system is responsive to individuals like oneself—are lower on average among people with disabilities. Regardless, this accounts for only a small part of the turnout gap between people with and without disabilities. The perception that people with disabilities are a minority group was linked to lower voter turnout among people with disabilities in 1984 but not in 1986. Finally, voter turnout in 1998 was especially low among those who had recent onset of disability, suggesting there are psychological effects of learning to live with a disability. These results indicate that psychological factors are important in voter turnout among people with disabilities but do not point to factors that fully explain the turnout gap.

## INCREASING VOTER REGISTRATION AND TURNOUT

The voter turnout gap associated with disability is also reflected in voter registration rates: Only 62 percent of citizens with disabilities were registered to vote in 1996, compared to 78 percent of citizens without disabilities. This raises the question of whether people with disabilities face special barriers to registration.

In an effort to decrease barriers to voter registration, the National Voter Registration Act (NVRA) was passed and signed into law in 1993. The NVRA is often called the "Motor Voter Act" because it mandates that citizens be given an opportunity to register at motor vehicle agencies when their driver's licenses are obtained or renewed. More broadly, the NVRA requires states to offer voter registration in conjunction with any business at public service or assistance agencies as well as at offices providing state-funded programs for people with disabilities. In addition, states must provide for mail-in registration procedures, which can be especially helpful to people with mobility limitations.

The NVRA went into effect on January 1, 1995, but full implementation was delayed by the requirement for costly computerized communications between election officials at the state and national levels, and legal challenges by several states. Even in 2000, a survey showed that many agencies were not aware of their NVRA responsibilities. Some states had already implemented similar provisions by the time of the 1994 elections, but those changes did not substantially increase the turnout of nonemployed people with disabilities in that year; also, in 1998 and 2000, only 1 percent of people with disabilities who were registered since the NVRA took effect had done so at a disability or other social service agency. So far, the ability of NVRA reforms to increase voter turnout has been limited, but several studies suggest that registration among relatively uninvolved groups, such as African Americans and young people, has increased. Whether these newly registered citizens capitalize on their eligibility to vote may depend on other factors such as recruitment efforts and the salience of campaign issues.

New computer technologies have expanded the options for accommodating voters with disabilities. The Help America Vote Act (HAVA), passed in 2002, encourages adoption of these technologies, requiring each polling place to have at least one fully accessible voting system by January 1, 2006. In addition, HAVA promotes election access by requiring that each state allow electronic voter registration at disability agencies, all voting-related materials are available in alternative formats, and poll workers are provided disability etiquette training. The implementation and effects of HAVA remain to be seen.

## CONCLUSION

In sum, voter turnout is lower among people with disabilities than among the general population. The research has identified several reasons but has not been able to fully explain this gap, indicating that there is still much to learn. While existing research provides only limited insights, it seems likely that both individual and contextual factors—including accessibility problems, legal and policy barriers to participation, and the marginalizing effects of disability policy—play a role in depressing voter turnout among people with disabilities. Policies such as HAVA, aggressive enforcement of polling place accessibility, and increased voter recruitment among people with disabilities could make an important difference.

Higher voter turnout among people with disabilities—which could raise the number of voters in U.S. elections by up to 3.2 million—could have a major impact on electoral outcomes. Such increased turnout could reshape the political landscape, increase the responsiveness of public officials to disability issues, and further contribute to the personal and social empowerment of people with disabilities by affirming their equality and rights as citizens.

*—Lisa Schur, Todd Shields, and Kay Schriner*

***See also*** Citizenship and Civil Rights; Political Participation.

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## VYGOTSKY, LEV SEMYONOVICH (1896–1934)

*Russian psychologist*

Lev Semyonovich Vygotsky was born in 1896 in Orsha, Belorussia. He was a clinical psychologist, researcher, and theoretician, developing an avant garde approach to disability (defectology, or the general science of deficiency) that grouped together neurobiological, psychological, social, and educational aspects. By bringing new blood to special education, this new science led to the creation of several institutes in Eastern Europe, including Moscow's Institute of Defectology, which Vygotsky directed from 1929 to his death in 1934. He left behind numerous writings, which, under Stalin, took some time to reach Western countries.

Unlike his Western contemporaries, whose conception of disability he found to be negative, static, and too focused on the disabilities themselves, Vygotsky offered a dynamic and multidimensional model of the development of nondisabled and disabled children. The disability may be put to positive use by stimulating compensatory processes that allow development to take new paths. The dynamic forces of compensation, enabled through the flexibility of psychic functions, also require mediation of the sociocultural environment. Indeed, it is the interactions of living with others that form the substrate of development. A disabled child who lacks a sufficiently positive social environment, or who benefits from such an environment too late in life, will encounter greater difficulties.

The richness of this socioconstructivist approach to development has inspired new generations of research in the fields of disability and special education.

*—Isabelle Ville*

***See also*** Education, International; Psychology; Special Education.

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# W

## ▣ WAR

Except perhaps for the grinding, daily toll of industrial accidents in modern societies during the last two centuries, there has been no more constant a source of disability, whether due to injury or to chronic illness, than war, one of the oldest of human practices. Although this fact is widely acknowledged, it is largely underanalyzed. In the case of both civilians and members of armed forces disabled as a consequence of war, there has been an evident reluctance to come to terms with the price that military conflict has exacted on the bodies and minds of both participants and bystanders. Within the context of that neglect, however, governments, researchers and scholars, and the general public have paid much more attention to the male disabled veterans of military service in conventional, national armed forces than to civilians disabled by war. (We know much less about the historical treatment of disabled veterans in non-Western countries and about those male and female alike who served in unconventional military forces, such as guerilla armies.) Even then, the intensity of this emotional and material generosity shown toward the Western male disabled military veteran has generally declined with time after the war in which the veteran was disabled.

In contrast to disabled veterans, the bystander is not easily assimilated into the romanticized and heroic depictions of warriors that form part, although by no means all, of the representation of those disabled in war, and that provide some of the luster by which wars seem at some emotional and ideological level more acceptable. Relatedly, more resources and energy have been devoted to providing medical, rehabilitation, and reintegration services, including pensions, for disabled military veterans than for civilian war victims. Although disabled military veterans have been pioneers on the frontiers of the welfare state, such that the programs created for them and the methods of organizing assistance by states have later been applied to the general disabled population, there remains in most societies an abiding gap between the social provisioning of the two disabled populations, greatly favoring the veterans. Yet, even the disabled veteran of military service has been a neglected figure in the writing of history and official memories of war. Civilization may indeed require a short memory if it is willing to engage in large-scale violent conflict to resolve its problems. Consequently, we have a subject riddled with gaps and difficulties.

### THE DISABLING OF CIVILIANS

Evidence of impairment due to war is at least as old as the narratives of antiquity, but it has grown enormously in modern times. In the more distant past, the lack of highly destructive technology probably limited the number of war victims, while the poor state of medical care doomed large numbers of the injured and ill to a relatively quick death. War-related disability, moreover, could be claimed as one source of misery among many that doomed people to short, unhealthy, and impaired lives. In the modern era, the violence of warfare has spread outward into ever-larger populations, especially because of strategic aerial bombing, which has never been—and probably will never be—precise enough to avoid claiming large numbers of innocents as well as combatants. At the same time, however, medical therapeutics and rehabilitation techniques have become more effective at saving and reclaiming lives, so the number of survivors has grown alongside the number of victims. Yet, in the midst of such trends, the various difficulties, whether moral, psychological, or evidentiary, of coming to terms with the numbers and conditions of civilian victims continue.

To some extent, the problem of neglect is wrapped up in the dense moral fog that surrounds war itself. The calculus of victimology exerts endless pressure on the process of making sense of the consequences of war, as loser and winner contest their claims to both virtue and unjust suffering. World War II provides an illustration of this. The world waited almost 60 years for a study of the lethal and decisive Allied bombing of German cities and towns that concentrated not, as in British and American studies, on the strategy and logistics of aerial campaigns, but on their terrible human consequences. A sustained discussion was certainly needed because while on the official level it was stated that the targets were war industries and military concentration, it was well understood that the bombings were rarely precise and thus, in effect, targeted the civilian population. When that study was finally conducted, it was quite logically written by a German historian, Jorg Friedrich. However, every step of Friedrich's interpretive process, from his estimate of civilian casualties to his effort to establish a moral context for evaluating crimes against the noncombatant German citizens, was littered with the question of German guilt—for beginning the European war, for an especially lethal style of warfare that often targeted civilians, and for the Holocaust. It could hardly be claimed that Hitler's Luftwaffe, and toward the end of the war V-1 "buzz bombs" and V-2 rockets, failed to take their own lethal toll on British urban dwellers. Friedrich's claims that Winston Churchill, an uncompromising exponent of the strategy of aerial assault on urban centers, was a war criminal certainly rang hollow in the United Kingdom and elsewhere.

The same remorseless moral logic has characterized evaluation of the lethal World War II aerial campaigns over Japan, another aggressor nation brutal in the treatment of its adversaries, civilian and military alike, and responsible for the devastating surprise attack on Pearl Harbor that dragged a reluctant United States into war. Even such conventional assaults, comparable to similar raids over Germany in terrorizing civilian populations, as the devastating fire bombing of Tokyo in 1945 that is considered to have killed at least 87,000 civilians and injured 41,000, were dwarfed by the consequences of the deployment of the two atomic bombs in August 1945. There were perhaps 200,000 deaths in Hiroshima and Nagasaki attributable to the blasts by early November 1945. The majority of the dead and injured were civilians. The uniquely alarming injuries sustained by the *hibakusha* (A-bomb survivors), especially those tens of thousands exposed to radiation, have been well known since the immediate aftermath of the war. Their ranks included not only Japanese civilians but also Korean, Chinese, and other Asian forced laborers who were brought to Japan to work in war industries. Fetuses exposed to radiation in the womb were born with severe mental and physical impairments, and severely burned individuals, including most evidently those who were facially disfigured, were seen everywhere on the streets of Hiroshima and Nagasaki.

Americans have never been comfortable with sorting out the human consequences of the atomic bombs. During the occupation of Japan until April 1952, the American victors restricted research and publicity about radiation disease and other consequences of the bombs. The visit to the United States of 25 severely burned and facially disfigured young women, the so-called "Hiroshima maidens," for treatment marked not only a recognition of the civilian victims but a low-intensity, largely private effort to come to terms with the moral problem of these civilian casualties. Organizers of the visit included the Japanese Hiroshima Peace Center, American Quakers, Norman Cousins (the editor of the mass circulation weekly *Saturday Review*), and surgeons at New York's Mt. Sinai Hospital, with the cooperation of the American government, which provided air transportation for the women.

Such private efforts stopped well short of a formal acknowledgment of the toll the atomic bombs took on civilian lives. There is still resistance to such a national accounting. A major debate erupted in the United States as the 50th anniversary of the deployment of the bombs approached. The Smithsonian Institution, in planning for the commemoration of the bombings, stated that it would evaluate the necessity of the bombs and their human consequences and their role in bringing a speedy end to the Asian conflict. Veterans and patriotic groups and conservative politicians and journalists, angered by the seemingly moral equivalence being established between Japan and the United States, combined to create a storm of controversy over any effort to represent the larger issues presented by civilian targets and casualties, and they were successful in scaling back the goals of the exhibit.

Amid such ideological and partisan pressures and the general denial that surrounds the subject of civilian victims of modern warfare, it is perhaps to be expected that what has been done to help them has largely gone unheralded and unanalyzed, especially in nations suffering defeat, and has been done within budgetary constraints that were often tighter for civilian than military war victim programs. Following the two world wars, the spread of rehabilitation facilities and the creation of disability pension schemes served European civilians and military veterans. The programs bore the mark of specific historical circumstances, national traditions, and the qualities of national political leadership, as the examples of post–World War II Britain and Germany suggest. Because British industrial and agricultural workers had been drafted into their jobs and subject to injury, not only in war work but like other civilians in bombing raids, extending to them the same vocational rehabilitation programs created for disabled military veterans seemed just to both planners and the general population, especially in the context of Britain's emergent postwar social democratic mood. The Allies sought to install this sort of program in defeated Germany, but for rather different reasons. To combat militarism, at first the Allies insisted that there be no separate benefit system for disabled German veterans, whose needs the occupiers assimilated into the civilian disability system, then composed heavily of war victims. Because of a continuing national pride in the armed forces and feelings of obligation to those who had fought for their fatherland, even in the face of defeat and the taint of Nazism, the policy was so unpopular among Germans that it threatened to hinder efforts to win over the population in the emerging Cold War rivalry with the Soviet Union, and was gradually compromised. When Germans in the Western zone were allowed to govern themselves in 1949, the new government's first important accomplishment was the reconstruction of the relatively generous war veteran benefits program that had existed in the post–World War I Weimar Republic. In Japan, the restoration of self-government allowed the Japanese to push ahead in developing special services for the *hibakusha,* at first with activities on the local level by doctors in Hiroshima, and then with national legislation in 1957 and 1968 that provided medical, health, and welfare services to victims of the atomic bombs.

Although civilian war victims continue to lack access to the range and quality of services and income subsidies available to disabled military veterans, the moral grounds for debating the effects of war shifted notably in the late twentieth century toward much greater consideration of the consequences of war for the innocent bystander. Counterinsurgency wars, such as the Vietnam War, were especially criticized for insensitivity to casualties among civilians, who were often caught in the crossfire between guerilla and conventional forces. As with the burns caused by napalm in Vietnam, maiming resulting from unexploded ordnance, such as cluster bombs and especially land mines, became the basis for global campaigns of protest and remediation. There was no more powerful symbol of the damage such weapons caused bystanders than the iconic photo taken in 1972 of the nine-year-old Vietnamese girl, Kim Phuc, who was severely burned over 35 percent of her body. A South Vietnamese pilot had dropped napalm on her, members of her family, and other villagers, believing they were involved in an attack on ground troops he was sent to support. Growing awareness of the disastrous effects on civilians of aerial bombing campaigns and strategic missiles put considerable pressure on the United States to develop more precision weaponry and to use it with greater restraint in wars in Afghanistan and Iraq in the early twenty-first century. It was in this moral context, which highlighted the impersonal and random violence of terror from the skies, that it became possible for Jorg Friedrich to offer a moral reevaluation of the Allied bombing campaigns that for years had been viewed as the triumph of Allied air power in pursuit of victory against Nazism.

## DISABLED MILITARY VETERANS

### *Representation*

There is no doubt that disabled combat veterans have long been recognized as a source of special moral concern by the societies for which they have fought. They have also evoked intense anxiety and fear. To understand these contradictory responses, it is necessary to understand the ways in which in Western cultures, both warrior and disability discourses influence the understanding of the disabled veteran. The representation of disabled veterans is largely a product of the conflict and negotiation of these discourses, which lie in a state of constant tension, as we see in the ancient Greek narrative of Philoctetes. The root of these tensions lies in gendered assumptions about manhood. On the one hand, like Philoctetes, the warrior may be valorized as a symbol of male power and honor; on the other hand, pity and fear, the common emotions associated with our response to disability, serve to subvert honor and either infantilize and feminize the male or demonize him.

The ideal traits of the warrior have been steeped in ideas of masculine honor because war is the archetypical male experience, forming one of the borders of male and female. The warrior's character traits of courage, toughness, endurance, and a capacity for action have been fairly stable throughout the centuries, although the grounds for heroism have shifted from a chivalric emphasis on individual valor to peer groups' codes of behavior, emphasizing individual obligations to the combat group. Injury and disability incurred in war have been frequently viewed as, in Stephen Crane's ironically intended phrase, a "red badge of courage" for a warrior engaged in the worthy cause. Although wartime governments have sometimes been divided about allowing civilians to learn the extent of death and traumatic injury experienced by fighting men, in the belief that such knowledge was bad for morale, the disabled veteran as warrior hero has served as a particularly potent, public symbol for inspiring war efforts and loyalty to the state. When war ends, however, and memories of it begin to fade amid the general desire to return to a normal peacetime existence, the warrior hero gradually loses his luster and is reduced in stature to a beleaguered disabled man, whose needs may be perceived as both intrusive on the peacetime agenda and expensive. Thus, the generosity that his government and the public showed him through preferential public employment, pensions, vocational rehabilitation, prostheses, and education also begins to be challenged and, in time, even to recede.

As a disabled man, the veteran increasingly comes to be seen not as a warrior, but through the images by which people with disabilities have been conceived. For centuries in Western cultures, people have responded to disability and to disabled veterans with pity and fear. The veterans may evoke pity as innocent sufferers: In the case of veterans conscripted into armies, they are injured through no fault of their own and thus made to experience pain, a loss of autonomy, and exile from the community of the able-bodied, just as the wounded Philoctetes suffered physical exile on an isolated island. While the impulse to feel, if at times excessive, sympathy for the disabled veteran may be quite understandable, it has frequently been manipulated for instrumental purposes, thus popularizing pity. Twentieth-century veterans' organizations, such as the American Legion and a broad array of World War I–era German organizations, learned how easily a democratic polity can be manipulated through the potent, guilt-inducing symbolism of badly injured or ill veterans, especially when backed by powerful veterans' lobbies and bloc voting. Pity would not go unchallenged, however, for during World War I the idea of aggressive normalization through physical restoration and vocational training, which had been propagated first on behalf of the rehabilitation of injured and ill industrial workers in the late nineteenth century, spread among all of the major belligerents, allies and enemies alike. By the final year of that war, it came to constitute a counterdiscourse to traditional ways of conceiving of disabled veterans' postwar prospects; it insisted that every effort be made to return the disabled veterans to the community and to the workforce, and thus to oppose those influences that cast him as a feminized shut-in, lacking a man's place in the world.

The disabled evoke fear because physically and mentally impaired people have historically suggested sinfulness, deformity of the soul, and loss of moral autonomy. These conceptions cast the impaired individual as, alternately, revengeful, bitter, and self-absorbed; dependent, irresponsible, and parasitical; or monstrous. Neuropsychiatric disability also raises more immediate fears, given that it is associated with a direct physical threat to the observer and to social order itself. Although Americans have associated the enraged, antisocial, unpredictable madman possessing advanced weapons training with the Vietnam War veteran suffering from post-traumatic stress disorder, in fact, as Shay and others have suggested, societies have long been haunted by fears of the disruptive potential of men schooled in violence and possessing unpredictable mental states. Two of the earliest domiciliary institutions established for the care of aged and disabled veterans, France's Hôtel des Invalides (1633) and Britain's Chelsea Hospital (1685), were founded partly in the belief that there were many such men and that it was necessary to remove them from the streets in the name of public safety. Impoverished as many of them were and unable to reintegrate themselves into society, they were believed to have turned to begging, picking pockets, and violent thievery.

### *Public Policy*

Protecting society against the disabled veteran, however, has not been the primary reason for the increasingly elaborate and frequently, at least at their inception, generous programs of social assistance that have come to characterize the response of modern societies to disabled veterans. Most Western societies historically have had at least two parallel tracks for assisting those construed to be in need, one for veterans and one for the general civilian population. The former is not only older than the general welfare state, but has been governed by different principles and rules and has been more generous in its provisions. The veterans' provision itself has not been a single entity. Although assistance for both groups has been governed by a common justification, disabled and able-bodied veterans have not been provided for equally. Disabled veterans consistently have been treated better than able-bodied veterans and indeed than perhaps any other cohort in society, including impaired civilians, whether disabled in peace or as bystanders in war. The liberal veteran provision is a consequence of the understanding—widely articulated in seventeenth-century England, in the era of the French Revolution, during the American Civil War by both North and South, and then universally accepted in the twentieth century—that assistance for and recognition of veterans must not be considered charity. Instead it is a reward for—and implicitly, too, an incentive to inspire—service to the state. In the case of disabled veterans, it is also a repayment for a personal sacrifice that is greater than simply time served. Thus, assistance is conceived as earned and a right. While assistance for disabled veterans generally came before that for the general population of veterans, in twentieth-century modern mass democracies, it has been increasingly given generously to all veterans, who now in some societies have life-long entitlements to medical care and education long after they have left the armed forces.

While programs of pension assistance and medical and domiciliary care for injured and ill veterans can be traced back to antiquity and appear here and there in early modern Europe, the dawn of the modern system of assistance for disabled veterans appears in history alongside the appearance of mass conscripted armed forces in the late eighteenth century and thereafter.

In the 1790s, in response to both egalitarian ideology and the invasion of the country by opponents of the Revolution, Revolutionary France briefly democratized pensions and qualifications for residence at the Hôtel des Invalides, which under the Bourbon monarchy had been largely limited to officers, before the pendulum swung backward toward elite privilege under Napoleon. Following the American Civil War, the federal government developed an elaborate and expensive pension system, which was administered by a centralized bureaucracy in Washington that, anticipating the modern welfare state, created a complex process for inspecting and classifying the bodies of disabled veterans of the Union Army. Also established were a network of domiciliary institutions for homeless and disabled veterans (the National Home) throughout the northern and western states, and a program providing prosthetic devices for thousands of amputees. The major European military pension systems, especially the French system adopted in 1831, established pension rates based on the nature and degree of physical injury. Although it borrowed from this practice, the American system departed from European models in allowing popular politics to mold the continuing evolution of its disability pensions. Large budget surpluses resulting from tariff revenues and a competitive electoral politics that thrust the veterans' vote into a position of prominence in national and state elections, led to an enormously expanded population base of the American pension system. It became, in effect, an old age pension for all veterans older than 62 that cost, by 1914, $5 billion annually.

The American pension system served as a negative reference point for efforts in the World War I era that ultimately created the modern system of care and assistance for disabled veterans in Western societies. Its costs, partisan manipulation, and refusal to examine possibilities for disabled veterans' lives other than as permanent clients of the welfare state, all were rejected by those planning and implementing the national programs that emerged out of the unprecedented scope and scale of needs created by men injured in the Great War. At the war's end, 752,000 British veterans, 1,537,000 Germans, just over one million French, 70,000 Canadians, and 200,000 Americans, among others, were classified as disabled or chronically ill as a consequence of service. The positive reference point was provided by the progressivist efficiency ethic of modern industrial society, which conceived of the individual as a social and economic resource to be formed and conserved through rational state planning and, relatedly, by the experience of the successful vocational rehabilitation of victims of industrial accidents.

Although national variations in implementation and administration existed, the conceptual unity among the major belligerents began with a consensus around the goals of both the most complete physical restoration of the individual as possible and aggressive socioeconomic normalization. These goals were conceived of as a *right,* an entitlement that the veterans had earned through sacrifice. However, the ground on which this right was to be constructed shifted subtly from the "sacred debt" to maintenance by the state proclaimed by Revolutionary France. The disabled veteran possessed the right to be restored to the position of a self-supporting, productive modern citizen. The state and cooperating private agencies were to approach the disabled man with practical programs that encouraged him to be rehabilitated. The medical phase of treatment would be accompanied by occupational and physical therapy to accustom him to doing practical, worklike activities while gaining strength and agility. Even before completing medical treatment injured men might be put to useful industrial work, which helped some of the European belligerents to deal with acute wartime labor shortages. The most complete physical restoration possible must have its complement in social and economic restoration in civilian life, an argument recently advanced by civilian rehabilitation specialists, who had begun decades before World War I to apply these same ideas to disabled children and victims of industrial accidents in Britain, Belgium, France, and Germany. The United States had just made a national commitment to civilian rehabilitation in legislation passed only months before the country entered the European war.

Opportunities were to be presented to the disabled veteran for vocational rehabilitation geared to what he could do in spite of his losses. A man's options for work should be fitted not only to physical condition but also to his prior occupation and class origins and to such aspects of the larger social and economic context as local job markets where he was likely to reside. Analogous arrangements were to be created to assist neuropsychiatric casualties and those suffering from chronic illness, the most common of which at the time was tuberculosis. Pension systems, free prosthetics that emphasized function over aesthetics, preference in government employment, and fully subsidized medical care were promised as a reward and as an aid to—not a substitute for—normalization.

During the balance of the twentieth century, public policy sought to improve and to elaborate on, rather than find substitutes for, this program. Everywhere it was installed, the program faced similar problems. Three were especially pressing. First, there was the problem of impersonal administration. The large masses of disabled men dependent on state services came to feel demeaned as cogs in a vast bureaucratic machine, even while they were lauded as heroes. One way of confronting the perpetual complaints about bureaucratic administration, as was done in Canada and the United States, was to include disabled veterans and their organizations in planning and administering programs in the belief that they could do the job more compassionately and efficiently, with more credibility than career civil servants. Second, the problem of containing long-term costs was persistent, especially as the men whom the state was obligated to assist aged and experienced health crises. Governments found that commitments made in the flush of patriotic obligation and in times of economic expansion and fiscal stability ultimately became a burden in hard times. The political costs of cutting benefits were enormous, so governments attempted in World War II to learn one lesson from World War I: The armed forces inducted many men with existing medical and psychological conditions, and these conditions were often worsened by military service. When and where circumstances allowed for systematic manpower planning, as in Australia, Britain, Canada, and the United States, governments raised induction standards to exempt or, in line with wartime labor shortages, provide national service opportunities for men who were already feeble, sick, or emotionally unstable. This policy was geared especially to weeding out those vulnerable to neuropsychiatric breakdowns. Even with pre-induction screening, it was increasingly recognized that neuropsychiatric problems were caused not only by combat, but also by military service that pulled men out of their normal lives and subjected them to psychological pressures that many could not handle. Once viewed as evidence of malingering or cowardice, neuropsychiatric illness became one of many new illnesses and impairments that late twentieth-century armed forces and governments had to take into account. This was the third problem, and it grew more insistent in the late twentieth century. The changing nature of warfare created new sources of disability, such as exposure to radiation among those military personnel ordered to be present near nuclear weapons tests in the 1940s and 1950s, exposure to the chemical poisons that resulted in Agent Orange illness among troops deployed in Southeast Asia, and Gulf War syndrome.

Throughout the twentieth century, governments in the developed world succeeded in achieving improved subsidized medical care, improved vocational rehabilitation, and innovations in prosthetic and assistive devices for disabled veterans. But the way forward was by no means even. Economic contractions limited the ability of governments to fund assistance programs for growing numbers of veterans. In part, fears of escalating costs led to resistance to acknowledging responsibility for the new chronic illnesses caused by the changing conditions of war. Disabled and able-bodied alike, veterans often found that the state was less generous to them than it had been to their grandfathers and fathers who were veterans of previous wars. During the twentieth century, however, the outstanding development in the field of public policy was the growth and improvement in all facets of the disabled veterans' provision.

### *The Experience of Solidarity*

So often is the disabled veteran portrayed in popular culture, journalism, and scholarship as a client of the welfare state that there is a tendency to believe that the ultimate source of his social identity and group formation is his relationship to the state. Disabled veterans' organizations have formed for the purpose of pressuring the state to be more generous in financing entitlements and giving symbolic recognition, and these groups have built solidarity around activity as a political pressure group. While the state has been deeply involved in the lives of disabled veterans, the point is easily exaggerated. There are three distinct sources of the process by which disabled veterans have come to understand themselves as a group and to organize as such: an historical event (participation and injury in a war, in specific historical, cultural, and political contexts); an experience of medical treatment, rehabilitation, and reintegration; and an ongoing relationship with government as a source of material benefits and symbolic recognition. The state is, of course, implicated in all of these, for it is the state that has put men in uniform, cared for them when injured or ill, and assisted them on the path toward normalization. However, each of these sources also owes a great deal to interactions with the able-bodied public, to cultural representations of both disability and veterans, and above all, to a solidarity born of collective experience. While disabled veterans have had a singular and broadly ramifying relationship with the state, they have also had especially close relations with one another, and these relationships have been crucial in forming their identities and political orientations. This collective orientation contrasts with the experience, at least until recently in Western societies, of disabled civilians, which has been individual rather than collective.

At the heart of the collective nature of the disabled veterans' experience is disability itself; those injured in adulthood, after a lifetime of normal activity, have multiple psychological, social, and emotional needs that arise during medical treatment, rehabilitation, and reintegration. These needs hardly can be satisfied by government alone. The veterans' solidarity was built initially on the collective experience of military service, war, and injury. For reasons of efficiency and with an eye to inspiring high morale, military medicine developed the practice in the twentieth century of putting men with the same injuries and illnesses together for treatment, so that alongside the combat unit, the hospital ward and rehabilitation facility have been a *locus classicus* of disabled veterans' identity and group formation. It was in such facilities, through discussions with one another and not simply with doctors, that men came to understand the limits and possibilities of their situation and reached understandings about what for them might be a normalized existence. Lacking the psychological counseling that became widely available in the late twentieth century, disabled veterans of the world wars acted as their own counselors, talking about such essential issues as establishing new relations with parents, wives, children, and girlfriends; dealing with staring and other types of unwanted attention; confronting fears about sexual intimacy; learning to use prosthetics and assistive devices; overcoming environmental obstacles; framing realistic employment aspirations; and above all, avoiding the roleless, self-pitying, and anger-driven life that led frequently to alcohol abuse, probably the most common maladjustment of disabled veterans throughout history.

Cohorts were formed in these institutional settings that ultimately became the basis for smaller veterans' organizations composed of men with common injuries, such as the *Bund Erblindeter Kreiger* in Germany after World War I and, after World War II, the Blinded Veterans Association (BVA) in the United States and the Canadian Paraplegic Association (CPA). Disabled veterans have belonged to the larger veterans' organizations—both the mixed organizations, composed largely of the able-bodied majority of veterans, and the composite organizations, which brought together men with a wide variety of disabilities. It was, however, in these smaller, single-population organizations, built on shared experience and camaraderie, that the most complete synthesis of disabled veterans' needs and aspirations for normalization might be found. In such organizations, too, the struggle against the limitations imposed on people with disabilities was fought. The BVA led protests against New York City municipal health regulations that barred guide dogs from restaurants. One of the CPA's founders, Lt. John Counsell, a spinal cord–injured veteran, successfully campaigned to have the lightweight, self-propelling Everest & Jennings wheelchair made available to Canadian veterans to enhance their mobility.

We are now in a position to see that the disabled veteran's history and self-understanding is significantly more complex than may be grasped by merely considering him a client of the welfare state. At the core of his experience is disability—the negotiations and struggles of living with a disability in societies that frequently resist, at varying levels of consciousness, integrating people with impairments into the social systems of daily life. In this sense, although much—including particularly generous state assistance—has separated the experience of disabled veterans from that of disabled civilians, both populations have taken part in common struggles to win a broader place in the world.

*—David A. Gerber*

***See also*** Amputation; Disabled Veterans; Ethics; Veterans.

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## WHEELCHAIR

A wheelchair is any seating surface (e.g., a chair) that has wheels affixed to complement or replace an individual's ability to move from place to place. This includes everything from large, bulky, manually powered wheeled wicker chairs to high-tech, electric-powered wheelchairs that can climb stairs. In 1932, Herbert A. Everest, a mining engineer with a disability, and Harry C. Jennings, a mechanical engineer, collaborated to design and patent the cross frame wheelchair. They later formed Everest & Jennings, Inc., one of the largest international wheelchair manufacturers. Their design became the standard for the wheelchair industry that exists to this day.

Typically, a wheelchair consists of four wheels: two large wheels in the rear that are used for propelling the wheelchair, and two small wheels in the front that swivel, called casters. The large wheels support the majority of the individual's weight and provide the primary means of propulsion. The casters facilitate maneuverability; they are similar to the casters found on the front of grocery carts. Traditionally, wheelchairs are divided into two categories: manual and electric-powered. These categories are defined by the mechanism used to propel the wheelchair. A manual wheelchair is propelled by human power, and an electric-powered wheelchair is propelled by an electrically based power source (typically a battery and electrical motor).

A manual wheelchair is powered either by the individual using the wheelchair or by an assistant.

The most commonly recognized manual wheelchairs are seen at hospitals and nursing homes. Individuals who have the strength and endurance to independently propel the wheelchair typically use manual wheelchairs. They can propel the wheelchair in different ways. For instance, individuals with a spinal cord injury can use their upper extremities. Individuals who have had a stroke that affects only one side of their body can use one upper extremity and one lower extremity. Individuals who no longer have the strength to walk without a walker or cane or the endurance to walk with one can use their lower extremities. An assistant or attendant propels the manual wheelchair when individuals cannot do it themselves.

Manual wheelchairs can be divided into numerous categories based on their intended use and design. The most basic characteristic that distinguishes manual wheelchairs is the frame design, but wheelchairs are also categorized by style, material, and weight

### *Style*

A standard folding wheelchair has a cross-brace design (X-frame), which allows the wheelchair to fold laterally via a scissor-like action. These wheelchairs are very popular because they can be easily folded for transportation. The limitation to folding frame wheelchairs is that they tend to be heavy and have reduced performance characteristics compared with a rigid frame manual wheelchair. A rigid frame does not incorporate a folding mechanism into the design, thereby significantly improving aesthetics, performance, strength, and weight.

### *Material*

Another feature that distinguishes wheelchairs is the type of material used. Initially, manufacturers used steel in all manual wheelchairs (primarily mild steel) because of its low cost and ease of machinability. The last 20 years has seen numerous advances in the materials used to manufacture wheelchairs. Now they are made using primarily steel, aluminum, and titanium. Steel is limited to standard wheelchairs that have folding frame mechanisms. Aluminum is now used throughout the wheelchair industry, primarily in ultralight wheelchairs and some lightweight wheelchairs. Aluminum has a higher strength-to-weight ratio than mild steel, thereby reducing the overall weight of the wheelchair, and it has the added advantage of being resistant to corrosion. Finally, titanium has begun to appear in ultralight manual wheelchairs, further reducing the weight because of its high strength-to-weight ratio. Titanium also is resistant to corrosion. The key limitations to titanium are its relatively high material costs compared with steel and aluminum and the greater difficulty in machining or welding titanium.

### *Weight*

In general, there are three wheelchair weight categories: standard, lightweight, and ultralight.

Standard wheelchairs are typically folding frame wheelchairs that are manufactured using mild steel. They are the heaviest of manual wheelchairs, usually weighing more than 18 kilograms with limited adjustability in components. These wheelchairs are designed most often for temporary use and are usually found in medical facilities (e.g., hospitals and nursing homes).

Lightweight wheelchairs also are typically folding frame wheelchairs. They have many adjustable components and are available with many features. They also tend to be lighter than standard wheelchairs (typically between 13 and 18 kilograms) because they are usually manufactured using aluminum.

Ultralight wheelchairs have the best performance characteristics of the three weight categories. As expected, these are the lightest-weight wheelchairs (typically less than 13 kilograms) because they are manufactured using aluminum, high-performance steel, or titanium. However, the key difference between lightweight and ultralight wheelchairs, besides weight, is an adjustable rear wheel axle. A horizontally adjustable rear wheel allows for the optimal placement of the rear wheel on the frame. This makes it easier for the individual to reach the rear wheels during propulsion, reducing stress and strain on the upper extremities.

The frame is the most basic unit of a manual wheelchair and the most influential in terms of performance. However, the components that are attached to the frame to generate a functional manual wheelchair are significant as well. The key components are the tires, the wheels, the axles, the casters, the leg rests, and the armrests.

### *Tires*

Wheelchair tires are either solid rubber or pneumatic (air-filled). Solid rubber tires are almost always used with standard wheelchairs and sometimes with lightweight wheelchairs. These tires provide a hard ride and have a high rolling resistance, but they have low wear rates and are low maintenance. Pneumatic tires are almost always used with ultralight wheelchairs and sometimes with lightweight wheelchairs. These tires provide a softer ride, lower rolling resistance, and are lower in weight, but they have high wear rates and are high maintenance (particularly in maintaining appropriate air pressure).

### *Wheels*

The wheels are usually spoked (wired) or molded (mag). Wheel sizes range from 12 to 26 inches in diameter, depending on the purpose of the wheelchair. Molded wheels have low maintenance requirements; however, they are significantly heavier and less responsive than spoked wheels.

### *Axles*

Rear wheel axles are either fixed or quick-release. Like solid rubber and pneumatic tires, fixed axles are almost always used with standard wheelchairs, quick-release axles are almost always used with ultralight wheelchairs, and either fixed or quick-release are used with lightweight wheelchairs. Fixed axles are a bolt and locknut that require tools to remove and attach the rear wheel to the frame. A quick-release mechanism has a button on the end of the axle that allows for easy removal of the tire without any tools. This may be critical for disassembling a wheelchair when transporting it in an automobile. The fixed axle is low maintenance, while the quick-release axle requires frequent monitoring.

### *Casters*

The casters range in size from 3 to 9 inches in diameter, with the majority falling in the 5- to 8- inch range. The caster tires can be solid rubber or pneumatic but are limited to either mag or solid hub wheels.

### *Leg Rests*

The leg rests are fixed, swing-away, or elevating. They consist of a hanger that is attached to the frame and a footplate that supports the individual's feet. Fixed leg rests are integral to the frame; they produce a lighter-weight system since there are fewer components. Swing-away leg rests allow for the removal of the leg rests from the frame in order to facilitate transfers into and out of the wheelchair. Elevating leg rests allow the lower extremities to be positioned at different angles with relation to the seat surface, thereby raising and lowering the leg position. This is often critical to address an individual's specific physiologic issues (e.g., swelling in the lower extremities).

### *Armrests*

The armrests are either fixed height or adjustable height. Armrests facilitate transfers by providing a hand-hold for the individual. They support the upper extremities when the individual is not propelling the wheelchair, and they provide a means for weight-shifting if the individual has the strength to lift his or her bodyweight using the upper extremities.

*—Carmen P. DiGiovine*

***See also*** Assistive Technology; Seating and Positioning; Wheelchair, Electric; Wheelchair, History of.

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# WHEELCHAIR, ELECTRIC

An electric-powered wheelchair (EPW) is propelled by an electrically based power source, typically motors and batteries. An EPW is also referred to as a power wheelchair. The first powered wheelchair appeared during World War I when an engine was added to a manual wheelchair. The demand for the wheelchairs, however, did not exist until nearly 30 years later.

A joystick, similar to that used with a computer game console, is the most basic and common device used to control an EPW. Advancements in control systems allow individuals to control a wheelchair using any voluntary movement. For example, a wheelchair can be controlled using head movement, breath actuation, tongue movement, or lower extremity control. Initially, EPWs were merely heavy-duty, manual folding frame wheelchairs that were powered by lead-acid batteries, motors, drive belts, and pulleys. These conventional power wheelchairs were very simplistic systems. They required the use of the joystick to control the wheelchair's movement, and programmability did not exist. The seating system typically consisted of a sling seat and back upholstery, which significantly limited postural support for the individual.

The advent of the power base allowed for significant mechanical advancements in EPWs. The power base separated the EPW into two components: the base, which provided the mobility, and the seating system, which provided the postural support. At the same time that a shift from a conventional power wheelchair to a power base wheelchair was taking place, significant advancements were occurring in electronic systems. Some of these mechanical and electrical advancements included the ability to add power tilt and recline systems and programmable performance settings (forward speed, turning speed, and acceleration).

Two types of drive mechanisms are used on EPWs: indirect drive and direct drive systems. Indirect drive systems (pulleys and drive belts) are used on conventional EPWs. Direct drive systems (gear box) are used on power base wheelchairs. Today, the vast majority of power wheelchairs use a power base with a direct drive system. Twelve V wet cell and 12 V gel cell batteries are used to provide the current required for EPWs. Typically, two 12 V batteries in series (24 V total) are required. Because of the maintenance requirements of wet cell batteries, gel cell batteries are the battery of choice. Although these batteries are similar in size to batteries used in the automobile industry, automobile batteries cannot be used for EPWs.

EPWs also can be classified based on the location of the drive wheels. There are three types of wheelchairs: front wheel drive, mid- or center wheel drive, and rear wheel drive. Traditionally, rear wheel drive EPWs were preferred because of their similarity to manual wheelchairs in design and maneuverability. However, center wheel drive wheelchairs have gained popularity because they provide increased maneuverability.

Push-rim–activated power assisted wheelchairs (PAPAWs) incorporate features of both manual and electric-powered wheelchairs. A PAPAW typically consists of an ultralight manual wheelchair with an external power source (batteries and motors). It complements an individual's ability to manually propel the wheelchair rather than replaces that ability, as is done with an EPW. The push-rim contains sensors that detect the direction and magnitude of force applied to it by the individual. The motors are then activated and assist in the propulsion of the wheelchair.

*—Carmen P. DiGiovine*

***See also*** Assistive Technology; Seating and Positioning; Wheelchair; Wheelchair, History of.

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WheelchairNet (www.wheelchairnet.org)

# WHEELCHAIR, HISTORY OF

Wheeled chairs have a long history. The earliest representation of a wheeled chair is an image on a sixth-century Chinese sarcophagus, although like the wheel and the chair, the history of wheelchairs probably dates back to 3500 B.C. It is possible that wheeled chairs entered Europe around the twelfth century, along with the wheelbarrow, but the first recorded use of self-propelled chairs by disabled people was not until the seventeenth century. Johann Hautsch made several rolling chairs for occasional use in Nuremberg during the early 1600s, and a disabled watchmaker named Stephan Farfler made a three-wheeled chair that he could propel by use of a rotary handle on the front wheel in around 1655. Mechanical "invalid chairs" (*wheelchair* is an idiom of the twentieth century) that employed a range of cranks and rotary devices increased in use from the late seventeenth century. They were designed as a means of transport primarily for the wealthy. By the beginning of the eighteenth century, wheelchairs began to appear in surgical and medical instrument catalogues as vehicles to transport patients. Styled like armchairs, these wood, wicker, or iron machines, with large wheels at the front and one caster at the rear for balance, were ornate, heavy, and cumbersome.

A variety of forms of the bath chair, originally designed around 1750 by James Heath of Bath to transport the sick to take the waters at the pump room or to bathe in the baths, dominated the British scene in the nineteenth and early twentieth centuries. The bath chair was halfway between an apparatus for injured, sick, or disabled people and a rickshaw-like mode of transport used by wealthy Victorians. Toward the middle of the nineteenth century, wooden wheelchairs with caned seats and backs also appeared, especially in the United States, where Civil War veterans used them. However, despite the introduction of wire-spoke wheels and rubber tires (borrowed from the bicycle) at the end of the nineteenth century, few wheelchairs during the first half of the twentieth century facilitated independent mobility outdoors.

The 1950s in both Britain and the United States saw the ascendancy of the relatively lightweight, tubular-steel folding wheelchair. The most celebrated example of this design is probably the Everest & Jennings (E&J) single X-brace folding wheelchair, first developed in 1933 by Herbert Everest (a wheelchair user since 1919 after a mining accident) and his partner Harry Jennings. However, the "invention" of the E&J wheelchair was not an isolated event. Chester Hockney had patented a tubular-steel folding wheelchair in 1907, and in Britain J. and A. Carters offered a wooden "folding" wheelchair in 1902. An American contemporary of E&J, Samuel Duke, also developed a tubular-steel folding wheelchair in 1934 from which he started the American Wheel Chair Co., and Dingwall & Son (Engineers) Ltd. marketed the first British tubular-steel folding wheelchair in 1948.

In contrast to earlier wheelchair designs, the folding tubular-steel wheelchairs afforded wheelchair users the ability to leave the home and travel for the first time. In addition to their ability to interface with other forms of transportation, folding tubular-steel wheelchairs were around half the weight of their wooden predecessors, and with large propelling-wheels at the rear and casters at the front, they were better able to negotiate steps and curbs.

In both North America and Britain, the rise to dominance of the tubular-steel folding wheelchair was due in no small part to the actions of the state. Shortly after World War II, both the U.S. Veterans Administration and the Canadian Department of Veteran Affairs began to supply E&J wheelchairs to disabled veterans. These lucrative contracts enabled E&J to grow into the most successful wheelchair company in the United States, holding a near monopoly on the North American prescription market by the 1960s. In Britain, too, the monopoly of the state-run wheelchair service, with its concentration on standardization, facilitated the ascendancy of the tubular-steel folding wheelchair when the Ministry of Health designed and distributed its own version (the Ministry Model 8).

Equally important, however, the ascendancy of the lightweight folding wheelchair design was due to wheelchair users' increasing control of the technology. Whereas World War I produced colossal numbers of soldiers returning with missing limbs, to which the technical solution was the prosthesis, World War II and the mass production of penicillin by 1945 resulted in a new constituency of *active* wheelchair users: people surviving with spinal injuries. The burgeoning of state-organized resettlement and rehabilitation services, including rehabilitation engineering, raised expectations among this group of being independent. The polio epidemics of the late 1940s and early 1950s, thalidomide in the 1960s, and the Vietnam War in the 1960s and 1970s all had a similar effect.

In matters of wheelchair design, wheelchair users were predominantly concerned with making the technology lighter, more reliable, and higher performing. Although wheelchair manufacturers in both Britain and the United States adopted this innovative path, it was from wheelchair sports that the ultralightweight revolution drew inspiration. Emerging from independent shifts in rehabilitation practices and philosophy following World War II (initiated by Ludwig Guttmann in Britain and Tim Nugent in the United States), wheelchair sports generated groups of wheelchair athletes who began to tinker with their wheelchairs to improve performance. During the next 40 years, this experimentation eventually challenged dominant thinking about wheelchair design and set the tone for manual wheelchair technology at the end of the twentieth century. The symbol of this sea change was Motion Designs' Quickie, an ultralightweight rigid-frame wheelchair developed by Marilyn Hamilton, Jim Okamoto, and Don Helman in 1979. Quickie transformed the orthodoxy of what an "everyday" wheelchair should look like and how it should function. Reworking innovations developed by wheelchair athletes such as Jeff Minnebraker, Motion Designs introduced color, aesthetics, and high performance to the mass wheelchair market.

Powered wheelchairs first emerged in a form that people with severe impairments could use in the late 1940s and 1950s. Despite a range of designs that existed during this period, it was George J. Kline's development of a friction motor and joystick in 1953 that influenced the form of powered wheelchairs for the next two decades: standard wheelchairs with motorized attachments. Designs for powered mobility progressed through the 1950s and 1960s, and more robust indoor/outdoor designs such as Raymond Biddle's BEC wheelchair emerged. The late 1960s also saw the introduction of proportional controllers by the Motorette Corporation and Penny & Giles, along with the greater use of microprocessors and computer technologies in wheelchair controllers.

Special or adaptive seating was another important innovation in wheelchair design that emerged from pediatric services in both Europe and North America during the early 1970s. Innovators in special seating were motivated by finding technological solutions to the problem of pressure sores and support for skeletal deformities, joint instability, and unusual body dimensions, but inextricably linked with those solutions was the idea that this technology would facilitate social inclusion for people with severe and complex physical impairments. Originally, seating engineers designed their seats as inserts, but during the 1980s, they worked with wheelchair manufacturers to develop a separate chassis on which to mount either standard or special/adaptive seating. This innovation led to one of the most significant design changes in powered wheelchairs in the 1990s: the power chassis, which divorced wheelchair design from the anthropometric and ergonomic considerations of seating.

In the early twenty-first century, wheelchair design is reaching for the stature of high technology with the introduction of the IBOT and the push-rim–activated power-assisted wheelchair (PAPAW). The IBOT, developed by Independence Technology, is a powered wheelchair that incorporates gyroscopes and computer technology to enable it to stand, be in motion at standing height, negotiate steps and curbs, and travel over a variety of uneven terrains. The PAPAW, currently marketed by a number of large wheelchair manufacturers, is a hybrid of powered and manual wheelchair technologies that employs motors to supplement the power applied by the user to one or both push-rims during propulsion or braking. It remains to be seen whether either design will dominate wheelchair provision in the future.

*—Brian Woods and*
*Nick Watson*

***See also*** Assistive Technology; Participation; Physical Activity; Seating and Positioning; Wheelchair; Wheelchair, Electric.

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## WILHELM II, EMPEROR

**(1859–1941)**

*German emperor*

Wilhelm II was, from 1888 to 1918, the last German emperor and Prussian king. Under his reign, the German Empire, the so-called Wilhelmian Empire founded in 1870/1871, was transformed from a backward agrarian country into one of the leading industrial nations of Europe. However, the great European and global ambitions of Germany led to World War I, which in turn led to 10 million casualties. The end of the war was essentially also the end of the German monarchy.

Emperor Wilhelm II was born on January 27, 1859, as Prince Friedrich Wilhelm Albert Victor. He was the first child of Prince Friedrich Wilhelm of Prussia, later Emperor Friedrich III, and his wife, Victoria, Princess Royal of England. Because of a difficult breech birth, Wilhelm II's left arm was paralyzed and about 15 centimeters shorter than the right. It was debated whether or not his brain was damaged during birth because of a lack of oxygen. His physical impairment had great biographical and historical consequences because it did not fit with the social image of a crown prince. His mother, in particular, could never come to terms with it. Numerous often cruel attempts at therapy and a merciless education from his tutor shaped the childhood of Wilhelm II and most likely led to his later rejection of his parents and their liberal outlook. His cruel tricks and violent verbal attacks, which occasionally had serious consequences for foreign policy, were well known. Early in his life, Wilhelm II's psychological health was doubted by his own family, as well as by contemporary psychiatrists.

After studying law and political science in Bonn, marrying Auguste Viktoria in 1881, and receiving military training, Wilhelm II took over the reign from his father, who had ruled only briefly. His political influence varied during his 30-year reign. Wilhelm II embodied the many ambivalences of his epoch: He encouraged scientific and technical development and enlarged the Navy to satisfy his global militaristic ambitions. His relentless fight against the Social Democrats, his antiparliamentary stance, and his unrealistic sentiment about the God-given rights of the monarchy exacerbated internal political conflicts. In November 1918 Wilhelm II fled to Doorn, in the Netherlands, to escape the first German Republic and, most likely, to avoid being indicted as a war criminal.

He lived there until his death on June 14, 1941. He hoped until the last that the monarchy would be reinstated, and apparently he could not see any fundamental contradictions between National Socialism and his own political views. Not least his notorious anti-Semitic diatribes made clear that there were important ideological continuity lines in German politics.

*—Petra Lutz*

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## WILLOWBROOK STATE SCHOOL

Willowbrook State School in New York was conceived in the late 1930s by parents and professionals concerned about those who were then called “mentally deficient.” When proposed, it was intended to be a state-of-the-art facility to care for and educate such persons. As such, it joined the ranks of many large American institutions that were also proposed and built for such purposes. These had begun to be constructed in the United States during the mid-nineteenth century and continued to be built into the twentieth century. Such places were part of society’s overall efforts to provide for the welfare of people who, before around 1850, had no avenues for education and self-betterment. At first, the schools tended to be relatively small places whose basic purpose was to educate residents and, if possible, return them to their communities. Over time, with the advent of the scientific movement of eugenics—a viewpoint that created fear of people who were seen as having genetic abnormalities—institutions became less educational and more custodial. In the 1920s and 1930s, they regularly practiced sterilization of residents as part of society’s solution to what was called “the menace of the feeble-minded.” Conditions in New York institutions worsened significantly during the Depression and again during World War II.

The immediate reasons for Willowbrook State School’s construction on Staten Island stemmed from parents’ perceived need for such an institution near New York City. A multipurpose hospital located on Randall’s Island had been closed down. Parents in New York City in the 1930s began to lobby for a school to be built and formed a coalition with professionals from the American Association on Mental Deficiency. Staten Island was considered the ideal place; it was within the City of New York but geographically isolated since no bridge or tunnel linked it to the other boroughs. Staten Island was physically near, yet socially isolated and invisible, a clear pattern in the location of many institutions across the country. Despite community resistance, $12 million was allotted for construction at the Willowbrook site.

Thus, Willowbrook State School was built in the late 1930s, an era when the government provided resources for many public works. This explains why its buildings are similar to other institutions built at the same time, to some degree sharing certain basic architectural features. Willowbrook was designed to serve as home, school, and work for as many as 2,000 residents. It was to take mainly residents from the city, but also it was intended to house those who lived in other New York State institutions and schools, which during the 1930s and 1940s had become increasingly overcrowded. It was to have state-of-the-art facilities and training for staff.

Just before Willowbrook was to open, World War II began. From 1940 until 1947, the grounds served as Halloran Veterans Hospital, which was operated by the military. After the war, a prolonged battle emerged between New York State and the Chiefs of Staff about returning the facility to New York State for its original purpose. In 1947, the Chiefs of Staff relented to public pressure, and Willowbrook State School received its first students with developmental disabilities. Between 1947 and 1954, veterans and disabled persons shared the facility. Governor Dewey found himself in a difficult position of having to be sympathetic to both the pleas of veterans who wanted Willowbrook to remain their home and those of parents who needed placements for their children. Eventually the veterans were forced to leave but not without resistance.

The school’s initial years of operation were documented in the only borough-specific daily newspaper in New York City, the *Staten Island Advance.* Some articles also appeared in the *New York Times* and *New York Post.* These articles reveal the hopefulness of the situation when the school first opened. Willowbrook quickly became the largest employer on Staten Island, and the care of the residents, while perhaps primitive and scientifically naïve by current standards, bore no resemblance to the neglectful and abusive conditions that came later in its history. In its early years Willowbrook was one of the more progressive and well-informed institutions of its type. There was even a staff-training manual, a rarity for the era. This is not to say that there was no abuse in these early years, as evident from oral histories of persons who came to Willowbrook during this time. The first major case of abuse reported in the newspapers occurred in 1952.

Willowbrook accepted “patients” quite easily. All that was needed was a physician saying that the child or adult required evaluation. This could be done at the facility itself, which resulted in a “drop-off” policy.

Census figures taken from newspaper accounts indicate a rapid initial growth in Willowbrook's population, including the admission of many young children. During the 1950s, there was evidence of some overcrowding, and with federal funds, the facility built additional buildings in the early 1960s to accommodate a larger and younger population. During this same period, the quality of life on the wards at Willowbrook appeared to deteriorate significantly. This occurred for primarily two reasons. First was the broadening of the admission criteria so that almost any person, with or without disability, could and would be admitted. Willowbrook began to be used as a warehouse for the "socially undesirable" of New York City, and this led to a great increase in the number of people living there. As many as 6,000 patients lived on the grounds, and at least a substantial minority had no disability. The second reason for deteriorating conditions was that New York State experienced a terrible budget shortfall during the 1960s, and the City cut the budget in all service sectors. This combination of census increases and financial cuts led to an increase in the resident-to-staff ratio at Willowbrook. In 1965, Robert Kennedy compared conditions at the school to a "snake pit." Given the number of patients at Willowbrook, the manipulation of parents to consent to medical research, and many family members' relative lack of concern, the staff used the residents during this era in various forms of medical experimentation, which while technically legal at the time were by today's standards illegal and unethical. This included the purposeful infection with hepatitis of children who had intellectual disabilities.

With so many people living at Willowbrook, with so few people taking care of them, and with a lapse in government support or oversight, a social disaster occurred. In fairness, such disasters occurred not only at Willowbrook but also at institutions all over the United States during this period. There appears to have been an epidemic lack of social conscience. As bad as conditions were at Willowbrook, it may not have been the worst of institutions in the United States. During this period, children and adults with and without disability who found themselves in institutions such as Willowbrook were systematically subjected to the most abusive and neglectful living conditions, outside of the concentration camps in World War II and the Civil War, perhaps ever created in the history of the United States. Because of overcrowding and inadequate resources, conditions on the wards at Willowbrook became "sub–kennel-like." Neils Erik Bank-Mikkelsen, a Danish visitor to the school in the 1960s, remarked, "In Denmark we don't let our cattle live this way."

In the early 1970s, additional budget cuts created nearly unbelievable conditions at Willowbrook. Staff-to-resident ratios were as low as 1 or 2 to 70. This essentially meant that no supervision at all was possible on many wards. The feeding time for children who could not feed themselves fell to approximately three minutes. Many "patients" were starving, and some died from asphyxiating food while being fed. During the early 1970s, a situation already completely unacceptable on moral or legal grounds became exacerbated, intolerable, and without precedent in American civil society.

Despite newspaper articles that exposed the conditions at Willowbrook, nothing was done. Jane Curtin of the *Staten Island Advance* wrote several articles about Willowbrook and documented the conditions there with photographs. Parents who had children at Willowbrook, particularly the Parents Benevolent Association, began to protest the intolerable situation. In the early 1970s, these parents were joined by professional staff employed at the school.

Finally, in early 1972, at the invitation of Dr. Michael Wilkins, one of the physicians allied with the parent group, a young television reporter for the ABC network, Geraldo Rivera, was given a key to one of the wards and "invited" to Willowbrook to record conditions (Rivera 1972). This event was to change the course of history for people with developmental disabilities. Rivera arrived on the Willowbrook campus unannounced and with a television crew. Without permission, he and crew entered building number six and videotaped. Rivera's tapes were broadcast nationally. They graphically depicted the neglect and abuse of children and adults. The images were accompanied by a narrative describing the smell of feces, urine, and death. The videos showed children and adults unclothed, lying in their own filth, and some restrained in straitjackets, sitting on the floors in crowded, unsupervised "day rooms." Rivera's tapes were so graphic, so condemning, that their national broadcast virtually began a movement to close institutions like Willowbrook overnight.

The parents who had been demonstrating, but "shouting in the wind" as one of them put it, were joined by various groups and filed a lawsuit in federal court over the inhumane living conditions. This lawsuit began the legal processes that resulted in the signing of the Willowbrook Consent Decree in 1975. Lawyers for the plaintiffs, that is, individuals and organizations representing the interests of the more than 5,000 residents who lived at Willowbrook at the time, and lawyers for New York State spent several years working out a detailed agreement about the process for and conditions of closing Willowbrook. The consent decree, a monumental legal agreement, became a model for similar decrees around the nation. The signing into law of the Willowbrook Consent Decree by Governor Hugh Carey is another chapter in the legacy of Willowbrook and one of the most significant events in the civil rights movements by and for people with developmental disabilities. Its history is documented in the 1984 book *The Willowbrook Wars* by Rothchild and Rothchild. It is important to consider not only the negative heritage of Willowbrook but also its positive legal impact on the civil rights of this population.

The Willowbrook Consent Decree created what is known as the Willowbrook class. The class contained anyone who resided at Willowbrook at the time the decree was signed into law. The consent decree described the conditions of placement that had to be met for anyone in the class, down to the number of towels he or she was to have. The decree created a very detailed system of monitoring and oversight of the class members, including the Commissioner's Task Force on Willowbrook that directly evaluated class members' current living situations. The obligations specified in the consent decree are to be met until the last of the "class clients," as they are sometimes referred to, pass on. This means, incidentally, that the Willowbrook case, in some form or another, is one of the longest open cases in American legal history. Since March 1993, the Willowbrook Consent Decree has been legally known as the Willowbrook Permanent Injunction.

Partly because New York State had decided to decrease its populations in all state institutions and state schools, in 1978 it created the Office of Mental Retardation and Developmental Disabilities (OMRDD). It was the OMRDD that oversaw the closure of Willowbrook. The late 1970s through Willowbrook's closure on September 17, 1987, represents yet another important story in Willowbrook's legacy. During this time, a partnership among the State, OMRDD, and not-for-profit agencies created neighborhood and community-based supports and services for former residents of institutions such as Willowbrook. This was the era of "communitization" and "normalization," when huge steps forward were made in the civil rights movement for people with developmental disabilities. This is a particularly fascinating period and one not well documented either in books or in films.

It is very difficult to generalize about the current welfare of persons who lived at Willowbrook. How people have coped with their experiences at Willowbrook varies widely. Some were broken, perhaps irretrievably. Others were deeply scarred, and these scars are still visible in their behavior today. Still others have seemingly left Willowbrook behind in their lives. From their behavior, one cannot tell they were ever there.

In 1993, the College of Staten Island moved to its current location, the converted campus of the Willowbrook State School. The State spent more than $400 million for redesign and reconstruction. Some old buildings were torn down, and new ones were built. Almost all of the old structures have been refaced, and there is very little indication of the site's previous use. One sees instead a beautiful and expansive college campus. While such a refitting is both remarkable and praiseworthy, perhaps the one thing we should take away from the history of Willowbrook is to "never forget."

*—David Goode*

***See also*** Abuse and Hate Crimes; Children with Disabilities, Rights of; Community Living and Group Homes; Institutionalization and Segregation.

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# WITCHCRAFT

Technically, the term *witchcraft* hinders an understanding of the phenomenon that it intends to identify. Rather than a descriptive term referring to the practice of magical or diabolical arts, most scholars prefer *witch-hunting* because it redirects attention to those better understood as persecuted on behalf of economic, gender, racial, physical, and cognitive differences. *Witch-hunting,* then, identifies the practice of attempting to slander individuals—almost always women—on the basis of social transgressions. One can find episodes of witch-hunting throughout history, but often epidemics of witch-hunting broke out during times of extreme social duress. Specifically, charges of witchcraft were made against an individual who challenged established authorities—those who violated entrenched codes of appearance, economic stability, or belief. While such practices of slanderous accusation originated in Europe, this entry focuses on the variant strain of such behavior as it evolved in seventeenth-century United States.

## SEVENTEENTH-CENTURY NEW ENGLAND

Perhaps because witch-hunting was common in Europe, the Euro-American colonies participated in similar accusations from the very beginning of settlement life. Laws on witchcraft in the colonies all evolved from the 1604 English Statute (1 Jac. I, c. 12) that made "being a witch" punishable by death. Accusations of witchcraft were closely related to the experience of personal misfortune or a significant fall in social status. One consistent characteristic of witchcraft inquiries revolved around the accused and the accuser's health. Witches were often individuals who practiced midwifery in secret. Medical efforts by women led to suspicions among male authorities that the accused were exceeding their assigned roles in the domestic sphere. While mothers were expected to care for family members, treating others beyond that circle was considered illegal. Furthermore, the onset of inexplicable illness, bodily pains, and disability played key parts in the trial of witches; marks on and bodily ills in children, for instance, often prompted parents to worry about the source of such afflictions. In other cases, bodily blemishes discovered upon investigation of the accused's naked body provided convincing evidence of impropriety. In this sense, witch-hunting finds its grounding in interpretations of bodily vulnerability and difference. Those charged as witches were often accused of "looking different," and thus a hierarchy of appearance and functionality serves as a context for suspicions of witchcraft.

One of the earliest records of witch-hunting (1638) reveals that the case of Jane Hawkins of Boston turned on the fact that she had performed as a midwife during the "monstrous birth" in that year (Hall, 1991: 19). Since the Puritan magistrates considered "deformed fetuses" a sign of disfavor from God—therefore continuing the most ancient of ideologies about congenital disability—those present for such events were sometimes accused as a group. In Hawkins's case, she had been under suspicion for some time because she gave community women oil of mandrakes to facilitate their ability to conceive. Such acts angered a patriarchal establishment in that they violated conventions of gender-based authority. As a result, Hawkins was expelled from the colony with the consequent order that she not "meddle in surgery, drinks, plasters, or oils, not to question matters of religion, except with the elders' satisfaction" (Hall, 1991: 20). The mother of the disabled fetus, Mary Dwyer, also left the colony but returned to profess her faith as a Quaker in 1657. She was executed by the government in 1660 for heresy. While suspicions ran high during the seventeenth century toward women practicing the "medical arts," the birth of a visibly disabled child served as material evidence against those women who challenged the status quo. Two other Quaker women, Mary Fisher and Ann Austin, were stripped and searched for demonic "marks" during the 1650s. In each of these cases, bodies considered "deviant" prompted invasive investigations and secured the fate of those involved.

Symptoms considered disabling, such as seizures, deafness, vomiting, violent pains, or sickness, did not necessarily lead to accusations against the individuals affected; rather, such "disturbances of the body" often prompted others in the vicinity to be accused of supernatural manipulation. During outbreaks of witch-hunting, the different body itself was targeted as a sign and symptom of one's confederation with demonic forces. In 1648, Margaret Jones was hanged for causing disabling symptoms in those she touched; like Jane Hawkins, she too was suspected of practicing midwifery on the margins of colonial society. Jones's trial consisted of neighbors testifying that the accused had exchanged angry words with them for various reasons. One is struck while reading court testimonies from this period by the degree to which an accusation of witchcraft could be prompted by ordinary conflicts between residents—a missing utensil, a dropped dinner, or disagreements over land borders. All of these mundane events serve as legitimate evidence for an inquiry into witchcraft during this period.

Besides disease, disability, and congenital "deformity," charges of witchcraft also accompanied those who experienced bouts of severe mania, depression, or other psychiatric conditions. While such swings of emotion and cognitive states must have been relatively common among those living on the edge of what Puritan writers referred to as a "waste and howling wilderness," altered states of perception could lead to persecution. For instance, in 1641, colonist Mary Johnson was convicted of thievery. This conviction led the accused to confess to forming a compact with the devil and witnessing visions of the devil encouraging her while working in the fields and performing labors for her. This "voluntary" admission was the first recorded confession of witchcraft in the colonies, and Johnson was executed as a result (Hall, 1991: 23). Furthermore, one woman who was tried for slandering another with the accusation of witch was found not guilty based on the fact that she was "deprived of natural reason when she expressed those words charged on her" (Hall, 1991: 134). In 1671, Elizabeth Knapp was accused of being possessed because of her bodily mannerisms such as uncontrolled shrieks and outbursts of wild laughter. Readers of these transcripts encounter a number of individuals who profess their consort with demons in order to establish a state of mind that differed radically from that of most community members. Thus, some individuals went to their deaths while embracing the truth of an alternative psychiatric state of mind (what we might term "mental illness" today) in the guise of a confession of witchcraft. During these trials, the accused had no recourse to legal representation.

As mentioned earlier, once a charge of witchcraft was made credible through corroborating testimonies of malfeasance or "strange behavior," most individuals were physically searched for "witches' teats" or other discernible stigmata. Those who believed in witchcraft thought that witches met with devils at night, taking on the form of shape-shifting animals to suckle the devils. In other cases multiple bruises, moles, or visible blemishes could serve as physical confirmation of one's guilt.

By 1692, these relatively individual and isolated cases of consort with the devil turned into an unabashed rout of Satan as a conspiratorial presence controlling certain community members. The majority of charges during the Salem witch trials were similar to the previous cases cited here: seizures, possessions, monstrous babies, blemishes and deformities, personal misfortunes, and mental illness. When a group of girls experienced symptoms of "diabolical possession," the community hunted down scapegoats. The first three to be arrested—Sarah Good, Sarah Osbourne, and a West Indian slave named Tituba—led to a wider net of conspiracy, and ultimately, at least 19 individuals were executed for their presumed roles in these events. Early on in the public panic, evidence presented suggested that the conspiracy was so great that witching practices included formal meetings in the woods with Satan, the observation of black Sabbath, and covenant signings.

Witch-hunting brought together a powerful social alchemy of physical and spiritual realms. While disability status proved central to nearly every witching episode, disability itself did not automatically result in condemnation. While all witches presumably had "marks" that exposed their allegiance to the devils, many of the accusers used their own experiences of bodily vulnerability as the impetus for charges against another. Such instances help to describe the degree to which communities will pursue extravagant explanations for the existence of bodily, sensory, and cognitive variations. As with many other phenomena, bodies seem to cycle through periods of greater or lesser vulnerability; such perceptions seem, in part, to be based on our socially derived investments in homogeneity and the contingencies of health. They also condition ways in which we experience our own bodies as sources of discrimination, ridicule, and fragility. Of course, the witch trials resolved nothing that they set out to cure. Rather, they succeeded in deepening cultural obsessions with disability as a marker of maligned social identities.

*—David T. Mitchell*

***See also*** Normality; Religion; Stigma.

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## WOMEN

*See* Family; Feminism; Progressive Era Women in Special Education

## WOOLF, VIRGINIA (1878–1941)

*British writer*

Virginia Woolf wrote experimental novels, essays, and political tracts that reflect on British traditions, Victorian behaviors, and the myriad changes that occurred in the modern era prior to World War I. She also wrote about her reflections on the root causes of a series of mental breakdowns that she experienced throughout her life, and linked her experience of collapse to creative output. Her first recorded episodes of mental anguish occurred around the deaths of each of her parents, although throughout her life she sought extended rest cures in nursing homes. During the same time period that the father of psychoanalysis, Sigmund Freud, was expatiating on a "talking cure," Woolf herself wrote about the creative potential to be found after periods of bleakness. Much of her writing depicts characters experiencing their environment in oppressive ways. Characters find it necessary to creatively resolve social and artistic undertakings, from paintings, to relationships, to dinner parties, and these efforts are salves that also supply readers with reasons to live. Many of her contemporaries and acquaintances, including her husband, believed that Woolf experienced bouts of manic depression, which might today be labeled as "bipolar disorder."

Woolf herself would seemingly indicate the material causes of mental anguish. *A Room of One's Own* (1929) focuses on the material necessities that would enable women to make more significant contributions to social thought and academic work. With male privilege a paramount feature of intellectual life, Woolf theorizes that feelings of suffocation in women likely derive from patriarchy. Particularly in her first novel, *The Voyage Out* (1915), she implies that the constraints of femininity result in suffocating mental illness. Exclusion from voting, education, governance, and citizenship results in women achieving much less than their potential. Judith Shakespeare, a character invented by Woolf to express this idea, lies buried at the crossroads while her male counterpart, William, achieves an "androgynous mind" and goes on to write masterful drama.

The later *Mrs. Dalloway* (1925) connects the depression of a conservative politician's wife who feels the pressures and demands of staging a successful dinner party to a disabled veteran's death wishes as he undergoes a rehabilitation regime that requires him to avow manliness. Many of Woolf's works concern the dissolution and restructuring of identity as a matter of social imposition. She puzzles over how female identity requires acquiescence to domination and the role of reflecting back an image to a man of twice his natural size. Catering to masculine cultural biases prevents women from undertaking their own careers, either as individual subjects or as artists in their own right.

In "On Being Ill," Woolf contends that illness merits as much literary attention as love, warfare, and jealousy; she delves into the separate experience of the world that is the vantage of the bedridden. Her work sits at the cusp of a series of literary narratives that seek to vivify body travails, mental anguish, and artistic resolutions to such psychic troubles. Although

Woolf records feeling intense personal negation and depression, she is not immune from the eugenicist ideas of her own era. Feminist scholar Cora Kaplan recounts Woolf's recording of her own repulsion toward her "vacant-eyed" and "idiot" sibling Laura (1870–1945) (Caplan, 2000: 314), who died in an institution. This kind of disavowal expresses what contemporary theorists consider a social hierarchy, under eugenics, of passable—as opposed to offensive—disabilities. Disability disavowal, or the participation in a hierarchy of functional "severity," has always troubled efforts at collective organizing for both feminist and disability politics.

*—Sharon L. Snyder*

***See also*** Gender; Siblings of People with Disabilities.

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## WORK INCENTIVES

Work incentives can take many forms. To understand their application, one must first understand that there are three primary stakeholders in the employment process—the employment candidate, the employer, and any third parties that may support the employment placement process. While most employers would state that securing a qualified employee is incentive enough, often various incentives are available to support the employment outcomes of certain groups in the employment sector that are either not represented or underrepresented. These incentives are intended to encourage the employment candidate to seek work, encourage third party service providers to support the placement of specific types of employment candidates, and encourage the employer to make certain accommodations in the workplace or underwrite additional costs associated with providing certain types of work supports.

Incentives for employment candidates that support individual career development, job placement, and employment retention and advancement take many forms. These incentives are typically offered by federal or state government agencies in recognition of the fact that a person who receives certain types of disability benefits and public entitlements and who returns to work will be more self-sufficient and less reliant on public programs. The benefit is not only to the individual, who is able to be more self-sufficient, but also to the government through savings associated with decreased or terminated entitlements and the communities in which the individual is now working and contributing. The Social Security Administration (SSA) offers a few of these types of incentives as part of their return-to-work agenda for people with disabilities. In addition to the examples illustrated below, similar work incentives exist for individuals who receive veterans' benefits, subsidized housing, Temporary Assistance for Needy Families, and other public entitlements.

The SSA administers two benefit programs for individuals with disabilities: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). SSI is a means-tested disability benefit program that provides benefit assistance to individuals who demonstrate economic need and who are 65 or older or have a disability. SSDI benefits are paid to individuals, and their dependents, who have been employed and have paid Social Security taxes under the Federal Insurance Contributions Act (FICA). The legislative history of both the SSI and SSDI programs reveals the desire of Congress to provide every opportunity and encouragement to the blind and individuals with disabilities to return to gainful employment. During the past 20 years, legislative and regulatory changes in the SSI and SSDI programs have been enacted to incorporate work incentives aimed at reducing the risks and costs associated with the loss of benefit support and medical services as a result of returning to work.

Work incentive provisions administered by the SSA can help people with disabilities in three significant ways. First, they can help individuals pay for services or items that they need in order to work and help them to maintain, or in some cases even increase, their cash benefits until they are stably employed. Second, work incentives such as the Plan for

Achieving Self Support (PASS), Impairment Related Work Expense (IRWE), and Blind Work Expense (BWE) enable people with disabilities to recover expenses they incur while working. Finally, extended Medicaid provided under Section 1619(b) of the Social Security Act and the Medicaid Buy-In Program and Medicare Extensions incorporated into the Ticket to Work Act remove disincentives associated with working and possibly losing health care. The goals of the work incentive programs are to assist individuals to achieve gainful employment, increase independence, facilitate empowerment, and acquire self-support.

Incentives for employers fall into two primary categories: (a) tax credits and deductions for providing specific accommodations and removing physical barriers to the workplace, and (b) financial reimbursement for wage and training offsets. However, these should not overshadow the myriad of other incentives that exist for hiring individuals with disabilities. A study by the Dupont Corporation in 1990 reported several incentives, among them the fact that 97 percent of workers with disabilities rated average or above in safety and 90 percent rated average or above in performance of their specific job duties. Second to the contributions of a qualified employee with a disability are other financial incentives for diversifying the workforce.

Tax deductions and credits offered to employers as incentives are administered by the U.S. Internal Revenue Service (IRS). The Removal of Architectural Barriers Tax Deduction allows employers to deduct expenses from their tax liability for making a worksite facility or public transportation vehicle more accessible to both the elderly and individuals with disabilities. The maximum deduction is $15,000. The Disabled Access Tax Credit is a financial incentive for eligible small businesses that for the preceding year did not have more than 30 full-time employees or more than $1 million in gross receipts. Eligible expenses under this credit are those that enable the business to comply with requirements set forth under the Americans with Disabilities Act. The maximum credit in any given year is $5,000, and the credit cannot exceed the tax liability for the year. There is a $250 deductible, and only 50 percent of the eligible access expenses after the deductible is applied are allowed. The Work Opportunity Tax Credit (WOTC) is another incentive authorized by the Small Business Job Protection Act of 1996. The WOTC is a federal tax credit that encourages employers to hire certain protected groups of job seekers (including individuals with disabilities that meet certain eligibility criteria) by reducing the employers' federal income tax liability by as much as $2,400 per qualified new worker. Provisions are also allowed for part-time workers and qualified summer youth workers. A final group of incentives for employers are those classified as On-the-Job Training Programs. These are typically administered by the Workforce Development System or State or Federal Vocational Rehabilitation System and provide the employer a financial offset to cover wages during certain training periods of new employment.

A final group of stakeholders in the employment process are service providers. These are community private and public for-profit and not-for-profit entities typically charged with assisting and supporting individuals with disabilities in securing, retaining, and advancing in employment. Incentives for this important stakeholder typically take the form of reimbursement for services and supports rendered. Service providers are usually engaged in contractual relationships with state agencies to accept referrals and deliver employment-related services and supports. However, many service providers are not solely reliant on these fee-for-service structures and may be benefactors of philanthropic trusts, charities, and other fund-raising activities. Deviating from this more traditional fee-for-service structure are outcomes-based models or incentives. Under this paradigm, service providers are paid for specific employment outcomes achieved, not the actual services and supports rendered leading to the outcome. Some systems weight the amount of the actual incentive based on the outcome achieved, and variations in this paradigm place value-added emphasis on the self-determination and empowerment of the individual being supported. One example of this new paradigm is the Ticket to Work and Self-Sufficiency Program administered by the SSA.

The Ticket to Work and Work Incentives Improvement Act of 1999 included a provision to establish the Ticket to Work and Self-Sufficiency Program, which allows SSDI and SSI beneficiaries to seek employment services, vocational rehabilitation services, and other supports of their choosing needed to obtain, retain, or maintain employment and reduce their dependence on cash benefit programs. The Ticket to Work Program is voluntary, and a beneficiary who has been issued a ticket may use it to obtain services and jobs from any Employment Network (EN) he or she chooses or to the State Vocational Rehabilitation Agency (SVRA), so long as that EN or SVRA is willing to accept the ticket. In turn, once the ticket is accepted, the EN or SVRA provides employment services, vocational rehabilitation services, and other support services to assist the beneficiary in obtaining, regaining, and maintaining self-supporting employment as specified in the beneficiary's Individualized Work Plan (IWP), if developed with an EN, or Individualized Plan for Employment (IPE), if developed with the SVRA. The EN or SVRA will receive payment only if the beneficiary achieves certain work-related outcomes. At any time, a beneficiary can retrieve his or her ticket from an EN or SVRA and reassign it to another, so long as ticket eligibility requirements continue to be met.

*—Thomas P. Golden*

***See also*** Employability; Employment; Job Analysis and Placement; Job Retention; Job Training; Right to Work.

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# WORKERS' COOPERATIVES

A worker cooperative is a business owned by some or all of its employees. Members of the worker cooperative work in the business and govern and manage it. Worker cooperatives are democratically run. Each worker-member has one vote in decisions about business policies, working conditions, and other matters related to how the business is run. This contrasts with other business structures in which the number of votes corresponds to the number of shares owned in the company. In larger cooperatives, members elect representatives to the board of directors. Some worker cooperatives employ workers who are not worker-owners.

Worker cooperatives have a long international history and have developed in different regions as a result of different influences. The consistent theme is the intent to create and maintain meaningful work at fair wages, in businesses that are owned and run by the workers as well as being part of the social and economic fabric of the community. Worker cooperatives are one type of cooperative business; others include supplier cooperatives (e.g., agricultural cooperatives) and consumer cooperatives (e.g., housing cooperatives).

Global and national associations and federations such as the International Co-operative Alliance (ICA) and the Canadian Co-operative Association (CCA) have articulated the principles and values followed by worker cooperatives. In addition to the democratic nature of the business, these principles include open and voluntary membership and the equitable sharing of income and profits with members after some reinvestment in the operation of the co-op. Emphasis is also placed on education, training, and information for members and the public.

A strong emphasis in these businesses is "cooperation among cooperatives." Each cooperative aims to use services and products created by other cooperatives. Cooperatives share a concern for their communities and try to contribute socially and economically to the sustainable development of their respective communities locally, nationally, and internationally.

Worker cooperatives operate in many sectors, from farming to manufacturing, home care service to auto repair. Worker co-ops can be set up as for-profit or not-for-profit operations, with any surpluses returning to members. They can be small or large: The Mondragon worker cooperatives, founded in Spain in 1956, have grown to be one of the largest complexes of cooperatives with more than 60,000 workers and 150 businesses.

There are three ways that worker cooperatives can directly benefit persons with disabilities:

1. The cooperative may include people with disabilities in its membership and give specific attention to policies and practices that support workers with disabilities. For example, attention may be given to disability benefits, the inclusion of support personnel, or flexible work hours.
2. The cooperative may be set up specifically by or with people with disabilities to create meaningful work for them. Worker cooperatives may be initiated by social service agencies attempting to help their client obtain more meaningful work, with the intention that the cooperatives will become independently operated over time.
3. The cooperative may be structured to provide services to people with disabilities. Recent examples include Cooperative Home Care Associates in New York, Home Care Associates in Philadelphia, and Cooperative Care in rural Wisconsin.

Some countries have promoted cooperatives through economic and social policies. In several countries, worker cooperatives and other business models sharing some of the characteristics or values of worker cooperatives have developed for people who have experienced long-term unemployment or underemployment, including those with disabilities. These include the self-help cooperatives of the 1930s, social firms, and consumer businesses. In contrast to these, Employee Stock Ownership Plan businesses are more than 50 percent employee owned and do not have mandates to support workers with disabilities.

Currently, worker cooperatives appear to be enjoying renewed interest and growth, and cooperative businesses are evolving with support from governments interested in assisting workers from vulnerable groups or locales to achieve economic success in several countries around the world.

*—Lynn Cockburn*

***See also*** Employment; Right to Work.

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## WORKSITE MODIFICATION

Worksite modification represents an area of assistive technology that combines the principles of human factors, ergonomics, safety, and disability. Worksite modification has become an important strategy in the provision of reasonable accommodation required under the Americans with Disabilities Act (ADA). As a result, worksite modification services may be requested by employers or vocational rehabilitation counselors with state or community agencies. They may also be requested in worker's compensation situations when a worker is trying to return to a jobsite.

An accurate job description is necessary when considering worksite modification services. The description should not merely tell how the job has been physically done in the past but should describe the functional requirements of the job. For example, "transporting shipping boxes to pick-up area" would be more accurate than "carrying shipping boxes. . . ." The job description should also include expected productivity levels so that the outcomes of worksite modification efforts can be quantified.

Other key components of worksite modification services are an analysis of how the elements of the job description are being performed and an accurate description of consumer abilities. These components enable the consumer and service provider to consider different work techniques or a different layout of the equipment, so that the consumer can use his or her abilities to do the job.

Human factors and ergonomics are useful in analyzing the relationship between the worker and elements of the workstation. For office applications, the addition of seating that provides adequate support and adjustability is often involved. Being able to vary one's position throughout the workday can help reduce the development of discomfort such as low back pain. Also, adequate arm support and positioning can address issues faced by individuals with carpal tunnel syndrome.

When equipment is involved, it may involve modifying equipment already at the workstation or introducing new equipment. When changes are made to existing equipment, consideration must be given to shared use of tools or machinery and maintenance of all safety features designed into the original equipment.

New equipment may include commercially available devices made for the public and perhaps not used for the specific job, or devices made specifically for individuals with disabilities. Use of commercially available devices enables the benefits of mass production and quality control to be realized.

Where there is no commercially available device to use or modify, custom-designed, custom-fabricated devices are an option. These custom devices are often low-tech and low-cost. Jigs and fixtures may be used, for example, to stabilize parts being worked on or to reduce the number of steps involved in performing repetitive work tasks.

Worksite modifications are often valuable to all workers present at the jobsite. This may become evident at shared workstations or when several workers are doing the same job. Professionals involved in worksite modification may include rehabilitation engineers, occupational therapists, physical therapists, or ergonomists. The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) has a special interest group on Job Accommodations.

*—Glenn Hedman*

***See also*** Assistive Technology; Right to Work.

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Rehabilitation Engineering Research Center on Workplace Accommodations (http://www.workrerc.org)

## WORLD BANK

The World Bank is an international organization that provides long-term loans, grants, technical assistance, and advice to help developing nations reduce poverty and increase their economic growth. The World Bank is one of the largest sources of aid to developing nations, annually providing more than $20 billion to fund hundreds of projects. The bank's loans and grants are given primarily to the poorer nations of the world to fund projects that are often not attractive to private investors. Many of these nations use the funds to establish industries, implement environmental programs, and conduct infrastructure projects, including the construction of dams, electrical facilities, and roads.

The World Bank is a family of institutions technically known as the World Bank Group. Originally, the World Bank consisted of only one institution, the International Bank for Reconstruction and Development (IBRD), which began operating in 1946. Later, four other affiliated institutions were formed and joined the group. They include the International Finance Corporation (ICF), established in 1956; the International Development Association (IDA), established in 1960; the International Center for Settlement of Investment Disputes (ICSID), established in 1966; and the Multilateral Investment Guarantee Agency (MIGA), established in 1988.

The World Bank Group provides aid principally through the IBRD and the IDA. The IBRD raises most of its funds on the world's financial markets and lends to developing nations at interest rates that tend to be somewhat below those of commercial banks and with longer maturities. By comparison, the IDA aims to promote economic development through providing concessionary finance from funds contributed every three years by individual donor nations. The IFC promotes private sector investment by supporting high-risk sectors and countries. The MIGA provides political risk insurance (guarantees) to investors in and lenders to developing nations. The ICSID settles investment disputes between foreign investors and their host nations.

Member nations own the World Bank Group, and they are jointly responsible for how the bank is financed and how its money is spent. Specifically, the IBRD is owned by 184 member nations, while the other agencies of the bank are owned by 140 to 176 members.

A president and board of 24 executive directors manage the day-to-day operations of the World Bank Group. The member nations of the bank or their constituencies appoint the executive directors. The executive directors elect the president of the bank. The president is traditionally an individual from the United States because it is the largest economy in the world and has the greatest share of investments in the bank. The president is elected for a five-year renewable term. He or she chairs meetings of the board of executive directors and is responsible for the overall management of the bank. The current president of the World Bank Group is Paul D. Wolfowitz, who has been president since 2005.

The World Bank Group employs approximately 9,300 people, including economists, financial analysts, educators, environmental scientists, and engineers. The bank's employees work in the organization's Washington, DC, headquarters or in one of its 109 country offices.

During the World Bank's 60-year history, its focus has changed a number of times. Initially, the bank was almost exclusively concerned with the reconstruction of Europe and Japan after World War II. During the 1950s and 1960s, the bank's funds were relatively limited, and they were largely directed into infrastructure projects such as building electric power stations and transportation systems. During the 1970s and 1980s, the bank's funds greatly increased, and the magnitude of its lending commitments rose. There was a new interest in alleviating poverty, and the bank began lending more funds to developing nations. During the 1990s, with the fall of the Soviet Union, the bank increasingly made loans to fund new developing markets and private economic activities in Eastern Europe.

## THE MISSION, PRINCIPLES, AND VALUES OF THE WORLD BANK

### *Mission (last updated June 30, 2003)*

> Our dream is a world free of poverty.
>
> To fight poverty with passion and professionalism for lasting results.
>
> To help people help themselves and their environment by providing resources, sharing knowledge, building capacity, and forging partnerships in the public and private sectors.
>
> To be an excellent institution able to attract, excite, and nurture diverse and committed staff with exceptional skills who know how to listen and learn.

### *Our Principles*

> Client centered, working in partnership, accountable for quality results, dedicated to financial integrity and cost-effectiveness, inspired and innovative.

### *Our Values*

> Personal honesty, integrity, commitment; working together in teams—with openness and trust; empowering others and respecting differences; encouraging risk-taking and responsibility; enjoying our work and our families.

Over the years, the World Bank has been strongly criticized by academics, political activists, and nongovernmental organizations. Some believe the bank has been too conservative in its lending practices and has not done as much as it could to help the poorer nations of the world. Others believe the bank has given too many loans to poor nations and saddled them with inordinate debt, which they cannot possibly afford to repay. When they do not repay, the bank has mandated draconian structural changes to their economies without giving due regard to the effects of such changes on the nation's social progress and political stability.

In the United States, both the political left and right have criticized the World Bank. Some on the political left want the bank to allow the poorest nations to cancel repayment of their loans so they can devote more of their resources to health and education. Debt forgiveness, however, shrinks the bank's income and thus perhaps its future loans. In contrast, some on the political right want to leave all development to private enterprise. The World Bank, however, receives most of its income from loans to middle-income nations and then turns some of the modest profit on these loans to help poorer nations.

Starting in 2000, the World Bank has become increasingly concerned with how to include disabled persons in the economies and societies of developing nations. To address this issue, the bank has undertaken several activities. For example, the bank is working to expand and improve the collection of disability data in developing countries. It established an online clearinghouse to make documents concerning the disabled readily available to its member nations and the general public. It sponsored several international conferences on disability and development. The first conference was held in December 2002 and the second in December 2004. The bank also recently launched an educational program aimed at incorporating the various dimensions of disability into development policies and practices at the urban and municipal levels. The bank's first course on disability issues, held in Guatemala in May 2004, emphasized the inclusion of the disabled in urban transportation, housing, financing, and other areas.

In the future, the World Bank will face many daunting challenges. It will have to reduce poverty in developing nations while their populations continue to grow. The bank will also need to increasingly address the growing plight of poor nations in sub-Saharan Africa. Many of these nations are experiencing the effects of the HIV/AIDS pandemic, which is rapidly reversing many of the economic and social gains made during the past 50 years. As a result of HIV/AIDS, an entire generation of people is being lost, the number of persons with disabilities is increasing, average life expectancy is decreasing, and infant and childhood mortality is increasing. To reverse the effects of this devastating disease, the economies, health care, and educational systems of these nations will need to be greatly strengthened—and in some cases totally rebuilt.

*—Ross M. Mullner*

***See also*** Developing World; Economic and Social Development, International; Poverty.

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# WORLD HEALTH ORGANIZATION

The World Health Organization (WHO) is the specialized agency within the United Nations (UN) concerned with protecting and improving the world's public health. WHO's main objective is to attain the highest possible level of health for all people of the world. The organization very broadly defines health as "a state of complete physical, mental, and social well being and not merely the absence of disease or infirmity." WHO improves health by setting norms and standards, providing countries with technical advice and assistance, and advocating changes in public health policies. WHO is also the world's foremost source of international information concerning demographic and health trends, the occurrence and burden of chronic and infectious diseases and disabilities, and the provision of public health, medical, and environmental health services by countries.

## HISTORY

A number of international public health organizations preceded the World Health Organization. The WHO can trace its history back to 1851 when 12 countries met at the first International Sanitary Conference held in Paris, France. Other organizations that were forerunners of WHO include the International Office of Public Health established in 1907 in Paris and the League of Nations' International Health Organization established in 1923 in Geneva, Switzerland. After World War II, when the League of Nations was broken up, the members of the newly formed United Nations met in New York to discuss establishing a new international health organization. They drafted the constitution of the WHO, which stated that the proposed organization's overall purpose was the promotion and pursuit of "the attainment by all people of the highest possible level of health." With the ratification of its constitution by member nations, the WHO came into formal existence in 1948.

During its initial years, WHO focused its activity on the demands of post–World War II reconstruction, including the rebuilding of health services in war-affected countries. In the 1960s and early 1970s, WHO worked primarily on mass campaigns for the prevention, control, and eradication of malaria, tuberculosis, and sexually transmitted diseases. It also conducted activities to improve maternal and child health, environmental sanitation, and nutrition. In the late 1970s, WHO worked with other national and international organizations to help stop the spread of the ancient deadly infectious disease smallpox. Through its efforts, smallpox was the first disease in human history ever to be eradicated. Starting in the early 1980s and continuing to the present, WHO has broadened its focus to include treating and preventing chronic diseases, improving environmental conditions caused by air and water pollution, providing health care technology, and ensuring the production and distribution of essential pharmaceuticals to member states. WHO has also become the world's "health conscience" by actively promoting human rights and the principle of equity in health among all people of the world, including persons with disabilities. According to WHO's constitution, "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political, economic, or social condition."

## ORGANIZATIONAL STRUCTURE

The organizational structure of the WHO has changed little since its establishment in 1948. WHO is open to all member states of the United Nations, along with other nonmember nations or states that are invited to participate. Since its inception WHO has attempted to have universal membership, reflecting the belief that health concerns cannot be confined within national boundaries but require cooperation across all countries. Currently, the WHO is organized into four divisions: the World Health Assembly, the Executive Board, the Secretariat, and the Director General.

The World Health Assembly is the supreme decision-making body of WHO. It is composed of representatives from 191 member states. All member states are represented in the assembly's plenary and legislative body. Delegations of member states consist of not more than three delegates most qualified by their technical competence in the field of health, preferably representing the national health administration of each member state. Representatives of relevant international organizations and recognized nongovernmental organizations are also permitted to attend the assembly as observers. The Health Assembly's main functions are to decide major public health policy questions and to determine the overall policy direction of WHO's six-year General Programme of Work. The assembly also supervises the financial policies of WHO and reviews and approves the organization's budget. The assembly has the authority to adopt regulations in such fields as sanitary and quarantine requirements; determine the nomenclature for diseases and causes of death; and establish standards with respect to safety, purity, and potency of biological, pharmaceutical, and similar products. These regulations are binding unless member states choose to opt out from them. The assembly meets annually, usually in May. Each member state has one vote. In practice, the majority of the World Health Assembly's decisions are presented as recommendations or resolutions, and most decisions are made by consensus.

The Executive Board is the executive body of WHO that works to put into action the decisions and policies of the World Health Assembly. It consists of 32 members. Specifically, the board prepares the agenda and program of work for the next meeting of the Health Assembly. The board also is empowered to take emergency measures in case of epidemics or disasters. The World Health Assembly elects member states that will sit on the Executive Board. It is customary that at least three of the five permanent members of the United Nations Security Council (i.e., China, France, Russia, the United Kingdom, and the United States) serve on the Executive Board at any given time. Upon election, board members serve in a personal capacity as health experts rather than as representatives of particular governments. Executive Board members serve a three-year term. Each year there is a rotating turnover of one third of the membership. The board meets twice yearly, in January and after the World Health Assembly meeting in May.

The Secretariat is the administrative and technical staff of the WHO. It consists of about 5,000 public health, medical, economic, and support staff and other experts. Members of the Secretariat work at WHO's global headquarters, in the organization's six regional offices, and at field offices in countries throughout the world. WHO's Secretariat focuses its work on articulating consistent, ethical, and evidence-based policy and advocacy positions; managing information by assessing trends and comparing performance; setting the agenda for and stimulating research and development; catalyzing change through technical and policy support in ways that stimulate cooperation and action and help to build sustainable national and intercountry capacity; negotiating and sustaining national and global partnerships; setting, validating, monitoring, and pursuing the proper implementation of norms and standards; and stimulating the development and testing of new technologies, tools, and guidelines for disease control, risk reduction, health care management, and service delivery.

The Director General heads the Secretariat. Nominated by the Executive Board and elected by the World Health Assembly, the Director General is appointed for a period of five years. Among the primary responsibilities of the Director General are appointing Secretariat staff, preparing annual financial statements, and drafting WHO's proposed program budget.

The global headquarters of the World Health Organization is located in Geneva, Switzerland. The organization also has six regional offices: WHO Regional Office for Africa, located in Brazzaville, Republic of the Congo; WHO Regional Office for Europe, located in Copenhagen, Denmark; WHO Regional Office for South-East Asia, located in New Delhi, India; WHO Regional Office for the Americas/Pan-American Health Organization, located in Washington, DC; WHO Regional Office for the Eastern Mediterranean, located in Cairo, Egypt; and WHO Regional Office for the Western Pacific, located in Manila, the Philippines.

The regional offices were created because of the early recognition that effective international health cooperation requires both global and local actions, and because some of the regions already had international health organizations (i.e., the Pan American Health Organization), which were incorporated into the WHO. Each region is managed by a director and has its own staff. The regions are responsible for the policies and activities in their respective geographic areas.

## DISABILITY-RELATED ACTIVITIES

The WHO undertakes many activities to identify, help, and protect people with disabilities. Specifically, it works to ensure the human and legal rights of persons with disabilities, provides community-based rehabilitation services to treat the disabled, conducts various surveys to estimate the worldwide extent of disabilities, and develops, tests, and widely disseminates measures of disability.

The WHO's Disability and Rehabilitation team (DAR), for example, attempts to ensure equal opportunity and promote the human rights of people with disabilities by supporting member states in framing and implementing policies and involving community participation. Major activities of the DAR include establishing methods to quickly identify and reduce the impact of impairment, improving access to rehabilitation facilities and services, integrating rehabilitation services into nations' primary health care systems, promoting community-based rehabilitation programs, and strengthening the interactions among people with disabilities, health care workers, professionals, and the community.

To measure the extent of disabilities in populations and to determine worldwide trends in the occurrence of disabilities, the DAR periodically conducts surveys. Based on the results of a recent survey (2003), the DAR estimates about 600 million people, or up to 10 percent of the world's population, experienced some type of disability that caused difficulties in common daily activities. It found that 80 percent of the world's disabled lived in low-income countries. In addition, the majority of people with disabilities are poor and lack access to basic services, including rehabilitation facilities. The survey also found that the world's disabled population is increasing because of such factors as population growth, medical advances that preserve and prolong life, war injuries, landmines, the spread of HIV and AIDS, malnutrition, chronic disease conditions, substance abuse, accidents, and environmental damage. These factors are creating an overwhelming global demand for health and rehabilitation services.

The DAR publishes a number of guidelines, technical documents, and reports on disabilities and rehabilitation. Many of its publications are available in hardcopy and online. All of them are in English, and some are also available in Arabic, French, and Spanish.

To measure the extent, severity, level of impairment, and treatment of mental health disorders, the WHO World Mental Health Consortium is currently conducting the largest cross-national mental health survey ever undertaken. This face-to-face household interview survey of adults representing the general population of several countries asks respondents to assess if, during the previous 12 months, they had or were treated for a variety of mental disorders (i.e., anxiety, mood, impulse control, and substance abuse disorders). The ongoing survey will interview nearly one-quarter of a million people in 28 countries.

Survey results from more than 60,000 respondents from 14 countries indicate that mental disorders are common and often undertreated. In developed countries (Belgium, France, Germany, Italy, the Netherlands, Spain, Japan, and the United States) between 36 and 50 percent of people with serious mental disorders were untreated in the year prior to the interview. In less-developed countries (China, Columbia, Lebanon, Mexico, Nigeria, and Ukraine), the problem was even greater, with 76 to 85 percent receiving no treatment. The level of impairment associated with serious mental disorders in all countries was found to be staggering. Persons with serious disorders reported they were so debilitated that they lost their ability to function for between 30 and 80 days during the same period.

The WHO also periodically attempts to determine the global burden of disease by measuring the impact of the loss of healthy life from a large number of infectious and chronic diseases and injuries. The global burden of disease combines the loss of life from premature death with the loss of healthy life from disability. Disability is measured in units of disability-adjusted life years. Calculation of the disease burden is based on a number of assumptions that involve decisions about ethical values or social preferences. The key factors are the potential years of life lost from death; the discount rate, or extent of time preference for human life and health; and the disability weights used to convert life lived with a disability to a common measure of premature death. The concept of the global burden of disease has been widely used by developing countries to calculate the relative cost effectiveness of health interventions as a basis of policy reform.

Finally, the WHO has developed and promoted several standardized measures of disability. It first issued a standardized classification of disability in 1980 when it published the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The ICIDH, however, suffered from several conceptual and technical problems and was difficult to use. In 1993, the WHO began an international collaborative process for substantially revising it. With the participation of 65 countries, the group developed various drafts of a new classification of disabilities and extensively field-tested them to ensure reliability, validity, and comparability across cultures, languages, age groups, and genders. In 2001, the WHO issued the International Classification of Functioning, Disability, and Health (ICF).

The ICF provides a common framework for describing and measuring disability at both the individual and the population levels. It incorporates both a medical and a social model of disability. Briefly, the ICF identifies three dimensions of human functioning: body function (physiological functions of body systems including psychological functions), activity (the execution of a task or action by an individual), and participation (involvement in a life situation). Decreases in these dimensions are viewed as dimensions of disability. Disability is broadly defined in terms of impairments (problems in body function or structure such as a significant deviation or loss), activity limitations (difficulties an individual may have in executing activities), and participation restrictions (problems an individual may experience participating in life situations). The ICF can be used to classify specific categories of functioning in these disability dimensions, with qualifiers to assess severity and to identify whether the category is being used as a capacity or a performance. The ICF is available from the WHO in English, French, Spanish, Arabic, Chinese, and Russian. A multilingual CD-ROM version is also available.

*—Ross M. Mullner*

***See also*** Developing World; Health; International Classification or Functioning, Disability, and Health (ICF/ICIDH); Translating Theory and Research into Practice.

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Directory of the United Nations (http://www.unsystem.org)

World Health Organization Offices:

WHO Headquarters, Geneva, Switzerland (http://www.who.int)

WHO Regional Office for Africa, Harare, Zimbabwe (http://www.afro.who.int/)

WHO Regional Office for the Americas/Pan American Sanitary Bureau, Washington, DC: (http://www.paho.org)

WHO Regional Office for the Eastern Mediterranean, Alexandria, Egypt (http://www.emro.who.int/index.asp)

WHO Regional Office for Europe, Copenhagen, Denmark (http://www.who.dk)

WHO Regional Office for South-East Asia, New Delhi, India (http://www.whosea.org)

WHO Regional Office for the Western Pacific, Manila, the Philippines (http://www.wpro.who.int)

## WULFF, HILDE (1898–1972)

*German social worker and children's advocate*

Hildegard Wulff was a German social worker who founded and ran homes for children with physical impairments. In addition, she was active in the Women's and Disability Rights movements. Wulff was born on January 7, 1898—the daughter of an industrialist family in Ruhrgebiet, West Germany—and contracted polio at the age of two years. Her father exhausted all medical possibilities hoping for her stabilization and recovery. Indeed, her long clinic and hospital stays caused a separation between Hilde Wulff and both of her sisters and excluded her from educational possibilities. These essential childhood experiences later turned Wulff toward the vocation of social work and the foundation of homes for physically disabled children. In 1921, she established the pediatric home "Urdenbach" in Düsseldorf. From 1923 onward, she involved herself with the "Selbsthilfebund der Körperbehinderten" (Self-Help Alliance of the Physically Handicapped; 1919–1931), the first emancipatory self-help organization representing the interests of the physically disabled in Germany.

At this time, Wulff was already fighting for an inclusive education of both disabled and "healthy" children in public schools. In April 1933, just a few months after the National Socialists seized power, Wulff founded the Children's Home "Neu-Westend" in Berlin. From 1935 until the mid-1960s, she ran the home "Im Erlenbusch" in Hamburg. During the Third Reich, she probably housed political and racial victims of Nazi persecutions in both places. For political reasons, Wulff resigned from the "Selbsthilfebund der Körperbehinderten," which had developed into the National Socialist and racial hygienic–oriented successor organization "Reichsbund der Körperbehinderten" (Reich Organization of the Physically Disabled). She and the children she cared for all survived the National Socialist period. On July 23, 1972, Wulff died in her home in Hamburg.

*—Petra Fuchs*

***See also*** Childhood, Youth, and Adolescence; Eugenics: Germany; Nazism.

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# X

## XENODISABILITY

The neologism *xenodisability* (*xeno* meaning foreign) is designed to be synonymous with *zoodisability* (*zoo* meaning animal). Both terms refer to disability in the animal world—that is, foreign from the human.

In 1995, a group of schoolchildren on a field trip near Henderson, Minnesota, found that 11 of 22 frogs they encountered had limb and eye deformities. Since that time, biologists across North America have noted that frogs with limb anomalies—absent, deformed, or extra legs—are being born at a prodigious rate. Evidence now suggests that farming techniques have changed soil contents, promoting the growth of a parasite that induces these deformities in frogs. Like the canary's extreme sensitivity to gas, which made it an early warning system for coal miners, animal disability can be a harbinger of problems to come in the relationship between human beings and the environment. But the meaning of such problems is far greater for humankind.

The place of disabilities in the animal world, as it relates to humans, is many faceted. Humans' reasoning about animals with disabilities is sometimes indicative of humans' own social peculiarities. The thirteenth-century physician Aldebrandino of Sienna was curious about why humans are unable to walk when they are born, as other animals can. He concluded that the mother's menstrual blood poisons the human child, and only after the blood has been cleansed from the child's body is it able to walk. Disability in humans is partly revealed by comparison with animals, and vice versa. By comparing ourselves with other creatures, we have "determined" that our opposable thumbs have been critical to our developmental advantage, increasing our functional abilities in comparison with the species-level "disability" of nonprimates.

Animals are also widely used in more focused research, both as models for conditions that disable humans (e.g., the mouse model for Rett syndrome) and as test subjects for interventions, at either the mechanical or the cellular/molecular level (e.g., both large and small animals used in stroke studies).

At the cultural level, animals have been a ready symbolic or metaphoric venue for disabilities for millennia, as in descriptions such as "blind as a bat." Literature abounds with disabled animals, even stutterers, like the cartoon character Porky Pig. But observing the culture of real animals with disabilities has been equally valuable, if only more recent. Jane Goodall noted that chimpanzees exhibit some mutual wound-tending behavior when one of their number is hurt. Since the 1950s, Japanese macaques have been observed to have significant rates of physical disabilities. One study found the incidence at birth to be nearly 15 percent. Although the study found that infant mortality for macaques with disabilities was three times that of those without malformations, maternal "caretaking" evidently overrules natural selection, as many survive. One research team is now making a concentrated study of these mother-infant dyads.

While we study macaques and other primates with disabilities, these same species are trained as assistants to human beings with disabilities, just as dogs and other animals are. Xeno/zoodisability is a field with rich potential for increasing our understanding of the meaning of disability.

*—Walton O. Schalick III*

***See also*** Rett Syndrome.

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# INDEX

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# CHRONOLOGY

**1500 BCE** Egypt: The Ebers Papyrus, a medical textbook, devotes an entire chapter to eye diseases. It also shows that deafness is well understood and that clinical knowledge has developed.

**400 BCE** Graeco-Anatolian Hippocratic writings coin the word e*pilepsy* for a convulsive condition they view as a disease rather than a possession or punishment. Today, it is estimated that more than 80 percent of the 40 million people who currently have epilepsy throughout the world have little access or no access to contemporary treatments.

**300 BCE** China: *The Yellow Emperor's Internal Classic* is the first text to outline acupuncture. Ordinances on emergency relief for the disabled date to the Han Dynasty, 206 BCE–AD 220. Fiscal and administrative disability classification date at least to the Tang Dynasty, 618–907.

**1250–1350** High point of medieval medicalization during which theoretical explanations for conditions gain currency in Western Europe. Prior to this time, in the most general of terms, lay explanations held more sway, ranging from the superstitious to the spiritual to the vindictive. With the founding of the universities, medical theory, typified by the four humors, became more influential in governmental, legal, and elite social circles. Disabling conditions like epilepsy, strokes, and paralyses, as well as psychiatric conditions, increasingly fell under the social control of doctors.

**1400** Turkey: Deaf people work in the Ottoman Court from the 15th to the 20th centuries. Sign language becomes a recognized means of communication among both hearing and deaf courtiers.

**1593** England: The origins of disability as a social and political category emerge with the first state disability benefits being enacted by Parliament for those disabled in war.

**1593** Europe and the United States: English Parliament initiates Europe's first national system of benefits for rank-and-file disabled veterans. The first veterans' homes—France's Hôtel des Invalides, Britain's Chelsea Hospital, and Frederick the Great's Invalidenhaus in Berlin—are established in 1633, 1685, and 1748, respectively. Following the American Civil War, the U.S. government responds with a system of homes, preferences in government hiring, land grants, free prosthetics, and pensions for disabled veterans (however, southern veterans were limited to usually scanty state pensions).

**1601** England: The Poor Law is passed to provide family and community support for those unable to make a living for themselves.

**1604** Laws on witchcraft in the colonies all evolve from a 1604 English Statute that makes "being a witch" punishable by death. During outbreaks of witch-hunting, the "different" body itself is targeted as a sign and symptom of one's confederation with demonic forces.

**1697** England: The first English workhouse for people with mental and physical disabilities is established in Bristol in 1697.

**1704** Bethlem Hospital in the United States has 130 residents housing the "furiously mad."

**1714** ◆ Canada: The Bishop of Quebec opens the first building in Canada exclusively for the confinement of mentally disturbed individuals. It is adjacent to Quebec General Hospital.

**1749** ◆ France and England: Denis Diderot pens one of the most influential treatises on the blind and education in his *Letter on the Blind* in which he argues that the blind can be educated. In 1784, Valentin Haüy opens the first school for the blind in Paris. He perfects a system of raised *letters* to enable the blind to read. In 1828, Louis Braille modifies a raised *dot* system invented by Charles Barbier, which is used today by blind persons to read and communicate. In 1847, William Moon, an Englishman, develops an embossed script based on Roman capitals that blind adults can learn to read in a few days. It is the first reading system for the blind to be widely adopted across the world, but because it is costly to print, the Braille system, which can be produced by blind individuals for themselves, overtakes Moon's system.

**1755** ◆ France, the United States, and Germany: The Abbé Charles-Michel de l'Épée establishes the first state-supported school for the training of young deaf children, where he teaches sign language. The school serves as an inspiration for the establishment of other European schools and has a dramatic impact on social attitudes toward the deaf. In 1817, Thomas Gallaudet and Laurent Clerc establish the Asylum for the Deaf (now American School for the Deaf) in Hartford, Connecticut. Clerc imports the French sign system, which influences the makeup of contemporary American Sign Language (ASL). In 1778, Samuel Heinicke establishes a school in Leipzig, Germany, where the "oral method" is used.

**1800** ◆ France: Victor of Aveyron, a "feral child" found in southern France, is brought to Paris. Jean Marc Gaspard Itard, a French physician, develops a systematic training program for the boy and works intensively with him for five years. Itard considered his attempt at educating Victor to be a failure because the boy did not learn to use a language. Nevertheless, Itard's disciples, including Edouard Séguin, Maria Montessori, and Alfred Binet, continue his work by establishing classes for children considered to be "mentally retarded."

**1802** ◆ France: The world's first pediatric hospital, L'Hôpital des Enfants Malades, is founded.

**1817** ◆ The American School for the Deaf is founded in Hartford, Connecticut. It is the first school for disabled children in the Western Hemisphere.

**1817** ◆ James Parkinson, a London physician, describes what is to become known as Parkinson's disease.

**1817** ◆ Thomas Gallaudet and Laurent Clerc open the American Asylum for the Education of the Deaf and Dumb in Hartford, Connecticut.

**1828** ◆ Frenchman Louis Braille, blind from childhood, modifies a raised-dot system of code, one of the most important advances in blind education. It not only allows the blind to read at a much faster rate but also makes it possible for the blind to be teachers of the blind. UNESCO creates the World Braille Council in 1952.

**1829** ◆ France: Louis Braille publishes an explanation of his embossed dot code.

**1832** ◆ Samuel Gridley Howe is chosen to direct what is later to be called the Perkins School for the Blind in Boston. It becomes the model for schools around the nation. Laura Bridgman and Helen Keller attend Perkins. In 1837, Ohio establishes the first state-sponsored school for the blind.

**1834** ◆ England: The English Poor Law Amendment stipulates five categories of those unable to work: children, the sick, the insane, defectives, and the aged and infirm. This sets the stage for the development of specialty institutions that isolate the disabled from the community.

**1841** ◆ P. T. Barnum purchases Scudder's American Museum in New York City. This moment is considered to be the beginning of the "Golden Age" of freaks, which persists until the 1940s. The tension between freaks and disability rights comes to a head in 1984, when disability rights activist Barbara Baskin successfully lobbies the New York State Fair to remove Sutton's Incredible Wonders of the World Sideshow, featuring a limbless man who performs as the "Frog Boy," from the midway.

**1843** ◆ Due to the influence of Dorothea Dix, an American social reformer, the Massachusetts legislature allocates funds to greatly expand the State Mental Hospital at Worcester. Dix also plays an instrumental role in the creation of 32 mental hospitals and becomes nationally known for her reform efforts. By the late 1840s, Dix focuses on developing a national plan that addresses the treatment of people with mental illness.

**1846** ◆ William Thomas Green Morton discovers anesthesia and in 1867 Joseph Lister provides a model for antisepsis. These new technologies play a central role in the future of aesthetic surgery as well as surgical intervention for every type of disability that calls for it. Penicillin is discovered in 1929, cutting mortality rates in hospitals dramatically.

**1848** ◆ The North Carolina School for the Deaf begins the first publication for Deaf persons with its school newspaper, *The Deaf Mute.* First published in 1907, the *Matilda Ziegler Magazine for the Blind* is an ongoing Braille publication.

**1848** ◆ Samuel Gridley Howe founds the first residential institution for people with mental retardation at the Perkins Institution in Boston.

**1851** ◆ In the United States there are 77 residential institutions for children, 1,151 by 1910, and 1,613 by 1933. By the 1950s and 1960s, family members and politicians throughout Western Europe, Canada, and the United States push for the deinstitutionalization of people with disabilities.

**1851** ◆ The first International Sanitary Conference is held in Paris, France, with 12 countries participating. It leads to the World Health Organization, the WHO, which formally comes into existence in 1948.

**1857** ◆ Edward Miner Gallaudet, youngest son of Thomas Hopkins Gallaudet, establishes the Columbian Institution for the Instruction of the Deaf, Dumb, and Blind, located in Washington D.C. Its college division, eventually known as the National Deaf-Mute College, is the world's first institution of higher education for deaf people. Abraham Lincoln signs its charter on April 8, 1864; today it is known as Gallaudet University.

**1857** ◆ English philosopher Herbert Spencer is first to use the expression "survival of the fittest." The application of his idea in combination with Charles Darwin's theories in his 1859 book, *The Origin of the Species,* is called Social Darwinism. It is widely accepted and promoted in Germany in the 1920s and leads Adolf Hitler to express prejudice against the weak, sick, and disabled.

**1863** ◆ Louis Agassiz, a significant American naturalist, advocates the permanence of different races and worries about the "tenacious influences of physical disability" if races were mixed.

**1864** ◆ Germany: Karl Ferdinand Klein, teacher for deaf-mutes, and Heinrich Ernst Stotzner are considered the founding fathers of the *training school,* which calls for schools to be created for less-capable children with the goal of improving their lot. Training schools remain in effect today, but critics maintain that there is an over-representation of socially and economically underprivileged students in this type of setting experiencing little academic success.

**1868** ◆ Sweden: The Stockholm Deaf Club is the first recorded organization of people with disabilities.

**1870** ◆ England and Wales: Education for children with disabilities begins when universal elementary education is first introduced around this time. From 1895 onward, schools for "defective" children spring up. In 1899, Alfred Eichholz, an inspector of special education, draws up key recommendations, which leave their mark on the historic 1994 Education Act legislation. In 1978, the Warnock report introduces the term *special needs education,* which soon gains acceptance worldwide. With the 1994 UNESCO Salamanca Statement and Framework for Action on Special Needs Education, a major shift in organizing educational services for children with disabilities is confirmed internationally.

**1876** ◆ Isaac Newton Kerlin, Edouard Séguin, and others establish the Association of Medical Officers of American Institutions for the Idiotic and Feeble-Minded Persons. Today, it is known as the American Association on Mental Retardation. Séguin, who staunchly believes in the educability of those with significant cognitive disabilities, is styled as “apostle to the idiots,” by Pope Pius X, reflecting the attitude of the time.

**1880** ◆ The United States National Association of the Deaf (NAD), the first organization of deaf or disabled people in the Western Hemisphere, is established. In 1964, the Registry of Interpreters for the Deaf (RID) is formed to establish a national body of professionals who are trained and certified to enable communication between deaf, signing persons and nondeaf, speaking persons.

**1880** ◆ Helen Keller is born in Tuscumbia, Alabama. An illness at the age of 19 months leaves her totally deaf and blind. In 1887, Anne Sullivan, recently graduated from Perkins Institution for the Blind, joins the Keller household as Helen’s teacher and remains Keller’s companion for nearly 50 years. For many, Keller’s story is the quintessential overcoming narrative.

**1881** ◆ The Chicago City Council enacts the first American “ugly law” forbidding “any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view.”

**1882** ◆ The first major federal immigration law in the United States, the Immigration Act of 1882, prohibits entry to “lunatics,” “idiots,” and persons likely to become unable to take care of themselves. Most of the restrictions that apply specifically to disability are removed from U.S. law in 1990. Today, disabled immigrants are still denied an entry visa if they are deemed “likely to become a public charge.”

**1887** ◆ Walter Fernald serves as superintendent of the Massachusetts School for the Feeble-Minded (now known as the Fernald Center) from 1887 to 1924. Unlike most of his colleagues, Fernald moderates some of his earlier extreme views and eventually develops one of the country’s largest “parole” systems for moving institutional residents back into smaller, community-based residences.

**1887** ◆ The American Orthopaedic Association is founded. German and British counterparts are founded in 1901 and 1918, respectively.

**1895** ◆ The chiropractic profession is founded. This type of care is used to relieve musculoskeletal pain, one of the most common causes of disability.

**1899** ◆ Maria Montessori and a colleague open the Scuola Magistrale Ortofrenica in Rome, an educational institute for disabled children and a training institute for instructors. Her method relies on the concept of sensory-based instruction as a means for developing intellectual competence. Her methods allow the child the greatest possible independence in order to foster his or her own development (the child’s own inner “building plan”).

**1904** ◆ Sir Francis Galton, half first cousin of Charles Darwin, defines the term e*ugenics* (which he coined in 1883) in a paper he presents to the Sociological Society on May 16. He argues for planned breeding among the “best stock” of the human population, along with various methods to discourage or prevent breeding among the “worst stock.” Galton also develops the idea for intelligence tests. The term *feeblemindedness* is defined as broadly as possible and is widely used by eugenic social reformers to conflate myriad social problems. Further naming, classification, and labeling provides eugenicists with a troubling rationale for treating people with coercion, disrespect, and profound inhumanity. Persons within the various categories of sub-normality become particularly vulnerable to state-sanctioned segregation, institutional confinement, and enforced sterilization. Eugenics is widely practiced in Europe, the United States, and Canada, culminating in the systemic murder of more than 260,000 disabled people by the Nazis between 1939 and 1945. Today, the so-called new eugenics, known as "human genetics," appeals to the needs of the individual. Critics (some of the first in Germany), however, criticize individualistic eugenic approaches and disclose the connections between human genetics, national socialist racial hygiene, and eugenics.

**1905** ◆ Alfred Binet and Theodore Simon publish the first intelligence scale, known as the Binet-Simon Test.

**1908** ◆ The publication of Clifford Beers's *A Mind That Found Itself* initiates the mental health hygiene movement in the United States. Speaking out against mistreatment and neglect within the system, Beers establishes the Connecticut Committee of Mental Hygiene, which expands in 1909, becoming the National Committee for Mental Hygiene and is now known as the National Mental Health Association. In 1940 there are 419,000 patients in 181 state hospitals. In 1943, the patient-doctor ratio is 277:1, and by the mid-1950s in New York state alone, there are 93,000 inpatients. The Bazelon Center for Mental Health Law, founded in 1972 by a group of committed lawyers and professionals in mental health and mental retardation, attempt to improve mental health service provision through individual and class action suits. In 1980, a group of these lawyers form the National Association of Rights Protection and Advocacy (NARPA). One-third of its board of directors must identify themselves as current or former recipients of mental health care. The association is committed to the abolishment of all forced treatment.

**1908** ◆ Pastor Ernst Jakob Christoffel establishes a home in Turkey for blind and otherwise disabled and orphaned children. This grows into Christoffel-Blindenmission (CBM), an independent aid organization of Christians of various denominations united to help disabled people in third world countries. Today, it supports more than 1,000 development projects in 108 countries. In 1999, CBM, other agencies, and the World Health Organization initiate VISION 2020: The Right to Sight, a global initiative for the elimination of avoidable blindness by the year 2020.

**1909** ◆ Germany: The German Organization for the Care of Cripples is created as an umbrella organization for the care of the physically disabled. The Prussian Cripples' Care Law of 1920 for the first time provides a right to medical care and scholarly and occupational education for this group.

**1912** ◆ Henry H. Goddard publishes *The Kadikak Family,* supports the beliefs of the eugenics movements, and helps create a climate of hysteria in which human rights abuse of the disabled, including institutionalization and forced sterilization, increases. In 1927, the U.S. Supreme Court, in *Buck v. Bell,* rules in favor of forced sterilization of people with disabilities, further fueling eugenics movements—the number of sterilizations increases.

**1914** ◆ By this date, Sigmund Freud develops his most enduring influence on the study of disability, namely, the theory of psychosomatic illness in which a psychopathological flaw is given corporeal form as a symptom, thereby establishing the notion that people succumb to disease or disability because they feel guilty about past or present repressed desires.

**1918** ◆ The Smith-Sears Veterans Rehabilitation Act passes, authorizing VR services for World War I veterans. In 1916, the National Defense Act marks the beginning of the U.S. government's supportive attitude toward rehabilitation. In 1920, the Smith-Fess Act marks the beginnings of the civilian VR program. The Social Security Act of 1935 establishes state-federal VR as a permanent program that can be discontinued only by an act of Congress.

**1919** ◆ Edgar "Daddy" Allen establishes what becomes known as the National Society for Crippled Children. In the spring of 1934, the organizational launches its first Easter "seals" money-making campaign. Donors place seals on envelopes containing their contributions. The seal is so well-known that it becomes part of the organization's official name. Today, Easter Seals assists more than one million children and adults with disabilities and their families annually through a nationwide network of more than 500 service sites. During the 1920s, Franklin D. Roosevelt inspires the March of Dimes.

**1920** At about this time, the Shriners open hospitals for the care of crippled children. President Herbert Hoover establishes a "Children's Charter" in 1928 highlighting the need to attend to the needs of crippled children.

**1921** Franklin D. Roosevelt contracts poliomyelitis. Despite damage to his legs (which makes him a wheelchair user) and deep depression, through enormous rehabilitative effort, he eventually re-enters politics and becomes president of the United States. His triumph over personal disability becomes legendary. Critics, however, fault him for choosing to minimize his disability in what is called his "splendid deception." He establishes a center for the treatment of polio patients in Warm Springs, Georgia, called the Georgia Warm Springs Foundation (1927), which hires medical specialists from Atlanta to direct orthopedics. In 1937, President Roosevelt becomes the prime mover behind the National Foundation for Infantile Paralysis Research.

**1921** Mary L. McMillan (Molly) establishes the American Women's Physical Therapeutic Association, which is known today as the American Physical Therapy Association (APTA).

**1921** The American Foundation for the Blind is established.

**1921** Canada: Researchers isolate the hormone insulin. In 1922, Frederick Banting, Charles Best, J. B. Collip, and J.R.R. Macleod produce and test the pancreatic extract on people with diabetes, for which they are awarded a Nobel Prize. Insulin becomes a wonderful treatment for diabetes, but not a cure.

**1921** France: Three historical waves of advocacy movements can be identified beginning with the National Federation of Injured Workers (FNAT) in 1921 and other organizations that focus essentially on the protection of rights. Another factor that stimulates advocacy groups in the first wave is the wounded veterans of World Wars I and II. A second wave dates from the period after World War II. Many advocacy groups form between 1950 and 1970, such as the Union of Associations of Parents of Maladjusted Children (UNAPEI) in 1960. A third wave finds a gradual emergence of three types of associations: those that run specialized facilities (for example, Living Upright, which, in 1970, leads to the creation of the first group living facility); those interested in trade unions; and those represented by user-advocate associations. Financing comes in large part from public funds, thereby creating a government-association partnership.

**1922** The founding of Rehabilitation International sets the stage for the establishment of other international organizations of and for people with disabilities that link together throughout the world. Later international organizations include, among numerous others, the World Federation of the Deaf (1951), Inclusion International (1962), the International Association for the Scientific Study of Intellectual Disability (1964), Disabled Peoples' International (1981), and the International Disability Alliance (1999).

**1925** The American Speech-Language-Hearing Association, today the American Academy of Speech Correction, is established to provide high-quality services for professionals in speech-language pathology, audiology, and speech and hearing science, and to advocate for people with communication disabilities.

**1928** Charles Nicolle is the first deaf person to be awarded a Nobel Prize.

**1929** Seeing Eye establishes the first dog guide school in the United States.

**1930** The Veterans Administration is created to administer benefits, promote vocational rehabilitation, and return disabled veterans to civil employment. There is a record of provision for disabled veterans in the United States since the Revolutionary War and the Civil War. After World War I, three agencies administer veteran's benefits.

**1932** Herbert A. Everest, a mining engineer with a disability, and Harry C. Jennings collaborate to design and patent the cross-frame wheelchair, which becomes the standard for the wheelchair industry that exists today. Developed during World War I, the first powered wheelchair appears, but doesn't gain popularity for another 30 years.

**1935** President Franklin D. Roosevelt signs the Social Security Act of 1935 on August 14. Beginning in 1956, SSA amendments provide disability benefits.

**1935** By 1935, in the United States more than 30 states pass laws allowing for the compulsory sterilization of those deemed genetically unfit in state and federal institutions. By 1970, more than 60,000 people are sterilized under these laws.

**1935** As a result of being denied participation in the Works Progress Administration (WPA), six young people with disabilities hold a sit-in at the offices of New York City's Emergency Relief Bureau, demanding jobs in non-segregated environments and explicitly rejecting charity. The League of the Physically Handicapped is born out of this activism and operates in New York from 1935 to 1938. The League identifies social problems that remain issues today.

**1935** Peer support in the United States is traced to the establishment of Alcoholics Anonymous in this year. Interest in peer support increases in the 1960s and is adopted by the disabled community. Movements, such as the Center for Independent Living, and groups, such as the National Spinal Cord Injury Association, make peer support one of their major activities.

**1936** The American Academy of Physical Medicine & Rehabilitation is founded, leading to the approval of the American Board of Physical Medicine & Rehabilitation by the American Medical Association in 1947.

**1937** The Fair Housing Act of 1937 passes with a mandate to assist the poor, a group that includes people with disabilities, by creating public housing. However, it is not until the Rehabilitation Act of 1973 that housing law specifically deals with discrimination faced by individuals with disabilities in housing programs that receive federal funding. The 1988 amendment to the Fair Housing Act of 1968 extends protection for people with disabilities beyond those of Section 504 of the Rehabilitation Act to include private housing.

**1939** The Nazi regime institutes the Aktion T4 program in Germany. Children and, later, adults with disabilities are selectively killed both in hospitals and in special centers. The program was officially terminated by Adolf Hitler in August 1941, but practitioners "informally" continued it through a phase historians have called "wild euthanasia."

**1940** State activists for the blind, including Jacobus Broek, come together in Wilkes-Barre, Pennsylvania, to charter the National Federation of the Blind (NFB). In 1957, the NFB publishes the first edition of the *Braille Monitor,* which is still in print today. In 1960, dissatisfied NFB members form the American Council of the Blind (ACB).

**1940** Paul Strachan establishes the American Federation of the Physically Handicapped, the nation's first cross-disability, national political organization.

**1942** The American Psychiatric Association develops a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles.*

**1943** The LaFollette-Barden Act, also known as the Vocational Rehabilitation Amendments, adds physical rehabilitation to federally funded vocational rehabilitation programs.

**1943** The United Nations is established on October 24 by 51 countries. The global Programme on the Disability is the lead program concerning disability. Many other types of programs, activities, and instruments include the 1975 Declaration on the Rights of Disabled Persons, the 1981 International Year of

Disabled Persons, the 1982 World Programme of Action Concerning Disabled Persons, the 1983–1992 UN Decade of Disabled Persons, and the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In 1988, the first UN Disability Database (DISTAT) publishes statistics from 63 national studies covering 55 countries and the 2001 publication presents 111 national studies from 78 countries, indicating a growing interest worldwide for the collection of usable data. In 2005, a UN Ad Hoc Committee continues to consider a Convention on the Rights of Disabled Persons that is a legally binding human rights instrument. Today the UN membership totals 191 countries.

**1943** Sweden: In possibly the first reference to the concept of normalization, the most significant driving force in the ongoing closure of state-run or state-funded institutions for people with a disability is made by the Committee for the Partially Able-Bodied, established by the Swedish Government. Through the advocacy of people such as Niels Erik Bank-Mikkelsen, normalization, with its profound positive effect on the lives of people who were once removed and segregated from society, remains relevant today.

**1944** Richard Hoover invents long white canes known as Hoover canes that are used by many blind people.

**1944** The word *genocide* first appears in a book by a Polish lawyer Raphael Lemkin titled *Axis Rule in Occupied Europe* in which he describes Nazi Germany's practices but also seeks the adoption of legal restrictions so that genocide will not occur. In 1948, the United Nations adopts a declaration and then a convention on genocide that describe both against whom genocide might be directed and acts constituting genocide. Article 6 of the Rome Statute of the International Criminal Court (ICC), established in 2002, uses language identical to that in the UN convention to define genocide. More than 90 countries are parties to the ICC, but not the United States.

**1945** President Harry Truman signs into law an annual National Employ the Handicapped Week. In 1952, it becomes the Presidents' Committee on Employment of the Physically Handicapped, a permanent organization, which reports to the President and Congress.

**1945** Canada: Lyndhurst Lodge, the first specialized rehabilitation center for spinal cord injury (SCI) in the world, and the Canadian Paraplegic Association, the first association in the world administered by individuals with SCI, are established.

**1946** The first chapter of what will become the United Cerebral Palsy Association, Inc. is established in New York City. It is chartered in 1949, and along with the Association for Retarded Children, it becomes a major force in the parents' movement of the 1950s.

**1946** The National Mental Health Foundation is founded by attendants at state mental institutions who aim to expose abusive conditions. Their work is an early step toward deinstitutionalization.

**1946** The National Institutes of Mental Health (NIMH) are founded in the United States.

**1946** Europe: The European Union is founded on September 17 in Paris. It consistently shows its commitment to eliminating discrimination on many fronts through joint declarations, resolutions, directives, and action programs. With regard to disability, the European Union supports actions in favor of people with disabilities, principally in the form of European Social Fund interventions. Action programs aim at facilitating the exchange of information between member states and nongovernmental organizations with a view to identifying good practices, integrating people with disabilities into society, and raising awareness of related issues. The EU Council of Ministers Recommendation on the Employment of Disabled People (1986) calls on member states to "eliminate negative discrimination by reviewing laws, regulations and administrative provisions to ensure that they are not contrary to the principle of fair opportunity for disabled people." Further steps are taken in 1996 when a communication on equality of opportunities for disabled people sets out a new European disability strategy that promotes a rights-based approach, rather than a welfare-type approach. This is strengthened in 1997 when the heads of state act to strengthen Article 13 of the European Community Charter of Fundamental Social Rights of Workers (1989), giving the European Community specific powers to take action to combat a broad spectrum of discrimination that includes disability.

**1948** ◆ The National Paraplegia Foundation is established as the civilian branch of the Paralyzed Veterans of America.

**1948** ◆ The World Health Organization is established. The WHO actively promotes human rights and the principle of equity in health among all people of the world, including persons with disabilities. Today it consists of 191 member states, but strives for universal membership. In 1980, the WHO publishes the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and issues a revised version in 2001, the International Classification of Functioning, Disability, and Health (ICF).

**1948** ◆ The United Nations General Assembly adopts the “Universal Declaration of Human Rights,” which promotes and affirms the fundamental rights to life, liberty, and security; to medical care and social services; and to the benefit from scientific progress and its uses.

**1948** ◆ Sir Ludwig Guttmann organizes the first Stoke Mandeville (England) Games for the Paralysed, thus launching the Paralympic movement. The Games become international in 1952. In 1960, the first Paralympic Summer games are held in Rome and the first Paralympic Winter Games follow in 1976. The Paralympic Games are multi-disability, multi-sport competitions and have become the second-largest sporting event in the world, only after the Olympic Games.

**1948** ◆ World War II bomber pilot and war hero Leonard Cheshire establishes what is to become the largest charitable supplier of services for disabled people in the United Kingdom. In the 1960s, the resistance of disabled people who live in one Leonard Cheshire home, Le Court, plays a major role in establishing the British disabled people’s movement. In the late 1990s, the Leonard Cheshire organization establishes the Disabled People’s Forum, which is run by disabled people and supports disabled people’s involvement and empowerment.

**1949** ◆ Timothy Nugent founds the National Wheelchair Basketball Association, and the first Annual Wheelchair Basketball Tournament takes place.

**1949** ◆ Europe: The Council of Europe, an intergovernmental organization, is founded. Its activities cover all major issues facing European society other than defense. Human dignity, equal opportunities, independent living, and active participation in the life of the community form the heart of the Council of Europe’s activities in relation to people with disabilities. The European Social Charter of 1961 and its revision in 1996 include specific wording and expand the rights of individuals with disabilities.

**1950** ◆ The Social Security Amendments of 1950 provide federal-state aid to the permanently and totally disabled (APTD), which serves as a limited prototype for future Social Security assistance programs for disabled people.

**1950** ◆ The National Mental Health Association is formed with the mission to continue 1908-advocate Clifford W. Beers’s goals of “spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health.”

**1950** ◆ The National Association for Retarded Children (NARC) is established by families in Minneapolis. It is the first and most powerful parent-driven human-services lobby in the nation to emerge in the 1950s.

**1950** Amniocentesis is developed by a Uruguayan obstetrician. Later, advanced prenatal testing provides a battery of powerful medical tools to predict risk of disability and provide information to parents about their pregnancies.

**1951** With the founding of the World Federation of the Deaf, the deaf community becomes international.

**1953** Francis Crick and James Watson propose a three-dimensional structure for the DNA molecule. The paper they publish also gives clues to genetic mechanisms. Today, more than 6,000 monogenic disorders have been identified, and these affect approximately 1 in 200 live births.

**1955** The polio vaccine, developed by Dr. Jonas Salk, becomes available, thus ending polio epidemics in the Western world. A new oral vaccine, developed by Dr. Albert B. Sabin, is approved for use in 1961.

**1956** Social Security Disability Insurance (SSDI) becomes available through amendments to the Social Security Act of 1935 (SSA) for those aged 50–64. Other important amendments to SSA include the following: 1958: provides for dependents of disabled workers; 1960: removes age limit; 1965: Medicare and Medicaid provide benefits within the framework of the SSA (until 1977); 1967: provides benefits to widows and widowers over the age of 50; 1972: Supplemental Security Income (SSI) establishes a needs-based program for the aged, blind, and disabled; 1984: the Social Security Disability Reform Act responds to the complaints of hundreds of thousands of people whose disability benefits have been terminated; 1996: President Clinton signs the Personal Responsibility and Work Opportunity Reconciliation Act, making it more difficult for children to qualify as disabled for SSI purposes.

**1959** The UN Declaration of the Rights of the Child is adopted; the UN Convention on the Rights of the Child is adopted in 1989. A central principle of both documents is access to education for all children including those with disabilities. In 1993, a related UN document, the Standard Rules for the Equalization of Opportunity, extends this to preschool children, and in 1994, UNESCO's Salamanca Statement and Framework for Action specifies the provision of special education for children with disabilities or learning difficulties. These documents constitute a universal bill of rights that can serve as a framework in the development of national policies worldwide.

**1961** The American Council of the Blind is established.

**1961** Europe: The European Social Charter (ESC) protects "the right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement." In 1996, it is revised, updated, and expanded to take account of social changes.

**1961** Michel Foucault's work *The History of Madness in the Classical Age* becomes obligatory reading for those concerned with the archaeology of madness and its treatments. It continues to be an academic *rite de passage.*

**1962** Battered child syndrome is defined. Researchers estimate that the incidence of maltreatment of children with disabilities is between 1.7 and 3.4 times greater than of children without disabilities.

**1962** Russia: The Moscow Theater of Mime and Gesture is the first professional deaf theater in the world. It has been in continuous operation for more than 40 years and has staged more than 100 classic and modern plays.

**1963** Congress enacts new legislation to ensure funding for a comprehensive program of research on mental retardation through the National Institute on Child Health & Human Development. In 1965, the Office of Economic Opportunity launches the Elementary and Secondary Education Act (ESEA), commonly known as Project Head Start. The goal is to prevent developmental disability by providing increased opportunities for disadvantaged children in the preschool years.

**1963** The Developmentally Disabled Assistance and Bill of Rights Act (DD ACT) is authorized, with its last reauthorization in 1996. It focuses on individuals with developmental disabilities such as intellectual disability, autism, cerebral palsy, epilepsy, and hearing and visual impairments, among others.

**1964** The Civil Rights Act is passed. It becomes the model for future disability rights legislation.

**1964** France: L'Arche is established. By the beginning of the twentieth-first century, it includes more than 113 communities in 30 countries. "The Ark" is a distinctive style of community living, based on "core members" and "assistants," who view their commitment as sharing life *with* people with disabilities, rather than as caregivers.

**1965** Newly enacted Medicare and Medicaid provide national health insurance for both elderly (over 65) and disabled persons.

**1965** The Vocational Rehabilitation Amendments of 1965 are passed. They provide federal funds for the construction of rehabilitation centers and create the National Commission on Architectural Barriers to Rehabilitation of the Handicapped.

**1965** The Autism Society of America is founded.

**1967** Deaf actors establish the National Theatre of the Deaf (NTD). It is the world's first professional deaf theater company and the oldest continually producing touring theater company in the United States. Today, after almost 40 years, the NTD chronicles over 6,000 performances. The National Theatre Workshop for the Handicapped begins in 1977 and the Other Voices Project in 1982. These groups are among the earliest groups formally to place the disability experience at the heart of their creative endeavors.

**1967** Heart transplantation is introduced. This technology is preceded by open-heart surgery developed in the 1950s and coronary bypass and internal pacemakers in the1960s. The Framingham Heart Study begins in 1948. It collects data over the next decades that help identify major risk factors contributors to heart disease.

**1967** Paul Lemoine in France in 1967 and Kenneth Jones and David Smith in the United States in 1973 independently describe the condition fetal alcohol syndrome (FAS), which comprises a recognizable pattern of birth defects attributable to the adverse effects of maternal alcohol abuse during pregnancy.

**1967** England: St. Christopher's Hospice in South London opens. It is the first attempt to develop a modern approach to hospice and palliative care.

**1968** Congress enacts the Architectural Barriers Act. The ABA requires access to facilities designed, built, altered, or leased with federal funds.

**1968** The Fair Housing Amendments to the Civil Rights Act of 1968 guarantees civil rights of people with disabilities in the residential setting. The amendments extend coverage of the fair housing laws to people with disabilities and establish accessible design and construction standards for all new 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.

### *Directories*

Directories are hierarchically arranged subject guides composed of websites chosen by or recommended to editors of the directory (Table 4). Usually, directories follow a template in which major subject categories such as health, sciences, social sciences, or humanities are posted on the top-level page. Each of these links leads to lists of narrower subcategories. The links on the second level lead to narrower subcategories, and so on. A sample hierarchy from the directory created by Google (available at http://directory.google.com) lists the following subject breakdown: Society → Disabled → Disability studies.

Directories provide Web searchers with the ability to browse recommended resources in various subject areas without having to enter specific search terms. Other useful attributes of directories are that they often contain summaries and evaluations of websites.

**Table 3** Resources for Finding Subject-Specialized Search Engines

| *Name* | *URL* |
|---|---|
| CompletePlanet | www.completeplanet.com |
| Direct Search | www.freepint.com/gary/direct.htm |
| InfoMine | www.infomine.com |
| Invisible Web Directory | www.invisible-web.net |
| Librarians' Index to the Internet | www.lii.org |
| Search Engine Colossus | www.searchenginecolossus.com |

**Table 4** Selected Directories

| *Name* | *URL* |
|---|---|
| eBlast | www.eblast.com |
| Google Directory[a] | http://directory.google.com |
| Internet Public Library | www.ipl.org |
| LookSmart | www.looksmart.com |
| Yahoo! Directory[a] | www.yahoo.com |

a. These sites contain both directories and general search engines.

### *Article Indexes*

Article indexes allow researchers to search by topic for published articles in magazines and scholarly journals. Researchers could certainly locate journal and magazine articles using a freely available search engine such as Google, but they would merely be skimming the surface of what has been published. While the Web provides access to *more* content, it does not provide comprehensive access to research published in journal articles. Article indexes are for the expressed purpose of finding journal articles. With a few exceptions (such as PubMed, an article index of health sciences journals developed and maintained by the National Library of Medicine), article indexes are not freely available on the Web. Libraries purchase subscriptions to multiple article indexes covering a wide spectrum of disciplines. The indexes available through a given library are often dictated by the curriculum of the college or university that the library serves. Thus, large research institutions offer a greater number of specialized article indexes than smaller institutions and public libraries. Due to licensing agreements between article index providers and libraries, off-site access to indexes is usually limited to faculty and students of a college or university. However, there are many libraries that allow members of the public to use their article indexes from within the library. A local public library would be a good starting place for those not connected with academic or commercial organizations.

Since article indexes are proprietary products developed by companies for sale to libraries, they tend to offer specialized search features that are not always available on freely available search engines. These features include subject headings, thesauri, abstracts (summaries of articles), and frequently the full text of articles. Researchers should familiarize themselves with online tutorials, "help" screens, and "about" pages to increase the effectiveness of their searching.

Freely available article indexes relevant to disability studies include the following:

- PubMed: A product of the National Library of Medicine, which includes more than 14 million citations for biomedical articles dating back to the 1950s. URL: http://www.ncbi.nlm.nih.gov/entrez

- CIRRIE: Center for International Rehabilitation Research Information and Exchange, a database containing more than 24,000 citations of international research published from 1990 to the present. URL: http://cirrie.buffalo.edu

### Catalogs

While researchers can search indexes to find articles on specific topics, they can search online catalogs to find books. Some catalogs list the books available at individual libraries, while others contain the holdings of multiple libraries and institutions. The individual catalogs of public libraries and universities are usually freely available on the Web. The most comprehensive catalog is called WorldCat, developed by an organization called OCLC (Online Computer Library Center). WorldCat lists books available at public and academic libraries throughout the world. Like most article indexes, WorldCat is not freely available on the Web and must be accessed through a library.

### Listservs

Listservs are mailing lists on the Internet that facilitate online discussions on various subjects. They allow researchers within a given field to communicate about scholarly issues via email. People customarily sign up for Listservs by sending an e-mail to the Listserv address stating that they wish to subscribe. Several Listservs related to disability studies are listed in Table 5. In addition, Web searchers can perform a search on a database called tile.net to search for Listservs by topic.

**Table 5** Disability Studies Listservs

| *Name* | *URL* |
|---|---|
| ADA-LAW | http://listserv.nodak.edu/archives/ada-law.html |
| Disability-Research Discussion List | http://www.leeds.ac.uk/disability-studies/discuss.htm |
| Disability Studies at Yahoo.com | http://www.groups.yahoo.com/group/disabilitystudies |
| Disabled Student Services in Higher Education (DSSHE-L) | http://listserv.acsu.buffalo.edu/archives/dsshe-l.html |
| Women's International Linkage on Disability (D-WILD) | http://groups.yahoo.com/group/d-wild |

## SEARCH STRATEGIES

Since search capabilities vary from site to site, Web searchers should use online "help" screens and tutorials to learn search tips and strategies for improving their search results. Some search techniques common to several Web-based search tools are summarized below.

### Quotation Marks

When entering a search, users should enter phrases in quotation marks to stipulate that they would like the results to contain a specific word combination and order. For instance, multiword concepts such as "disability studies," "adaptive technology," and "section 508" should be entered within quotation marks. Proper names can also be entered within quotation marks.

### Truncation

Truncation symbols allow Web searchers to simultaneously search for multiple endings of a given word. For instance, assuming that the asterisk is the designated truncation symbol in a search engine, entering the word "impair*" would produce results including all forms of the word after the root, including "impair," "impaired," "impairment" and "impairments." In addition to adding truncation symbols to the end of words, users may also insert internal truncation symbols if there are potential variations for the spelling of the middle of a word. For instance, entering the word "colo*r" would simultaneously search for the words "color" and "colour." "Help" screens or "search tips" usually list the designated truncation symbol for a given database.

### Boolean Logic

Developed by the English mathematician George Boole, Boolean logic is a mathematical framework that Web searchers can apply to broaden or refine their searches. There are three words, or *operators*, that Web searchers can use to combine their keywords to perform more complex searches: AND, OR, and NOT. The three Boolean operators are summarized below, along with potential applications. It is important to read the online "help" section of a database before performing a Boolean search, as Boolean searching does not work in all databases.

### *Using the Boolean Operator "AND"*

Combining words with "AND" narrows a search, as the database retrieves only items that contain *all* the words entered. The second search example below will produce fewer results than the first, since there are three keywords that must appear within the content of each result.

"disability studies" AND theory
"disability studies" AND theory AND history

### *Using the Boolean Operator "OR"*

Entering the term "OR" between keywords stipulates that any, but not all, of the words entered must appear within the search results. Using "OR" is a way of searching for synonyms or related terms when there are multiple words for the same concept. The example below shows how you could broaden your search if you wanted to search for multiple adaptive technology applications in a search engine. The second search example will potentially produce more results than the first, since there is an additional keyword that the results could include.

JAWS OR "Ruby OpenBook"
JAWS OR "Ruby OpenBook" or "window eyes"

### *Using the Boolean Operator "NOT"*

Entering the Boolean operator "NOT" after a word stipulates that the word should not appear within the results. Using "NOT" in a search can be particularly useful if a word is frequently used in multiple contexts and you wish to eliminate results dealing with a particular topic. In the example below, the second search will ideally eliminate items relating to the state of New Mexico, given that the researcher is looking for information on legislation related to disabilities in the country of Mexico. The use of NOT can be too limiting. The second search would eliminate results that discussed both Mexico and New Mexico.

Disabilities AND legislation AND Mexico
Disabilities AND legislation AND Mexico NOT "new mexico"

### *Nesting*

Nesting allows Web searchers to simultaneously search for multiple search terms relating to the same topic. The grouping of synonymous terms within parenthesis is referred to as nesting, as multiple terms relating to the same idea are clustered together as a single concept. When using nesting, the words within the parenthesis are connected by the Boolean operator "OR."

To find information about software for people who are visually impaired, search results are increased by using nesting to group multiple words for each facet of the topic:

(software or "adaptive technology") AND ("visually impaired" or blind)

### *Plus and Minus Signs*

Most general search engines allow users to enter plus or minus signs before a particular word. Entering a plus sign before a word (e.g., +ADA) stipulates that the word must appear within the search results. A minus sign before a word (e.g.,–mobility) stipulates that the word should not appear within the results. Since some search engines also use plus and minus signs as substitutes for Boolean operators, it is important to view online "help" or "search tips."

### *Search Limits*

Most search engines allow users to limit their results by date, language, or document type. Limiting capabilities vary from site to site and are customarily outlined in online "help" screens. In general, article indexes have more sophisticated limiting capabilities than search engines that are freely available on the Web.

## EVALUATING WEBSITES

A researcher weighing the quality of a journal article faces a lesser challenge than a researcher considering a website as a potential resource. The publishing industry applies labels to periodicals of varying type: Scholarly journals, popular magazines, trade publications, and newspapers comprise the major categories. Articles submitted to scholarly journals undergo a peer review process by experts in a given field. If in doubt as to the suitability of journal for scholarly purposes, a researcher can consult a directory of periodicals such as *Ulrich's Periodicals Directory,* which indicates whether or not a journal is peer reviewed.

The fact that the Web has no comparable methods of control complicates the task of determining whether a website is appropriate for research purposes. While websites produced by certain types of agencies and organizations certainly undergo a form of *internal* review, the Web is a free forum; people can post anything they want, and no one has the right to force to take it down if it fails to meet certain standards of quality or accuracy. To complicate the matter, inaccurate or inexpert information can hide like a wolf in the sheep's clothing of sophisticated graphics, layout, and design. The Web has no peer review process to ensure quality. While none of the evaluation criteria outlined below can provide the final word as to the suitability of a website for scholarly use, a researcher who searches the Web with multiple evaluation criteria in mind expedites the process of finding quality information.

### *Authorship*

When determining the credibility of a website, researchers should use multiple techniques to determine the credentials of the author as well as the character of the organization hosting, or sponsoring, the site. If individuals are listed as authors, researchers should take steps to determine their credentials and reputation in the field by performing a search in a general search engine to find biographical information or other documents written about the author. This will also produce references to the author on the sites of other authors within a field. Researchers can also consult a number of biographical sources available at libraries, such as *Who's Who in the America* or sources tailored to particular fields of study, such as *Who's Who in Science and Engineering.*

Website addresses, or URLs (Uniform Resource Locators) can also provide hints as to author affiliations and potential bias. Personal websites are often hosted on commercial ISP (Internet Service Provider) Web servers such as aol.com, or geocites.com. URLs of personal websites often contain first or last names, as well as percent (%) or tilde (~) signs. While personal websites may contain authoritative information, researchers should question why the same content does not appear on a site sponsored by an educational or research organization.. Was the site created as a pastime or to serve as a forum for airing personal views? Or does the site reflect serious scholarship backed up by other credentials and research published in scholarly publications?

Every website URL ends with a *domain name*, usually a series of three letters preceded by a period. The domain name denotes the type of institution that hosts the website and can often provide clues as to the purpose or potential bias of a site. Common domain names include the following:

Educational sites: .edu
Government sites: .gov, .mil, or country codes (e.g., .uk = United Kingdom, .au = Australia, .do = Dominican Republic)
Nonprofit organization sites: .org
Commercial sites: .com

Most URLs contain multiple levels separated by slashes (e.g., http://www.nod.org/stats/). To learn more about the sponsor or publisher of a particular site, you can remove levels of the URL one by one to see where the site is hosted and determine the character of the sponsoring entity. For instance, if a site is hosted on the site of an association, viewing the mission statement on the home page of the association can provide clues as to the bias or purpose of the content. When judging the credentials of the publishing entity, researchers should look for contact information and institutional logos. In general, sites devoid of identifying information or contact numbers and addresses should raise suspicion.

### *Audience*

When evaluating a site, researchers should determine whether the content succeeds in addressing the stated audience through tone and presentation. Sites for adults should not have a childlike appearance or tone. Likewise, sites may be deliberately overrun by technical language or jargon to confuse or mislead a particular audience. High-quality sites clearly define their intended purpose.

### *Currency*

Medical research findings or population statistics may become obsolete at a faster rate than research in the humanities. Web researchers should check sites for copyright dates and the date of the last update. Broken links are a sign of neglect, as they may indicate that URLs have changed or become obsolete since the last update of the site. To verify the currency of information on a site, researchers should check for several sites covering the same subject matter.

### *Accuracy*

Determining accuracy involves further research to ensure that the claims or findings on a site are substantiated by other sources. If a site presents original research, the methods of the research and instruments used should be clearly explained, as well as potential limitations of the research. If authors make claims or conclusions, they should cite their sources, and these sources should be tracked down to ensure their existence and authenticity. Websites should contain a list of works cited or footnotes on par with any print book or article. Since websites sometimes include fabricated resources, and erroneous or incomplete citations, sources should be verified using library tools such as indexes and catalogs. Lists of works cited with multiple errors reflect irresponsible research. If a website contains links, the links should be checked. Researchers should be wary of websites populated by broken links or links to defunct websites.

### *Quality*

In general, sites that are poorly organized or sloppy should be approached with caution. Shoddy design may point to further weaknesses. Poor grammar and spelling errors are also red flags.

### *Bias*

While bias is not always a negative attribute, Web searchers should be cognizant of bias as the search for information. The bias of a website can be partially discerned by the domain name (as discussed above under "Authorship"). Commercial websites may be motivated by the goal to market a product or service. Nonprofit organizations may promote a political agenda. While bias may be clearly stated in mission statements and "about" pages, many websites deliberately shroud their bias. Thorough research involves consulting additional sources to determine the history and activities of a particular organization. If a site contains links to other sites, those links should be checked to discern the character and activities of the other organizations listed. If a site is sponsored by other organizations, researchers should consider the relationship between the sponsors and the creators of the site.

### *Special Considerations for Evaluating Health Information on the Web*

The American Medical Association (AMA) has published "Guidelines for Medical and Health Information Sites on the Internet" outlining evaluation criteria for websites publishing health information, whether for consumers or health professionals. While these guidelines are technically enforced only on sites sponsored by the AMA or affiliated organizations, they could be applied to all sites containing health information. Many of these guidelines mirror the previously outlined criteria for evaluating all websites, but there are certain factors that are heavily emphasized in the AMA guidelines, including the importance of peer review by experts in the field, the importance of clearly identifying sources of funding, an explanation of the relationship between individual researchers and the institutions sponsoring the research, the importance of clearly stating the purpose and intended audience of a site, and the need to address the stated audience in a consistent and effective tone. Seven criteria for assessing the quality of health information on the Internet have been developed by the Health Summit Working Group (Health Information Technology Institute 1999).

Information on health-related websites should be verified by checking sources such as journal articles, books, and other websites. These measures are needed as health information on the Web frequently includes unsubstantiated claims.

## OVERVIEW OF ACCESSIBILITY ISSUES ON THE WEB

Disability studies research is unique in that many scholars in the field have disabilities that may impact their ability to effectively search the Web. While in many ways the Web "evens the playing field" by making a vast number of resources available electronically, inaccessible design frequently places barriers on Web searchers with disabilities.

Principles of Web accessibility have been developed by the World Wide Web Consortium's (W3C) Web Accessibility Initiative (WAI). The WAI establishes guidelines for creating accessible websites, browsers, and authoring tools to increase the ease of use of the Web for users with disabilities. Multiple scenarios outlining potential challenges to Web searchers with disabilities are summarized in a W3C working draft titled "How People with Disabilities Use the Web" (2001). Among other scenarios, the document emphasizes that many Web searchers with cognitive or visual disabilities use OCR (optical character recognition) software, which reads Web page text and transmits the information to a speech synthesizer and/or refreshable Braille display. Many users with visual disabilities use text-based Internet browsers instead of standard graphical browsers. The successful use of these tools requires that images on websites be accompanied by descriptive text and *ALT tags*. ALT tags are textual labels that appear on the computer screen when a mouse moves over an image. Since visually impaired

Web searchers often enlarge Web-based text using screen magnification programs, Web designers must create pages with nonfixed font sizes that can be altered as necessary. These are only a few of the issues facing Web searchers with disabilities. Other population groups with disabilities discussed in the guidelines include individuals with cognitive disabilities, hearing impairment, and mobility-related disabilities. Readers should consult the WAI website for the complete guidelines (http://www.w3.org/WAI/).

To support the goals of WAI, an online tool called Bobby™ helps website developers test the accessibility of their sites and adhere to accessibility guidelines. By entering a URL into the Bobby website, a Web developer can generate a report outlining which features of the site need to be adjusted to make it "Bobby compliant" and adhere to both W3C accessibility guidelines and guidelines established by the U.S. government's Section 508, a 1998 amendment to the Rehabilitation Act requiring that all federal agencies make their electronic and information technology accessible to people with disabilities. Complete information about these guidelines can be found on the Section 508 website (www.section508.gov).

## CONCLUSION

While "one-stop shopping" in Google may be tempting, there is no single search engine leading to everything on the Web. Comprehensive and effective research in disability studies involves consulting multiple search tools, including but not limited to general search engines, subject-specialized search engines, directories, and indexes. In addition to using multiple search tools, Web searchers should experiment with multiple search strategies to maximize the effectiveness of their searching. As there are no standards of quality on the Web, researchers should apply multiple evaluation criteria to every website, verifying that research findings posted on sites are supported by other sources. Web accessibility is a crucial component to disability studies, as the Web has the potential to deliver equal content to all users but frequently presents barriers to people with disabilities by failing to adhere to standards of accessible design. Researchers can develop an awareness of accessibility issues on the Web by familiarizing themselves with the standards outlined by W3C's Web Accessibility Initiative and Section 508.

### Further Readings

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