ENCYCLOPEDIA OF
DISABILITY

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Liliane Foundation
National Center for Medical Rehabilitation Research (United States)
National Institute on Disability and Rehabilitation Research (NIDRR) (United States)
People First
Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)
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(1946-present)

J

JACKSON, WILLIAM HENRY (1889–1931)

English educator and priest

Father William Henry Jackson lost his sight in early childhood, became an Anglican priest, and worked in Myanmar (formerly Burma) for 14 years.

Formal education for blind children had been started at Moulmein by a newly blind teacher, Maung Pe Gyu, in 1900. A school opened at Rangoon in 1901, and some Burmese Braille books were produced. The Mission to the Blind of Burma was begun in 1914 by Will and Mary Purser, bringing people to Rangoon for eye surgery and providing education and job training to some blind children. Mary Purser's brother, "Willie" Jackson, who was ordained in 1912, had studied at London, Oxford, and Leeds. He traveled to Burma in 1917 with Will Purser and immersed himself in Burmese language and lifestyle: He "adopted Burmese dress and food; he sleeps on the floor without a mosquito curtain, and he eats his food with his hands and goes about without any covering on his feet or head" (Purser 1922).

Jackson engaged vigorously in education and skill training of blind Burmese children and young people, and he was a powerful role model. He accepted no limits to what blind people could do. In 1930, the government of Burma awarded him the highest civilian honor, the Kaiser-i-Hind gold medal. He died young but had inspired many Burmese blind people with the confidence to live fuller lives.

—Kumur B. Selim

See also Blind, History of the.

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JAHIZ, AL- (ABU OTHMAN AMR BIN BAHR) (776–777)

Arab intellectual and essayist

Al-Jahiz, nicknamed for his "goggle eyes" (*jahiz*), was an erudite, prolific, and notably ugly writer at Basra and Baghdad. His essays on many topics are still much quoted in the Middle East. Reacting against public disdain for his own facial appearance, he became one of the earliest advocates for greater acceptance of disabled people. Al-Jahiz (1954) asserted that impairments or odd appearance "do not hinder an individual from being a fully active member of the Muslim community or bar him from important offices"; on the contrary, these "may be called signs of divine blessing or favor." He distinguished various levels of hearing impairment and noted that when a deaf person could not speak it was because "having never heard sounds, articulated or otherwise, he does not know how to produce them" (Al-Jahiz 1969). Elsewhere, Al-Jahiz (1983) commented on the silent language of signs and gestures used at mealtimes by courtiers under the Sassanid rulers (224–636 CE).

—Kumur B. Selim

See also Abu 'l-`Ala al-Ma`arri; Abu 'l Aswad ad-Duwali; `Ata ibn Abi Rabah; Khalil, Al-; Middle East and the Rise of Islam.

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JERNIGAN, KENNETH
(1926–1999)

American activist

Kenneth Jernigan, born blind, was one of the preeminent leaders of the struggle for equality waged by blind people during the twentieth century. He served as president of the National Federation of the Blind (NFB) from 1968 to 1986, with one brief interruption in 1978–1979. As president emeritus, he remained actively involved in the NFB and its operations until his death in 1999. Jernigan was mentored by Jacobus tenBroek, the NFB's first president, and one of the most influential voices addressing discrimination against the blind in the United States.

Born in Detroit, Jernigan grew up in Tennessee on a family farm. He held many jobs as a young man, including furniture maker, insurance salesman, and, briefly, professional wrestler. He received a degree in literature from Peabody University, and soon after went to teach at the Tennessee School for the Blind. In 1953, he was encouraged by tenBroek to move to California to work at the Orientation Center for the Blind in Oakland. In 1958, he became the first blind director of the Iowa Commission for the Blind, a position he held until 1978. During his time in Iowa, the commission was transformed from the worst to the best agency serving blind adults in the United States, and Des Moines became the epicenter of the blind movement.

Jernigan joined the NFB in 1949, and he was its vice president by 1958. Jernigan's rise to power occurred in the context of a bitter struggle for the leadership and direction of the NFB, resulting in the expulsion of several state affiliates and the creation of a splinter group in 1961, the American Council of the Blind (ACB).

Jernigan's philosophy of blindness was that the average blind person could do the work of an average sighted person when the former was given proper blindness adjustment training. With such training, Jernigan asserted, blindness could be reduced to a mere physical nuisance.

—Brian R. Miller

See also Activism; Blind, History of the.

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National Federation of the Blind, www.nfb.org

JIRI, JAIROS (1921–1982)

African philanthropist

As African philanthropist and founder of the Jairos Jiri Association in 1950, Jairos Jiri and his accomplishments in Zimbabwe stand out in the history of

African rehabilitation services. The son of a local chief, Jiri obtained virtually no education. At the age of 18, he set out to Bulawayo, where he was struck by the fate of disabled people as beggars. Encouraged by the knowledge that something could be done, he took them into his home and generated help from others in teaching them basket making and shoe repair. The efforts institutionalized very quickly, first with the assistance of the colonial administration, and later with international aid.

This led to one of the largest associations of its kind, the Jairos Jiri Association, serving more than 13,000 disabled children and adults annually. Among its many establishments are schools, clinics, homes, hostels, vocational training centers, community-based rehabilitation programs, scholarship funds, orthopedic workshops, and outreach and follow-up integration programs. The association looks to (1) assist, treat, and rehabilitate persons with physical, visual, and hearing impairments; (2) establish clinics, schools, centers, and other institutions for the education and welfare of the handicapped; and (3) liaise with the government of Zimbabwe and local and international agencies.

—Patrick Devlieger

See also Developing World; Experience of Disability: Sub-Saharan Africa; Job Training; Vocational Rehabilitation.

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JOB ANALYSIS AND PLACEMENT

JOB ANALYSIS

The goal of a job analysis is to describe the tasks associated with the job and then articulate the human attributes necessary for successfully performing those tasks. Job analysis is an important part of what an industrial/organizational (I/O) psychologist does. Information from a job analysis is used for many purposes, and there are many methods for conducting a job analysis. This entry briefly describes these purposes and methods.

Purposes of Job Analysis

Information from job analysis can be used for many different purposes, such as job description, recruitment and selection, placement, performance assessment, training, compensation, criterion development, career development, legal issues, job design and redesign, and workforce reduction and restructuring. Professionals in human resources departments of business organizations and government agencies make extensive use of the information from a job analysis for these and other purposes. A disability-related application of job analysis occurs when rehabilitation counselors develop vocational plans to assist persons with disabilities obtain employment.

Methods of Job Analysis

Many of the methods used in performing a job analysis can be categorized into either a work-oriented approach or a worker-oriented approach. In a work-oriented approach, the emphasis is on the tasks performed by an incumbent or what a person does on the job. These tasks can be further subdivided into activities, and each activity may consist of several actions or elements. Two of the most well-known methods of job analysis in the work-oriented approach are the functional job analysis (FJA) and task inventories.

FJA was used in developing the *Dictionary of Occupational Titles* (*DOT*), which was designed to match people to jobs in the U.S. economy. The fifth edition of the *DOT*, published in 1991, provides information on more than 13,000 occupations in the U.S. economy. Task inventories are very popular in business organizations. Based on interviews with a small, representative sample of subject matter experts (SMEs) such as incumbents and supervisors, task inventories are developed and administered to incumbents and supervisors for gathering information on which tasks are performed on the job, how frequently tasks are performed, and their importance. In general, more tasks are included in a task inventory than in an FJA. Finally, another example of a work-oriented approach to job analysis is the critical incident technique (CIT). With CIT, SMEs are asked to recall specific instances of worker behavior, which represent either exceptional or unacceptable performance on the job.

In a worker-oriented (or person-oriented) approach, the emphasis is on obtaining information about the attributes and characteristics required for a successful performance on the job. These attributes and characteristics are commonly referred to as KSAOs (knowledge, skills, abilities, and other personal characteristics such as personality variables, interests, training, and experience). One of the most popular methods of job analysis in the worker-oriented approach is the Position Analysis Questionnaire (PAQ). It is a commercially available questionnaire, with computer scoring and multiple report-generation options. The PAQ consists of 194 items. Other examples of methods in the worker-oriented approach are the job element method, Job Element Inventory, Job Components Inventory, Occupational Analysis Inventory, and Common Metric Questionnaire.

A new method of job analysis, which reflects both the work-oriented and worker-oriented approaches, is the Occupational Information Network or O*NET. It was developed by the U.S. federal government and was designed to replace the *DOT*. The O*NET is a collection of databases with an expert computer system for facilitating person-job matches. The foundation of the content model underlying the O*NET centers on worker requirements, experience requirements, worker characteristics, occupational requirements, occupation-specific requirements, and occupation characteristics. The O*NET system is relatively new and web based, but it does not include all jobs/occupations.

Sources of Information

Typically, job analysts, incumbents, supervisors, and trained observers are the sources of job analysis information. This information can be obtained in interviews, via questionnaires, by observation, and by actually performing the job in question. Multiple sources and collection methods are often used in practice.

Each job analysis method has its own strengths and weaknesses, and no one method is adequate for all purposes. So the choice of a method must be based on the purpose for a job analysis. Careful consideration should also be given to the costs associated with implementing a given job analysis method.

JOB PLACEMENT

In filling vacancies in a given job, the emphasis is on finding the most qualified people for the job (or individuals most likely to succeed on the job). This is a case of straightforward selection. When there are vacancies for several jobs, one is concerned about how best to fill all vacancies simultaneously with the same applicant pool. This is a case of placement. That is, one is called on to *place* an applicant rather than to *select* an applicant. One may think of selection as choosing one applicant from among many applicants to fill a job opening. In contrast, placement involves matching multiple applicants with multiple jobs. In general, placement is more involved and complex than selection. In either case, reliable and valid job analysis information is a prerequisite.

Selection has received much more attention than placement by I/O professionals. Failure to attend to issues of placement can be long-lasting. All individuals who want to work should have the opportunity to do so. If an individual does not meet the minimal requirements for one job, she or he should be considered for other available jobs. That is, job placement should be given a top priority.

—Nambury S. Raju

See also Employment; Job Retention; Job Training; Vocational Rehabilitation.

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JOB RETENTION

Involuntary job loss either by plant closings, layoffs due to slack demand, or firings for cause will have negative short-run effects on discharged workers' earnings and can have significant long-term effects on the economic well-being of their families. Because the U.S. labor market is considerably less regulated by government than other Organization for Economic Cooperation and Development (OECD) countries and because only about 10 percent of U.S. private sector workers belong to unions, American workers have much less formal protection against involuntary job loss than workers in other OECD countries.

On the other hand, the greater flexibility of American labor markets also means that American workers are better able to enter the labor market and voluntarily move from one job to another. In addition, American firms are better able to adjust their mix of machines and labor in their production process, introduce new technologies, and compete in the international marketplace.

The end result is that the American labor market is more flexible, allows greater voluntary job mobility, and is better able to reward skilled and highly educated workers but also has greater wage inequality, more lower-paying jobs, and greater risks of involuntary job loss than the more regulated labor markets in other OECD countries.

Working-age people with disabilities in the United States likewise have much less formal job protection either via government regulation or union protection and must compete in much more dynamic labor markets than their counterparts in other OECD countries. Germany, for instance, has a formal quota system (that penalizes firms that do not employ a minimum percentage of workers with disabilities) and prohibits employers from dismissing workers based on their disability. In contrast, the United States forbids the use of job quotas and allows employers much greater freedom in hiring and firing workers. The Americans with Disabilities Act of 1990 (ADA) is the most significant piece of protective legislation for U.S. workers with disabilities and has strict limits on whom and how much firms must accommodate.

The United States experienced two major business cycles over the past two decades of the twentieth century—1979 through 1989 and 1989 through 2000. Over the first, the employment rates of working-age people with and without disabilities were pro-cyclical, falling over the recession years of the early 1980s and rising over the long period of growth from 1982 to 1989. However, the rise in the employment of those with disabilities was not as great as those without disabilities, so over the decade their employment rate fell relative to those without disabilities.

The relative employment rate of people with disabilities fell even more over the 1990s business cycle. While the employment of both those with and without disabilities fell from 1990, the business cycle peak year, to 1993, during the growth years 1993 to 2000 the employment of those without disabilities rose while the employment of those with disabilities fell. The employment rates of both those with and without disabilities fell between 2000 and 2003, but the employment rate of those with disabilities fell faster than that of those without disabilities.

Between 1979 and 2000, the household income of working-age people with disabilities remained about the same. Their wage-earning declines were offset by increases in their disability transfers (Social Security Disability Insurance [SSDI] and Supplemental Security Income) and by the greater earnings of other household members. But their overall household income fell relative to those without disabilities, whose income rose significantly over this period of substantial economic growth.

Most working-age people with disabilities experience the onset of their disability after they enter the labor market. Research shows that the social environment, rather than the impairment itself, is the critical factor in determining how long workers with disabilities remain in the work force. The average length of time before they apply for SSDI benefits following onset is 15 years, and only 72 percent of workers with disabilities will ever apply for SSDI benefits. The rest continue in the labor force until they exit onto the

Social Security retirement program. The timing of SSDI application is affected (holding the seriousness of the worker's impairment constant) by a worker's characteristics and the economic incentives he or she faces.

The variables that most affect how long a worker will delay application for SSDI following the onset of a work-limiting health condition are the worker's age at the onset of the condition, the worker's education, whether the worker was accommodated, and the relative rewards of working versus going onto SSDI.

Other things equal, younger and better-educated workers will delay application longer than older or less-educated workers. But accommodation matters. Employees who are accommodated by their employer stay in the labor force longer than those who are not. This is true across a wide range of accommodations. The most frequent firm accommodations are not costly from an accounting perspective, although they may be from a work organization perspective. They are changes in job hours and changes in job responsibilities.

But economic incentives also matter. Those workers whose future earnings are higher or who are less likely to be accepted onto SSDI will delay applying for benefits and continue in the labor force longer than workers with lower future earnings and higher likelihoods of SSDI acceptance.

These findings are based on the accommodation behavior of firms and their workers prior to the implementation of the ADA in 1992. About 23 percent of workers who experienced a disability were accommodated prior to 1992. Simulations that project the experience of these accommodated workers on all workers suggest that their average duration before applying for SSDI benefits would rise by about 2.5 years, if accommodation were provided to all workers following the onset of a disability. But this positive employment policy initiative could be offset by further easing of SSDI acceptance rules or increases in SSDI benefits relative to future earnings.

The recent employment experience of working-age people with disabilities is discouraging. Despite the increased duration in employment that accommodation brings and the likely rise in the percentage of workers with disabilities who were accommodated in the 1990s following the implementation of the ADA, their employment rates fell over the entire 1990s business cycle and has done so, relative to those without disabilities, since the mid-1980s. The causes of this decline in relative employment are controversial, but the preponderance of the evidence suggests that it was not caused by an increase in the severity of their impairments. Rather, the causes are related to the changing social environment faced by workers with disabilities.

The most likely cause is the substantial reduction in the eligibility standards for entry onto the SSDI rolls that occurred in the mid-1980s. Research has shown that U.S. workers who experience the onset of a disability in states with higher SSDI acceptance rates are quicker to apply for benefits and that in such states the employment rates of workers with disabilities are lower relative to those without disabilities.

It has also been argued that the increased costs firms must bear to accommodate workers with disabilities have made them less likely to hire such workers and that this unintended consequence of the ADA offsets its positive impact via increased duration on the job for those who are accommodated. The evidence of a negative ADA effect on employment is more controversial and has been shown to be sensitive to alternative definition of the population with disabilities.

Market forces influence the employment of working-age people with and without disabilities. The skills that people with disabilities bring to the job will affect their chances of employment, their duration on the job, and the age they leave the labor market. The wage premium that those with more than a high school education command has dramatically increased over the past two decades. This is true both for those with and without a disability. The best predictor of job market success is one's level of education, and in the constantly changing American job market, the long-term rewards to well-educated workers demonstrate its value. Hence those workers with good job skills and high education levels are the most likely to be retained by their employers during bad times and to command higher salaries during both good and bad times.

Government policy can also influence the employment of working-age people with disabilities. Pro-work policies that foster rehabilitation, job-enhancing skills, and accommodation will increase job retention and more generally integrate working-age people with disabilities into the labor market. Reduction of eligibility standards for SSDI and other disability transfer programs that require beneficiaries to demonstrate that they are not able to work before they can receive benefits will have the unintended consequence of further reducing the employment of working-age people with disabilities who could work.

—Richard V. Burkhauser

See also Americans with Disabilities Act of 1990 (United States); Disability Law: United States; Employability; Employment; Employment, International.

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JOB TRAINING

Job training, both for those employees new to the work setting and those needing to acquire additional work skills, is often viewed as a way of assisting the employee in mastering the essential function of a job. The outcome of such training is the development of skills that will allow the employee to meet the standards set by the employer. Job training can be viewed as generalized preservice and mentorship/apprentice training or training that occurs in response to a specific job. For persons with disabilities, when considering job training one has to consider the broader perspective of identification, accessing, and maintaining employment since these are intertwined in the process of securing and advancing in employment.

This entry briefly reviews the principles driving job training, approaches for persons with disabilities, and the challenges and opportunities to job training in the future. This overview will provide the reader with a broad view of job training for persons with disabilities from a philosophical as well as a practical level. While this entry addresses job training for individuals who have a disability, it is important to note that the approaches used are more similar than different for all job seekers, those with as well as without disabilities.

PRINCIPLES DRIVING JOB TRAINING

The changing perceptions about the capacity of persons with disabilities, advances in job training strategies, and new technologies have all contributed to a new way of looking at job training for persons with disabilities. The realization that persons with disabilities can and in many instances want to work has been supported in many countries by changes in legislation, policies, and practices that have encouraged persons with disabilities to consider employment and employers to view persons with disabilities as part of the workforce.

Legislation banning discrimination, providing incentives to hire, and establishing hiring quotas have all contributed to an increased awareness about the employment of persons with disabilities. In a complimentary fashion, the recent movement toward self-advocacy has also served to increase the awareness by persons with disabilities about the opportunities that may exist in the labor market. The combination of increased self-advocacy, changing ways to support and match individual skills to industry needs, and administrative incentives has served to support increased employment of persons with disabilities in many countries.

APPROACHES TO JOB TRAINING

The evolution of employment for persons with disabilities is reflective of overall societal perceptions of disability in general. This evolution has gone from no expectation to a recognition that persons with disabilities can and want to work. Job training approaches for job seekers who have a disability have moved from a pretraining or readiness design to one that places greater emphasis on on-the-job training. Early training efforts focused on the identification of individual deficits, the remediation of those deficits, and then the development of work-hardening or work tolerance skills. A myriad of work samples, paper-and-pencil, and trial work strategies were the cornerstone of job training strategies in many countries. These assessment approaches were based on deficit identification followed by remediation and skill development. This focus on deficit identification and work conditioning placed the entire responsibility for job success on adaptations by the individual with little recognition of any modifications in the actual work setting.

In the past two decades, the emphasis on job training has shifted to one of building on skills and interests and maximizing the abilities of the individual. Informal and formal assessments addressing preferences and interests were providing greater information than the more traditional work assessment tools. There was also a growing recognition that situational assessment, conducting an assessment in an actual work setting, provided greater information on both skills and interests. There continued to be, however, a focus on the person fitting the job. Moving from the utilization of situational assessments, job training in many countries has embraced the strategy of matching individual skills and interests to demands in the work setting. This focus has led to a "goodness of fit" perspective where job training is a combination of skill building and job modifications. Here both the individual and the job setting are adapting.

Paralleling this evolution of focus was a shift in the nature of the training setting. Total reliance on specialized training and work settings is giving way to direct placement and on-site supports based on the results of considerable research in supported employment. Job training is happening in the workplace with the assistance of an outside support, an employment training specialist, or job coach. This support addresses not only skill acquisition but also identification of available social supports that are naturally present in the work setting. The employment training specialist facilitates initial training, fading support and shifting the training and support to the employer and coworkers as the individual with disabilities approaches employer expectations and assimilates into the culture of the workplace. The linking of external supports to those naturally existing in the work setting and the training of coworkers as support resources, the hallmark of supported employment, are now common practice in many countries.

As a reflection of this shift, trainers have evolved from more formal skill trainers who may offer classroom instruction in an external setting to on-site employment training specialists. Training on the essential tasks of the job is not the only function of the employment training specialist. Job accommodations and job modification may be introduced to both support productivity and assist the individual with a disability in being successful on the job. Modifications may include the restructuring of tasks, the simplification of task sequences, the use of assistive devices and aids (e.g., pictures, cue cards), and the identification of coworker supports for the individual. Job training has moved away from specific skill acquisition to whole-job training including skill acquisition, social supports, and job modification.

FUTURE CHALLENGES

As the nature of an economy changes so do the demands of businesses. These demands require that the workforce adapt, continually acquiring new skills. During the farming and manufacturing periods, it was not uncommon for workers to remain at one job for their entire work history. With the advent of the technology and information era, job movement and job change became the rule rather than the exception and changes in tasks were at times a daily event in some industries.

More recently, with globalization, technology changes, and virtual work settings, the demands for increased flexibility and greater proficiency in the use of technology continue to change the job training arena. The idea of initial training has given way to continuous training where changes in the consumer marketplace have given rise to the creation of new products and new jobs. New approaches and technologies such as multitasking, voice-activated information systems, smart technologies, and virtual work settings, along with globalization and workforce diversity, are all requiring those involved in job training to think and behave differently.

These challenges are requiring job training professionals to think differently about both the nature of training strategies and the setting for the delivery of training. The rate of job change, the changes in job duties, and the increased use of distance education resources are an opportunity for job training to use technology for delivery of information as well as a way of reinforcing skill acquisition. Web-based training, Listservs, and chat rooms are all ways that job training can be delivered now and in the future. Common instructional materials delivered through electronic media and reinforced by local trainers or support staff assist persons with disabilities in learning new skills not only at time of job access but also as a way of maintaining employment. The use of multistimulus input systems (seeing, hearing, touching), vehicles for immediate feedback, and strategies for rapidly refreshing learned skills are all ways that job training can support both initial learning and job growth for persons with disabilities.

Effective strategies for job training have relevance for all employees. With older workers remaining on the job for longer periods of time, workforce mobility reflecting not just local but global tendencies, and increased recognition of the employment potential for job seekers with disabilities, effective job training strategies can be applied not only to job seekers who have a disability but also to older workers and the nonnative workforce in many countries. Job training has the potential for broadly supporting access and career development for both the emerging workforce and the typical workforce in the coming decades.

—William E. Kiernan and Robert L. Schalock

See also Affirmative Businesses; Consumer-Run Businesses; Employability; Employment; Jiri, Jairos; Job Analysis and Placement; Job Retention; Vocational Rehabilitation.

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JOHNSON, SAMUEL (1709–1784)

English author and lexicographer

Both a "great Cham" (tartar monarch) and "Caliban" (Shakespeare's deformed slave in *The Tempest*) of letters, Samuel Johnson gave his name to an age as the most prominent literary author of his day. Best known for his Herculean (and Sisyphean) achievement of the first modern dictionary of the English language (1755), Johnson also was an editor of Shakespeare, a moralist in a variety of genres—periodical essay, Juvenalian satire, heroic tragedy, apologue, travel narrative—and in his *Lives of the Poets* (1779, 1781) a legislator of the English literary canon. Yet he was often remembered by subsequent generations more as a character than an author.

Blind in one eye, deaf in one ear, scarred by childhood tuberculosis of the lymphatic system (known as "scrofula") and by smallpox, Johnson suffered throughout his life from what his biographer James Boswell termed "a horrible hypochondria," what the psychology of the period would have termed religious melancholy (his greatest fear was damnation) and what would now be considered severe depression. This inner torment was accompanied by rituals, compulsions, and convulsive "tics and gesticulations" that have recently been diagnosed as evidence of Tourette's syndrome but that during Johnson's own time evinced eccentricity (the stuff of eighteenth-century English notions of individuality) rather than pathology. At his life's close, Johnson survived a stroke, while suffering congestive heart failure, kidney disease, emphysema, severe arthritis, and "dropsy" manifested most dramatically as a hydrocele of the testis. He fought death to the last, deploring his doctors' caution in treating his dropsy and hastening his demise by self-scarification. Johnson's embodied afterlife arises partly from Boswell's devoted preservation of his conversation in the *Life of Johnson* (1792), but also from his epitomization of literary authority as a paradox that united monumental style with a singular body in ambiguous motion.

—Helen Deutsch

See also Blind, History of the; Deaf, History of the; Depression; Representations of Disability, History of.

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JOURNALISM

Although the political issues of people with disabilities rarely made the mainstream news until the 1990s, the people themselves have been in the news since American journalism began the practice of identifying sources by physical characteristics. The norms of journalism that developed by the early twentieth century meant that anyone who was not white or able-bodied would, in many cases, be identified by their ethnicity or disability. For example, an *Atlantic Monthly* article about the blind African American pianist and composer Thomas Bethune in 1862 was headlined "Blind Tom," which was his well-known moniker. Most disabled people did not garner the nineteenth-century media attention of Blind Tom, but any journalist writing about a person with a disability in the nineteenth century or the present would rarely fail to mention a disability, especially blindness or deafness. When Erik Weihenmayer climbed Mount Everest in 2001, every journalist mentioned his blindness.

However, these reports of individual people with disabilities in the news did not mean the issues that affected them made the news. In fact, journalism's focus on specific individuals with disabilities became the standard of coverage for decades. When the disability rights movement arose in the 1970s, activists and media researchers began questioning why journalists continued to write primarily about individuals with disabilities, rather than the major civil rights initiatives afoot.

RESEARCH ON REPRESENTATIONS IN JOURNALISM

The concept of handicapism is germane to journalistic coverage of people with disabilities. In developing the concept in 1977, Robert Bogdan and Douglas Biklen defined *handicapism* as "a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences." Their data and impressions suggested that mass media, by portraying prejudicial or stereotypical images of disabled persons, contributed to handicapism in society.

Therefore, many researchers began to take seriously the influence of journalism on the understanding of disability. Researchers from the areas of rehabilitation began to look at news representations. For example, rehabilitation researcher E. Keith Byrd and Timothy Elliot of Auburn University studied various aspects of media images of disability over the course of the 1980s. Psychologists also looked at news images of disability. James M. Gardner and Michael S. Radel studied both newspapers and prime-time television coverage of disabled people in 1978 to identify the major themes in coverage: dependence, independence, abuse, and deviance.

Disability studies scholars paid attention to journalistic images of disability in the 1980s as well, especially when major media issues arose. Douglas Biklen looked at the print media coverage of the 1984 Baby Jane Doe case, in which parents and doctors fought over the severely disabled baby's right to live or die, and the Elizabeth Bouvia case, in which a severely disabled woman wanted the right to starve to death. Biklen found that journalists uniformly "cast in terms of tragedy, of charity and its attendant emotion, pity, or of struggle and accomplishment."

The language used in journalism to characterize people with disabilities also has significance. Disability studies scholar and historian Paul Longmore studied the social meaning of language that referred to disabled people in 1985 and found three forms. One form represents people solely in terms of a disability and are therefore medicalized and dependent. This form creates abstract nouns from adjectives (the disabled, the deaf) or borrows medical labels such as "suffers from." Another form used euphemistic labels such as "special" or "exceptional." And the third form refers to politicized language that allows disabled people to create their own identity.

More mass communication scholars turned their attention to journalism and disability topics in the 1990s. The preeminent scholar in this area was John Clogston, a former radio journalist who was a wheelchair user. He wrote his dissertation at Michigan State University, "Reporters' Attitudes toward and Newspaper Coverage of Persons with Disabilities." In 1990, Advocado Press, the publisher of *The Disability Rag,* published Clogston's content analysis of the coverage of disability topics in more than a dozen major U.S. newspapers. Through his research, he developed five models of news media representation of disability, which fit into either a traditional or progressive category.

Clogston's traditional categories include the medical model, the social pathology model, and the supercrip model. In the medical model, disability is presented as an illness or malfunction. Persons who are disabled are shown as dependent on health professionals for cures or maintenance. In the social pathology model, people with disabilities are presented as disadvantaged and must look to the state or to society for economic support, which is considered a gift, not a right. In the supercrip model, the person with a disability is portrayed as deviant because of "superhuman" feats (e.g., ocean-sailing blind man) or as "special" because they live regular lives "in spite of" disability (e.g., deaf high school student who plays softball).

Clogston's progressive categories include the minority/civil rights model and the cultural pluralism model. In the minority/civil rights model, people with disabilities are portrayed as members of the disability community, which has legitimate political grievances. They have civil rights that they may fight for, just like other groups. Accessibility to society is a civil right. In the cultural pluralism model, people with disabilities are presented as a multifaceted people and their disabilities do not receive undue attention. They are portrayed as nondisabled people would be.

News media researcher Beth Haller used Clogston's models in her 1995 dissertation, "Disability Rights on the Public Agenda: News Coverage of the Americans with Disabilities Act." However, she added three models to reflect the changes in society that came with the 1990 Americans with Disabilities Act (ADA). In addition, Haller expanded the use of the models by recognizing that more than one model may be present in a story. This was especially appropriate in news stories about the ADA, in which government, business, and disability rights sources came together.

Haller's added traditional category model was the business model, in which people with disabilities and their issues are presented as costly to society and businesses especially. Making society accessible for disabled people is not really worth the cost and overburdens businesses; in other words, accessibility is not profitable. The two added progressive models were the legal model and consumer model. In the legal model, the media explain that it is illegal to treat disabled people in certain ways. The ADA and other laws are presented as legal tools to halt discrimination. In the consumer model, people with disabilities are shown to represent an untapped consumer group. Making society accessible could be profitable to businesses and society in general, because if disabled people have access to jobs, they will have more disposable income and less need for government assistance.

These models created a systematic way to study and categorize representations of people with disabilities in journalism. Clogston was also instrumental in developing the Media and Disability Interest Group as part of the Association for Education in Journalism and Mass Communication (AEJMC), which is the major academic organization for journalism scholars. Another founding member of the interest group and important journalism and disability scholar is Jack Nelson. He gathered together media scholars and edited a 1994 book looking at many aspects of the topic in *The Disabled, the Media, and the Information Age.* This was the first solely news media/disability-research focused book in the United States, although in 1987 Alan Gartner and Tom Joe edited a scholarly collection called *Images of the Disabled, Disabling Images,* which included some chapters on news and disability. A British study of disability images on TV, both fiction and nonfiction, resulted in a book in 1992. Guy Cumberbatch and Ralph Negrine's (1992) *Images of Disability on Television* found themes in news programs such as fitting into normal life, the physical progress of a person with a disability, the lack of understanding by society/individuals, and fighting for civil rights.

JOURNALISM FROM THE DISABILITY COMMUNITY

All this research over the years confirmed that news media do a mediocre job of covering people with disabilities and their issues. Because mainstream media presented stereotypes or no information at all, many disability groups created their own journalism. Many disability publications have a long history in the United States; for example, one that has been ongoing since 1907 is *The Matilda Ziegler Magazine for the Blind* Braille publication.

Like ethnic publications or the alternative press, the disability publications react to the same kind of exclusion and stigmatization that other outsider groups have experienced. Disability publications allow people to pull themselves together as a community with similar goals and aspirations. As Erving Goffman (1963) suggested in *Stigma,* people with a stigmatized status in society develop their own publications because they allow them to debate the societal issues related to them that rarely make the mainstream press.

Charlie Winston, who tracks the disability press annually in *America's Telability Media* guide, estimated that in the late 1990s at least 1,200 mass media resources for the disability community in the form of magazines, newspapers, newsletters, radio/TV programs, and recurring newspaper columns existed. Winston said the disability media range from an individual creating a two- to four-page newsletter at a very low cost to a glossy, four-color magazine such as *New Mobility* (telephone interview by author with C. Winston, March 26, 1999).

Lillie Ransom, in her 1996 dissertation on disability publications, identified three main patterns among the publications: activist/political, mainstreaming/assimilationist, and special interest. She said that a publication such as *The Ragged Edge* is embedded within the disability rights social movement, making it an activist/political model publication; *The Arc and the Dove,* a publication for the ARC of Maryland, fits within the mainstreaming/assimilationist model because they want people with mental retardation to be accepted in the mainstream community; and a publication such *as The National Amputee Golfer* is described as a special interest model. However, whatever their pattern, each publication has the commonality of serving people who are "outsiders" and who face societal barriers due to physical or mental difference. Disability journalist Douglas Lathrop explained that these disability publications reflect that people with disabilities think of themselves as a community.

In addition to giving a voice to the entire community of Americans with disabilities, disability journalism gives apt examples that people with disabilities are a multifaceted community. Because different disabilities make for different societal barriers, publications based on specific disabilities arose. For example, the U.S. deaf community has a long tradition of its own journalism. The North Carolina School for the Deaf began the first publication for deaf persons in 1848 with its school newspaper, *The Deaf Mute.* Other disability-related publications continued a tradition of fostering solidarity within the different subcultures of the disability community. After World War II, soldiers who had been disabled in war came home, which led to the Paralyzed Veterans of America's development of the magazine *Paraplegia News,* in 1946.

In terms of disability rights–focused journalism, disability publications such as *The Ragged Edge, Mainstream,* and *Mouth* helped fuel the disability community's civil rights agenda. *Mainstream* magazine began in 1975. (Its print publication ceased in 1999.) The precursor to *The Ragged Edge, The Disability Rag,* started in 1980. *Mouth* began in 1990. Lucy Gwin, the editor of *Mouth,* explained: "Nobody [in the mainstream media] is going to cover the disability-rights movement, so we're just going to have to cover it our own damn selves."

EFFORTS TOWARD BETTER JOURNALISM

A few people still believed that mainstream journalism could change its coverage patterns and do a better job of reporting on disability issues. They also realized that most Americans get their information from mainstream news media and that they could have significant influence on the general public's perception of disability rights. In 1988, the U.S. government tried to foment this change. The National Institute on Disability and Rehabilitation Research (NIDRR) funded a national workshop on news media and disability issues. A workshop organizer said the reason behind the project was that "recent news articles and features have tended to divide disabled individuals into two categories: the poor pathetic creature of charity or the heroic, undefeatable 'super crip.'"

Another government-funded project to improve journalism on disability topics was produced in 1989 by the Advocado Press. Edited by Mary Johnson, *The Disability Rag* editor, and Susan Elkins, the publications coordinator for the Research and Training Center on Independent Living at the University of Kansas, the manual, *Reporting on Disability: Approaches & Issues,* drew together contributions from activists, ethicists, writers, and broadcasters, all of whom had experience covering disability issues. Intended for use with journalism students, the manual gave guidance on reporting issues specific to disability topics, how to find new and less stereotypical angles in covering disability, information about disability rights history and laws, ethical considerations, and examples of good reporting on disability topics.

Several journalists who contributed to the manual went on to write important books about disability rights, which included information about news media coverage. In 1993, Joseph Shapiro of *U.S. News & World Report* wrote *No Pity: People with Disabilities Forging a New Civil Rights Movement,* considered one of the best journalistic books on the disability rights movement. Tari Susan Hartman and Mary Johnson wrote a book called *Making News* in 1993 that provided a guide to activists on how to get news coverage of disability rights issues. Johnson then deconstructed backlash against the ADA in her 2003 book, *Make Them Go Away: Clint Eastwood, Christopher Reeve and the Case against Disability Rights.*

Associations of journalists gained awareness of their flaws when reporting on disability issues by 1990. The American Society of Newspaper Editors formed its Disabilities Committee and in 1990 published a booklet, *Reporting on People with Disabilities.* Bill Beisky, the editor of the *Cape Cod Times* and the father of a daughter with a disability, instigated the development of the booklet. The booklet makes some suggestions on reporting issues but was primarily a language guide on the preferred terminology when referring to disability topics. In a similar effort, the Research and Training Center on Independent Living at the University of Kansas also released a terminology guide in 1990, *Guidelines for Reporting and Writing about People with Disabilities.* The guide is now in its sixth edition. To pursue similar efforts at journalism education, freelance photographer Suzanne Levine developed the National Center on Disability and Journalism (NCDJ) in 1998. NCDJ created an online style guide about disability terms, as well as posting tip sheets on topics such as interviewing people with disabilities and developing curriculum for teaching about disability in the college journalism classroom.

In 1993, the Freedom Forum Media Studies Center at Columbia University also addressed the news media's problematic reporting on disability in *A Parallel and Imperfect Universe: The Media and People with Disabilities* (Gazsi 1993). The Society of Professional Journalists (SPJ) began acknowledging the need for better coverage of disability issues as well. Its society magazine, *The Quill,* had been publishing occasional articles about the topic since the 1980s when Laura Rensom Mitchell wrote "Beyond the Supercrip Syndrome." By 2002, SPJ developed an online searchable Rainbow Sourcebook, which included sources on disability issues.

In the late 1990s, NIDRR again identified the need to better educate the public about disability issues through the mainstream media. It funded the San Diego–based Center for an Accessible Society, run by the former publisher and editor of *Mainstream* magazine, Cyndi Jones and William Stothers, and Mary Johnson of *The Ragged Edge.* Its charge is to get information about disability topics and independent living out to the general public. It does this by creating an online resource guide for journalists on a myriad of disability topics and by providing sources on disability issues for journalists. It also funds research to track major news media coverage of disability topics.

—Beth A. Haller

See also *Cripple*; Disability Culture; *Handicap*; Language of Disability; National Institute on Disability and Rehabilitation Research (NIDRR) (United States).

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JUDAISM

Central to Jewish disability issues is Scripture Tanach (Old Testament) and its interpretation, Talmud (oral law). Collectively, these (and later commentaries) are known/studied as Torah. References to numerous impairments abound, often conflated with other conditions including, most notably, childhood. With Scripture, especially Talmud (the first diasporic literature), virtually the only record of ancient everyday Jewish life, the nature of these references must be considered. Much of Talmud is utopian/idealistic. Largely composed of religious case law, its admonitions may more reflect common transgressions than common practice. In addition, disabilities are often used hypothetically to illustrate extremes in test cases.

Judaism prior to the destruction of the Second Temple and the first state of Israel (70 CE) was rooted in the priestly Temple cult and sacrificial rite. The "perfect priest" required physical "blemishlessness" to withstand the ardors of animal sacrifice in God's presence within the temple. The priest represented an archetypal ideal rather than a norm, a far higher standard than mere able-bodiedness. Although restoration of the temple and priesthood remains an idée fixe in Judaism, the diaspora's practical archetype became the sage (the professional rabbinate emerged only later). The precarious nature of diaspora—metaphorically, a disabled Israel—idealized intellectual attainment through Torah study, rather than physical perfection. Throughout and beyond the era of Bavli (the definitive Babylonian Talmud, fifth–seventh century CE) impairments become progressively better understood and accepted, if only incrementally until recent times.

A culture that idealizes intellectual discourse would naturally regard cognitive/communication impairments as most disabling. The Talmud subsumes these in the category *cheresh, shoteh v'katan*: deaf/mute persons, mentally ill/mentally disabled persons, and children. More than earlier Scriptures, Bavli recognizes nonverbal communication by the deaf/mute, the intermittency of some mental illness, and practical attainments of the developmentally disabled and maturing children. Thus, correspondingly, it advocates, within limits, greater rights and responsibilities for these groups. Judaism has never sanctioned infanticide.

With cognition and communication so privileged, mobility impairments are of little concern in Jewish law. Blindness is regarded as a disability only in a few contingencies. Several Talmudic sages were blind, including Rabbi Yosef, whose advocacy of rights and responsibilities for the blind is considered definitive. Still, disability is sometimes regarded as God's punishment, though also, as in Buddhism, an opportunity for atonement and even a conduit for prophecy.

Contemporary Judaism has virtually abolished the category *cheresh;* deaf/mute persons are no longer consider insensate. There are deaf synagogues, a deaf seminary, and deaf Jewish community centers. Israeli Sign Language is very similar to Palestinian Sign Language. Since 1992, Vertigo, an Israeli mixed-ability dance company, has toured worldwide.

Anti-Semitism is often expressed in a discourse of pathology and defect. In the context of nineteenth- and twentieth-century Western racism and eugenics, the Nazis implemented genocidal programs against Jews, people with disabilities, and others including Sinti/Roma ("Gypsies") and gays and lesbians.

—Alex J. Lubet

See also Deaf, History of the; Religion.

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JUKES, THE

The first of many editions of Richard L. Dugdale's *The Jukes, a Study in Crime, Pauperism, Disease, and Heredity* appeared in 1877. The book told the story of five generations of poverty, crime, and disability in the Jukes family, the fictitious name of a real family. Departing from the dominant antebellum claim that heredity represented capricious degeneration, Dugdale held that hereditary disabilities followed intergenerational patterns. Thus, alcoholism would not necessarily produce so-called insanity or feeblemindedness in later "skipped" generations, but it might well produce more alcoholism in the next generation, and with alcoholism came poverty.

Dugdale also stressed a relationship between heredity and the environment. Juke family members who lived in healthy surroundings were less likely to be paupers than were family members who lived in unhealthy environments. Drawing the attention of the emerging "scientific charities" movement, the book reached its largest audience after Dugdale's death in 1883. Departing from his insistence on the interrelationship between the environment and heredity, this audience appropriated the story of the Juke family to argue for the immutability of heredity. From 1883 to the 1920s, North American social welfare officials portrayed many poor, and often rural and white, families like the Jukes as hopelessly degenerate, victims of their ancestral vices and ignorance. For this reason, the story of the Jukes became a precursor of the eugenics movement in the United States and Western Europe.

—James W. Trent

See also Degeneration; Eugenics; Normality.

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JUSTICE

Theories of justice are, in part, about what people are entitled to—as members of a political community, or more controversially, merely as human beings. These theories differ in what they regard people as entitled to: fair play, respect, a minimum or an equal share of material resources, access to the various goods of life, psychological satisfaction, and recompense or redress for past wrongs by others or punishment for one's own wrongs. These entitlements are not mutually exclusive, of course, but theories of justice differ in the importance or emphasis they place on them. For example, concerns about appropriate and proportionate punishment are often seen as matters of corrective justice; appropriate resources, access, or satisfaction as matters of distributive, patterned, or end-state justice; and fair play and respect as matters of procedural or relational justice. The lines between and relationships among these different types of justice are vague and disputed. But more important, there is strong disagreement about what people are entitled to under all three rubrics.

These distinctions among types of justice are well illustrated by the claims of people with disabilities, claims that figure significantly in contemporary disputes about justice. For example, many disability advocates have questioned the claim of recent theories of distributive justice that people with disabilities have strong entitlement to the resources needed to correct their impairments. Without rejecting such entitlements altogether, advocates regard them as unduly influenced by a medical model, which sees disability exclusively in terms of biological impairment or dysfunction. Drawing on an interactive model of disability, they stress the need for resources to accommodate disabilities, to make the built environment accessible to people with disabilities. And because most societies have failed to make such accommodations, disability advocates often insist that people with disabilities are entitled to restitution or compensation for past exclusion. Finally, some disability advocates have seen the focus on distribution as misplaced: What disadvantages people with impairments is largely their stigmatization not their impairments. On this view, the primary goal of justice should be to eliminate that stigma and the social exclusion accompanying it; the redress of material disadvantages will follow.

For all these critiques, one of the challenges facing contemporary theories of justice in relation to disability is to avoid the strictures of the medical model; to see disabilities in interactive terms and to find justice and injustice in the terms of that interaction. Unfortunately, the recent debate among competing theories of justice has tended to reinforce the medical model, by assuming that the justice claims of people with disabilities are not only medical and rehabilitative but virtually inexhaustible, and by assuming that significant impairments preclude a high quality of life. In reviewing these theories, this entry points out their reliance on such dubious assumptions and then suggests ways in which those theories have been, or could be, modified and strengthened in response to the disability critique.

RELEVANCE OF IMPAIRMENT TO JUSTICE

Most societies make provisions for persons with disabilities. Medical, rehabilitative, educative, and other resources are provided to cure or treat health conditions or improve functional capacities. Social assistance, pensions, workers' compensation, and other forms of income supplements attempt to compensate people with disabilities for their inability to work. Antidiscrimination laws seek to redress intended or unintended denials of equal opportunity associated with misperceptions, stereotypes, and the stigma of disability. These and other laws require public accommodations, employment and education settings, and communications and transportation services to be accessible. Yet other laws and programs directly provide assistive technology and educational and employment opportunities to raise the level of economic and political participation by people with disabilities.

Some laws view impairments as functional deficits that get in the way of the person's social participation; others emphasize the social stigma of impairments and the obstacles that that creates for people with disabilities. As functional deficits, impairments create needs for services, resources, and accommodations. When laws and policies address these needs, the underlying rationale is distributive justice: Impairments negatively affect social participation, so justice requires that these disadvantages be ameliorated as much as possible. Laws that focus on the social stigma of impairments view lack of participation in basic areas of social life as harms inflicted on people with disabilities either through prejudice, misunderstanding, or neglect. On the face of it, the underlying rationale is compensatory, namely, to undo the damage to people with disabilities caused by individuals or, systematically, through existing social institutions.

Since impairments are relevant to social justice in two different ways—as functional deficits and as social markers—there is potential for confusion about the appropriate objectives of laws and regulations. A law requiring public schools to allocate resources to accommodate the specific requirements of children with disabilities should be viewed as responding to a demand of distributive justice (e.g., that all children should benefit from the educational experience). If we treat it as a compensatory law, then it is vulnerable to the plausible objection that most needs of most disabled children are not harms that any individual or institution has caused. On the other hand, an antidiscrimination law such as the Americans with Disabilities Act of 1990 (ADA) cannot be easily justified as a tool for securing distributive justice, since it exempts individuals and institutions from making reasonably accommodations for people with disabilities if doing so would impose an "undue burden" or "hardship" and it does not require the state to assume that burden, however reasonable the accommodation. But it is also difficult to see the ADA strictly as demanding procedural justice, because it *does* require that individuals and institutions sometimes incur substantial (although not undue) costs for reasonable accommodations, a material burden that has no obvious counterpart in most other antidiscrimination laws.

A more plausible stance to take here is that impairments are relevant to justice in several ways: For the sake of justice, we need to acknowledge that people differ with respect to their repertoire of functional capacities, and so differ in what material and social provisions they require to fully participate in society. We also need to recognize that impairments are fraught with social meaning, most of which is disadvantageous to people with disabilities, and that the harms that are caused—either intentionally or not—need to be addressed for the sake of justice. In some instances, it must be said, disability raises justice concerns that appear to move among compensation, distribution, and respect: If public buildings are not accessible to a person with a mobility problem, one might argue that the failure to retrofit the building is discriminatory, in failing to treat people with mobility impairments as potential users or residents of that building. And such a slight may require compensation. But one could also argue that the benefits of access to public buildings must be distributed, as fairly across the public as possible, and so excluding this individual is distributively unjust.

One might contend that if justice demands a response to unfair disadvantages associated with impairments, it does not matter whether that response is understood in terms of procedural, distributive, or compensatory justice. It is difficult to distinguish the disadvantages "naturally" associated with impairments from those created by the attitudes and behaviors of others, or social arrangements generally. It should therefore not matter much if we view accommodation and retrofitting as conferring on people with disabilities the resources they are entitled to as a matter of distributive justice, treating them with the respect due to them as equal members of the community, or compensating them for having failed to do what distributive or procedural justice requires.

Of course, neither accommodation nor compensation will be thought to be owed if one denies that the state has any obligation to achieve a particular distribution of resources or opportunities, if one regards disadvantages associated with impairments as "natural," and if one insists that the only procedural or relational obligations we owe, in the absence of special relationships, are honesty, trustworthiness, and conformity to jointly accepted rules. But most people reject such a minimalist view of distributive and procedural obligations, and a generation of disability scholarship has made it clear that many of the disadvantages associated with impairments cannot be regarded as natural. But the rejection of minimalist views leaves room for disagreement about the character and extent of the entitlements that people with disabilities can claim.

Much of the philosophical activity in this area has been in the domain of "patterned" distributive justice, in particular, in the explication of the kinds of equality, or constraints on inequality, that distributive justice should seek. Because distributive theories have been the most fully developed, and the most frequently criticized by disability scholars and others, especially feminists, this entry focuses next on those theories and their treatment of disability. The entry then assesses the challenges they face and the adequacy of alternative and hybrid approaches in meeting those challenges.

THEORIES OF DISTRIBUTIVE JUSTICE

Despite the obvious relevance of impairment to justice, recent theories of justice have by and large alternated between a benign neglect, tabling provisions for the impaired until a just "basic structure" for society has been established, and an oppressive solicitude, treating people with impairments as having a greater claim to restoration of normal functioning than the claims of "normal" members of society have to material resources. As Martha Nussbaum has pointed out in an important critique, the neglect or postponement of justice for people with impairments by the leading political philosopher of the past century—John Rawls—arises from three factors of continuing relevance for justice and disability. One is the basic "contractarian" character of Rawls's theory of justice, in which justice is derived from the agreement reached by self-interested bargainers ignorant of their position in society or conception of the good life. Although the stipulated ignorance secures a kind of moral objectivity to the contract, the objective remains individual benefit, and people with impairments, assumed to be less productive or costly to accommodate, tend to be excluded as unattractive bargaining partners. The second factor is the theory's need for a simple metric of comparative advantage—deficits in physical or mental function do not fit easily beside wealth and income in a single, summary metric of well-being. Third, and particularly relevant to cognitive impairment, the bargainers are assumed to be rational. People who cannot engage in practical reasoning, let alone elaborate calculations of expected utility, do not have a place at the bargaining table.

Other philosophers have attempted to accommodate people with disabilities within a Rawlsian, or more broadly contractarian, framework. The most well-known, and controversial, effort has been made by Norman Daniels. Rather than ignoring people with impairments or tabling their claims, Daniels makes the correction of impairments a matter of utmost urgency by insisting that claims to the restoration of normal functioning are stronger than even those of the economically worst-off members of society. Arguing that normal human functions are essential to equality of opportunity, Daniels gives priority to health care and other impairment-correcting resources. A person with disabilities on his view has a special claim on society if his or her level of functioning falls short of the normal range (as determined biostatistically). Impairments directly reduce the range of opportunities open to a person. So too do deficits in talent and skill, but justice only requires fair equality of opportunity, namely, the equalization of opportunity for persons with similar skills and talents.

Many critics, including disability scholars, have contended that Daniels's augmentation of Rawls requires excessive and inappropriate redistribution of resources to people with lower functioning at the expense of people with limited talents and skills, who may well experience greater social disadvantage. They dispute the centrality that Daniels accords to normal functioning for fair equality of opportunity, and the priority he assigns to its achievement or restoration. They suggest that his exaggerated premium on normal functioning reflects his uncritical acceptance of a medical model of disability, and his resulting neglect of the social contribution to disability.

Another influential philosopher offering a quasi-contractarian theory of justice, Ronald Dworkin, does recognize that social preferences and practices play some role in the creation of disability, but his response may be even less appropriate than Daniels's. Unlike Rawls, Dworkin simply stipulates that the members of society are entitled at the outset to an equal share of the world's resources, but he does not believe that this entitlement can extend to individuals' highly variable "internal" resources—functionings and talents. Dworkin attempts to deal with the "brute bad luck" of poor internal resources—impairments as well as limited, obsolete, or undesirable talents—by relying on a hypothetical insurance scheme. We are to imagine what people, ignorant of what opportunities they might want to pursue in life, would be willing to pay by way of insurance against the prospect of acquiring a disability. If we could reach a social consensus on what would provide fair compensation for blindness, immobility, or cognitive deficit, then that would be an objective measure of the cost of relevant resources that the state should, in justice, provide people with disabilities. The hypothetical insurance buyer is willing to insure against deafness or blindness, not because he believes that these conditions directly lower his quality of life but because they would be impediments to life plans he would have likely had, given the social environment in which it is reasonable to expect he will find himself.

Central to Dworkin's approach is the recognition that the social impact of disabilities is not identical to the functional impact of impairments: The extent to which an impairment limits one's equality of opportunity depends on the physical, social, and attitudinal environmental in which the individual with that impairment lives. Although this is an important insight from a disability perspective, Dworkin blunts its impact by assuming that we can generalize about the overall impact of impairments in any social environment. More important, he implicitly ignores the effects of systemic accommodation and environmental modification. The price the hypothetical insurer thinks is prudent is based on the need for individual material resources to deal with an utterly hostile and unaccommodating social environment. In short, while Dworkin recognizes the environmental cause of the disadvantages of disabilities, his scheme for a "just" solution involves no more than paying people with disabilities to live in a disability-unfriendly world.

It might be suggested that the underlying difficulties with Dworkin's account can be traced to the fact that it relies on material resources as a metric of advantage, measuring outcomes and compensating shortfalls by money. Dworkin favors resources over welfare, preferring a more objective metric over a subjective one, such as feelings of pleasure or satisfaction. A resource metric would not punish those with low expectations and modest tastes nor reward those with high expectations and extravagant tastes. Several philosophers have argued, however, that it is possible to have a metric of advantage based on capabilities, which are as objective as material resources but more sensitive to the multivalued character of well-being. The economist Amartya Sen and the philosopher Martha Nussbaum have proposed accounts of the goal of distributive justice in terms of equality of capability.

Sen (1980:217) defines *functionings* as the things and activities that people have a realistic choice among in their lives. A functioning is more than a physical or mental capability (and so more than the mere absence of an impairment). It also includes all of the social, physical, and attitudinal features of the person's environment that are preconditions to the realization of a choice. A *capability*, then, is a set of functionings over which a person has a choice. In general, the complete set of a person's capabilities describes his or her "positive" freedom over alternative ways of living.

Sen's approach is well suited to account for what disability scholars argue are the true disadvantages associated with disability. A limitation of functioning in Sen's sense is either the incapacity caused by impairments or, more often, the barriers imposed by features of the person's world that aggravate the incapacity or otherwise restrict the person's freedom to achieve his or her life plans. When both the impairment and the social environment contribute to the disadvantage, justice requires both impairment-relevant resources and public policy and social action to remove the environmental obstacles. Justice requires, in short, equalization of capabilities.

Achieving justice in this sense would not be without practical difficulties. Even if we agreed on what capabilities were critical and what level of each capability had to be reached—matters on which Sen is deliberately silent—it would not be an easy matter to identify all the barriers to achieving them or ascertaining what would effectively remove or circumvent them. Yet we are now in the territory of public policy, where these practical issues are at least well-known. There are, moreover, several potential policy tools that can be brought to bear: cash by way of compensation or income maintenance; tax adjustments; in-kind services; provision of employment and educational opportunities; provision of assistive technology and other impairment-relevant resources; antidiscrimination law to address specific abuses; mandated, publicly funded accommodations for work, school, and home; and public education to remove stigma and stereotyping. There are legal models for each of these strategies in most developed countries.

But once one moves to this practical level, some troubling features of Sen's approach come into view. Does justice require equality of capability across the board, and for everyone? Does every measurable decrement of capability entitle one to resources in the name of justice, or is there a minimal core of capabilities relevant to justice? If so, what is this core, and must it be the same for everyone? These are huge questions. Even if we could agree on the core, it is extremely unlikely that anyone, across a lifespan, would possess complete capability in all its domains. Impairments are ubiquitous across the population; almost everyone develops joint aches, muscle fatigue, and diminished vision, hearing, and memory as they age. Each of these impaired functionings, in unaccommodating settings, may limit some core capability. If we think it absurd that everyone should qualify for disability benefits, how do we set the thresholds? How much inequality in capability can we tolerate?

Some of these questions have been addressed in a forthright—if not always satisfactory—way, by Martha Nussbaum, who is specific and concrete, where Sen is vague and schematic, about the capabilities required for humanity and human flourishing. She has come up with a list of 10 capabilities that a just society must ensure its members achieve, at least to a minimal degree. Over the years, her description of these capabilities has become more general, in part because the more narrowly framed they are, the more categorically they are precluded by specific impairments. Thus, Nussbaum has gone from making "the exercise of the five senses" a requirement of humanity—which would deny the blind and deaf the status of human beings—to making it a condition of human flourishing—which would deny that the blind or deaf can flourish—to broadening the capability to encompass rich sensory experience from any combination of sensory modalities—which makes human flourishing available to the blind and deaf and imposes the obligation on a just society to ensure that they achieve it.

Yet every society will contain individuals whose impairments make the achievement of one or more core capabilities, however broadly framed, a practical impossibility. As Nussbaum recognizes, many severely retarded individuals, or individuals in permanent comas or persistent vegetative states, simply cannot fashion their own conception of the good life, no matter how intensive the support they receive from society. Nussbaum does not regard a society as unjust for failing such individuals; rather, she regards their incapacity as "tragic."

This survey of how disability figures in some prominent theories of distributive justice indicates the beginnings of a more serious attempt to come to terms with disability, without identifying it with impairments or treating it exclusively as a matter of health. Increasingly, philosophers are becoming aware of the more robust models of disability and their effect on traditional arguments about the demands of justice. Yet there remain difficult and practically significant issues arising out of the interaction between justice and disability with which future theories will need to deal.

CHALLENGES TO DISTRIBUTIVE JUSTICE THEORIES

Accounts of distributive justice are a target of disability critics who see them as inherently demeaning. This change is apt for contractarian theories that exclude people with disabilities from the bargaining table altogether because of their presumed low productively or lack of capacity to form a conception of the good life. We need not consider this critique further. But disability scholars have also criticized theories that are not contractarian and aim directly at equality, variously conceived. Equality theories are also seen as demeaning insofar as they treat disabilities as individual deficits that require special resources to achieve equality, rather than disadvantages resulting from unjust social arrangements. This critique raises more serious doubts about distributive approaches, even those that pay lip service to the interactive character of disability. Can distributive justice theory adequately accommodate the radical changes in attitudes, practices, and environment that justice truly requires?

The disability critique tends to favor more procedural or relational approaches, which identify stigmatization, exclusion, and oppression as the primary sources of injustice and insist on policies aimed directly at those evils. This critique has also inspired some mainstream political philosophers to develop hybrid approaches, which acknowledge the diagnosis offered by the critique but propose a constrained distributive treatment for the underlying injustice. The specific challenges of the disability critique require separate treatment.

Social Basis for the Disadvantages of Disability

The first challenge has been mentioned several times already: Philosophers writing on justice from a roughly egalitarian basis often assume that impairments intrinsically, and dramatically, reduce subjective or objective well-being by limiting basic activities such as walking, seeing, communicating, activities essential to most life plans. The problem posed by disability, as a result, has been to find "special measures" to compensate for functional deficit, whether by Dworkin's hypothetical insurance, Daniels's unlimited resource transfer to restore normal functioning, or Sen's equalization of capability. Philosophers writing from the disability perspective, such as Anita Silvers, argue that this obsessive concern with the comparative well-being of people with disabilities is not only demeaning—since it tends to view people with impairments as defective rather than neglected—but that it also ignores the sources of inequality faced by people with disabilities, namely, the disadvantages caused by unaccommodating, stigmatizing, and discriminatory social arrangements.

Although this critique has considerable merit, it is unlikely that it goes to the heart of the overall project of "patterned" distributive justice—to identify some arrangement of welfare, resources, opportunities, or whatever that can serve as the goal of redistributive policies. On the face of it, one need only identify the full range, and sources, of social disadvantage and adjust interventions appropriately to address the range of disadvantage the theory mandates must be reduced or eliminated. As we have seen in examining the capabilities approach, a clearer appreciation of the complexity of disability will also assist in theorizing about what is often called the "currency of equality," namely, what it is that egalitarian theories of justice seek to equalize.

Distributive Justice and the Goals of Accommodation and Accessibility

As noted above, there is no theoretical barrier to a theory of distributive justice based on an interactive model of disability, one that treats the individual's social environment as responsible for the disadvantages associated with impairments. Such a theory would challenge the assumption that impairments invariably, or in isolation, lower well-being, create inexhaustible needs, or severely restrict the range of available life plans. Yet the question remains whether the current crop of distributive theories can fully incorporate the social goals of accommodation and environmental modification for accessibility. The problem is that most theories share an assumption that has historically held an iron grip on disability policy, namely, that it is always cheaper, more efficient, and publicly acceptable to provide resources to individuals than to modify the physical or social environment in which they live.

The assumption ignores the fact that privileging the "standard environment" in this way means that disability policy will always be piecemeal and ad hoc, a "special needs" policy that confirms the prejudice that people with disabilities are inferior and cannot make it in the "real world." On the other hand, however, opening up the range of interventions for distributive justice to include changes to the environment is not without theoretical and practical difficulty. First, the standard physical, social, and attitudinal environment is disadvantageous to many people in society other than those with impairments. People who are poor cannot take advantage of financial opportunities or savings that are readily available to the rich; people who do not speak the official languages of a country share with sign language users the need for translation for public communication; and children of marginalized minorities, in common with children with cognitive impairments, may require substantial accommodations to benefit from education. Second, accommodations and environmental modifications must be individualized to be useful, but changes that accommodate people with one type of impairment may be useless or worse for those with other impairments or for the unimpaired population. Finally, for these and more general reasons of cost, convenience, and efficiency, there will inevitably be trade-offs, between individuals and groups, and between areas of social participation—employment versus education, access to shopping centers versus access to public buildings or houses of worship. These trade-offs need to be resolved, but it is unclear how to do so.

Although there are large issues, it is encouraging that they are paradigmatic problems of distributive justice rather than fundamental challenges to the project itself. And indeed, some headway has been made. The theoretical underpinnings of universal design, for example, directly address all three problems. Universal design in architecture and product design insists that buildings, public spaces, and products should be designed to be usable by people with the widest possible range of functional capacities as possible. Maximally inclusive design reduces the need for difficult trade-offs among groups and individuals; by eliminating the need for retrofitting and modifying a standard building or product, such design both responds to concerns about social cost and avoids the appearance that people with impairments are being given special privileges or unfair priority over other disadvantaged groups. Much more work needs to be done, but the notion of distributive justice may not be robust enough to encompass all issues of accommodation. Yet it needs to succeed, because an approach to justice focusing exclusively on disrespect, discrimination, and disparities in power will be unavoidably incomplete.

Antidiscrimination Protection Is Enough to Secure Justice

A more comprehensive challenge, reinforced by skepticism about the adequacy of distributive approaches, is posed by so-called relational theories of justice, such as Iris Young's, which focus not on distributional outcomes but on the unjust social relationships of oppression, domination, and hierarchy. The initial appeal of relational theories for disability is that they tend to highlight precisely the same kinds of oppressive attitudes, practices, and social arrangements that lie behind what the disability rights movement has identified as the basis for social injustice, discrimination. Thus, the much admired ADA, while applying only to those with actual or perceived physical and mental impairments, clearly locates injustice in stigma and the related attitudes of devaluation that suffuse social practice. For many disability advocates, the dynamics of discrimination are all that one needs to know to understand justice in the context of disability. Pattern-based distributional theories are, therefore, of little interest.

Although the debate is far from over, a growing consensus suggests that while antidiscrimination laws and policies, fully and competently enforced, do address the core evil in the treatment of people with disabilities, as a social policy for disability, these tools—and the background relational theory of justice—are radically incomplete. In structure, relational theories of justice adopt the core assumption of the procedural approach mentioned above, namely, that as long as the laws, social practices, and institutions are fair, whatever distributional outcomes that result, even if profoundly unequal, are just. In the case of disability, this means that if we could imagine a society in which all forms of prejudice, stigma, misunderstanding, and stereotyping of impairment were absent, where oppression, domination, and exploitation were no longer in evidence, social arrangements would be completely just with respect to people with disabilities, even if the current enormous gaps between able-bodied and disabled citizens in educational achievement, income, and employment remained, or even worsened.

But, it might be asked, if oppression and domination disappear, how could inequality remain? This could happen because an enforceable injunction against discrimination does not tell us what resources are required to meet impairment needs, or how we can alter the physical and social environment to accommodate the functional limitations of impairments, or what measures are required to make the social world more accessible.

To answer those central issues of disability policy, not only do we need to identify and measure the direct effects of impairments themselves (which will remain even if socially created disadvantage is eliminated), but, more vitally, since we do not have infinite resources, we need a standard for assessing the priority of the goals of access and accommodation. This implies our ability to decide what kind of equality we are aiming toward, or what kinds of inequality we are seeking to reduce. But these are not easy issues. Should we provide resources and make social changes to the point where everyone has "equal opportunity" in one of its myriad senses; or to the point where all burdens and benefits are equalized; or to the point where all citizens are equally satisfied with their lives? These are radically different standards. Having eliminated oppression and discrimination, we will of course be committed to, for example, redesigning our educational systems and structuring jobs so as to accommodate people with limited cognitive functioning. But how do we do that? Unfortunately, the purely antidiscrimination approach gives us no guidance.

Only a theory of distributive justice can provide a sense of the practical objectives our commitment to justice demands of us.

Disability Justice, Prioritarism, and Democratic Equality

Although the antidiscrimination approach has limitations as a theory of justice, it has played an important role in refining distributive accounts. Criticism of those accounts by disability scholars has converged with, and increasingly reinforced, challenges from mainstream philosophers about two features of egalitarian accounts: (1) their acceptance of equality as the objective, although it is not attainable on almost any metric and its single-minded pursuit may compel perverse results, such as "leveling down" the better-off to reduce inequality; and (2) their adoption of comprehensive notions of well-being, which concern all or most aspects of a person's life.

Rawls's own theory was neither strictly egalitarian nor concerned with equality in any comprehensive sense. While it required equal liberty for citizens, it accepted inequalities in "social primary goods" as long as they benefited the worst-off members of society. And his list of primary goods, ranging from income and wealth to the social bases of self-respect, was intended to include assets valuable on any reasonable conception of the good, not to serve as proxies for a particular comprehensive conception. But many influential political philosophers following Rawls, such as G. A. Cohen and Dworkin, have offered accounts that are both more egalitarian and more comprehensive than that of Rawls.

In recent years, other philosophers have voiced discomfort with one or both of these features. Some, such as Derek Parfit, have pointed out that a single-minded policy of equalizing well-being—which might well involve a dramatic leveling-down to an unacceptable, but equal, minimum—ignores the moral concern for people's absolute levels of well-being. Parfit argues for giving priority to the worst off in society, rather than trying to achieve an across-the-board reduction in inequality. "Prioritarian" accounts have problems of their own (how to characterize "the worst off'"), but they represent a more general concern about theories of "comprehensive equality" that ask too much of society and seek outcomes that are either impossible or contrary to other important values.

Thus, Richard Norman has rejected comprehensive egalitarian distribution on the commonsense ground that people are unequal in countless ways, not all of which should, or even could, be remedied. Antiegalitarians may have a point when they argue that seeking equality in the face of human diversity is at best Sisyphean, at worse unimaginably oppressive. Some people are incurably shy, others form relationships easily but destroy them just as fast; others strike a balance between these extremes. Even if we could somehow redistribute emotional sensitivity (or compensate the shy or emotionally volatile), would that be a proper role for a just society? Norman thinks for these inequalities we should just say, "That's life," although they lead to inequalities in well-being. Of course, the same may be, and has been, said of impairments.

But if egalitarianism cannot sensibly require the elimination of all inequalities and disparities, what does it require? One proposal is that justice requires the achievement of "democratic equality," that is, that society should eliminate all and only those disparities in well-being that threaten to undermine basic social or political roles in status and participation. Amy Gutmann (1987), for example, has argued in the context of education that principles of democracy implicitly create a democratic distribution threshold: "sufficient resources to education to provide all children with an ability adequate to participate in the democratic process" (p. 136). This threshold is measured in part by the objective of preventing unjust relationships created when some are excluded from political processes that affect all, and in part by an appraisal of what skills and abilities are required for political participation. The threshold, significantly, does not require equality of skill and ability, only the minimum necessary for political participation. The goal is not to "level down" to the threshold, but to guarantee it for all, including children with impairments, while at the same time providing some additional resources for children with the natural abilities to exceed the threshold.

Recently, Elizabeth Anderson has proposed a similar but more general threshold of democratic equality.

Drawing from both the "patterned" and procedural approaches to distributive justice, Anderson argues that the inequality that is truly unjust is that of a hierarchy of social rankings purporting to reflect intrinsic worth (which, in turn, invariably generates inequalities in the distribution of freedom, resources, and welfare). Following Sen, Anderson argues that eliminating the social hierarchy requires redistribution of those capabilities that people require to avoid, or escape, entanglement in oppressive social relationship. Alternatively, justice requires that everyone possess the capabilities necessary for functioning as equal citizens in a democratic society. These are the capabilities required to participate in the activities of civil society, and at bare minimum, those needed to function as a human being: "effective access to the means of sustaining one's biological existence—food, clothing, medical care—and access to the basic conditions of human agency—knowledge of one's circumstances and options, the ability to deliberate about means and ends" (Anderson 1999:317–318).

With respect to disability, Anderson argues that democratic equality demands that people with disability have "good enough access to public accommodations that they can function as equals in civil society." She makes it clear that "good enough" does not require strict equality of resources (or equality of satisfaction or subjective utility), nor does democratic equality require the elimination of disparities in happiness, pleasure, or resources that are not explicitly required for equal citizenship. On the other hand, achieving (more than perfunctory, but truly) effective access to medical care (one of the preconditions for functioning as a human being) is unachievable in even the most resource-rich society. And if equal citizenship requires freedom from pain or debility, then Anderson's goal is utterly unreachable. Similar points can be made about the "basic conditions of human agency": We could spend an indefinite amount on education, training, and support for people with cognitive disabilities without achieving deliberative competence.

The problem appears to be that, motivated by the perversity of leveling down to achieve welfare, resource, or even capability equality, Anderson sets the bar at "sufficient for equal citizenship," which, in practical terms, is either too vague to be useful or utterly unachievable. Ironically, Anderson is equally open to the objection that "equal citizenship" sets the threshold too low, since it is compatible with a joyless and barren life, and too high, because the capability preconditions make a huge demand on social resources. Nonetheless, as Richard Arneson has argued, democratic equality is useful as a rough proxy for well-being, which remains a contentious notion. As is usual in philosophical theorizing, some compromise has to be found between an account of well-being that is complete enough to be intuitively plausible and one that is concrete enough to guide the evaluation, and reform, of actual societies.

CONCLUSION

There is an intriguing symmetry in the challenges facing distributive and relational accounts of justice as they apply to disability. Distributive accounts must recognize the centrality to justice of equal social and political participation, and develop metrics of individual well-being in which the capacity and opportunity for such participation figure prominently. Relational accounts, in turn, must make the notions of nondiscrimination and nonoppression sufficiently determinate to guide the reconstruction of the physical and social environment. Hybrid approaches such as Anderson's—which require that all citizens be brought up to a minimum standard for democratic participation, not to any comprehensive equality—raise hopes for a convergence between extended conceptions of distributive justice and structural accounts of discrimination and oppression.

Those hopes, however, may be illusory. Justice, as Michael Walzer, David Miller, and others argue, may be irreducibly plural. Although both distributive and relational accounts of justice appear to be guided by a principle of equal concern and respect, the former emphasize concern, the latter, respect. The two kinds of accounts focus on inequalities that, however closely correlated, may be morally distinct. The failure to take adequate account of atypical functioning in the design of the physical and social environment may be a fundamentally different kind of wrong than the treatment of people with atypical functions as inferior beings. These wrongs may require different remedies:

the former, redistribution; the latter, recognition. Perhaps, then, a single theory of justice cannot do justice to both aspects of impairments, as sources of functional limitation and as stigmatized differences. We may require both distributive and relational accounts to guide disability policy. But even if the attempt to integrate the two in a democratic threshold account cannot succeed, it provides valuable insight into the kinds of revisions we need to make in both.

—David Wasserman and
Jerome E. Bickenbach

See also Citizenship and Civil Rights; Civil Rights Backlash; Democracy; Ethics.

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K

KALLIKAK, DEBORAH (1889–1978)

American subject of eugenics research

In his widely read eugenic study of 1912, *The Kallikak Family,* Henry H. Goddard introduced Deborah Kallikak as a quintessential example of "defective" heredity. At the age of eight, Deborah entered the Vineland (New Jersey) Training School after troublesome behavior marked her as potentially "feeble-minded." As Goddard and his fieldworkers gathered information on her familial background to assess the possibility of "hereditary taint," she became scientifically valuable for her relationship to a large and extended family "notorious for the number of defectives and delinquents it had produced" (Goddard 1912:16). Goddard invented the surname Kallikak from the Greek words for beauty (*kallos*) and bad (*kakos*) to indicate that the distant progenitor had produced both a *good* line and a *bad* line of descendants. In effect, Goddard's study scientifically designated Deborah, her living relatives, and her ancestors on the "bad" line as human *evidence* of the hereditary nature of feeblemindedness.

At the time of Goddard's writing, Deborah was 22 years old, but Binet tests charted her mental age at 9. Her accomplishments, however, make this diagnosis troubling. Deborah loved music, writing stories, gardening, and caring for children, but her inability to understand numbers and money, lack of abstract thought, and stubbornness convinced Goddard she was feebleminded. The most biased aspect of his diagnosis was the presumption she would lead a "vicious, immoral, and criminal" life outside an institution (Goddard 1912:12). Goddard used Deborah to exemplify the dangerous "borderline" types he designated as "morons," highly functioning but "defective" individuals who, if not properly identified and confined, threatened society with the inevitable result of producing more of their kind. Deborah died in 1978; she lived 81 of her 89 years in an institution.

—Michelle Jarman

See also Developmental Disabilities; Eugenics; Henry Herbert Goddard; Mental Retardation, History of.

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KANNER, LEO (1894–1981)

Austrian-American psychiatrist

Leo Kanner was one of the most influential American clinical psychiatrists of the twentieth century. He has been referred to as the "father of child psychiatry" in the United States, and his textbook *Child Psychiatry,* first published in 1935, remained a standard reference work for 50 years. Kanner is perhaps best known for his description of "early infantile autism" in 1943 as a distinct clinical syndrome. Based on his observation of 39 children with similar behavior, Kanner described a common profile whereby the children did not relate "in the ordinary way" to people or situations. Instead, Kanner (1943) described a child whose "behavior is governed by an anxiously obsessive desire for the maintenance of sameness that nobody but the child himself may disrupt on rare occasions" (p. 243). Although he was to repudiate the term (and the theory behind it) by the 1970s, Kanner also coined the term "refrigerator mother" to describe the supposed emotional frigidity of parents that he thought caused, or at least contributed to, their children's autistic behavior.

Kanner was born in Klekotow, Austria, in 1894, and received his medical degree from the University of Berlin in 1921. He moved to the United States in 1924, and from 1930 until his retirement in 1959 was on the faculty of the Johns Hopkins Medical School. Even after his retirement, Kanner remained professionally active as a visiting professor at numerous universities and maintained a clinical practice until shortly before his death in 1981 at the age of 86.

—Philip M. Ferguson

See also Autism; Psychiatry.

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KATADA IBN DI`AMA AS-SADUSI (CA. 679/680–735/736)

Arab scholar

Katada ibn Di`ama as-Sadusi was blind from birth and had Bedouin origins. He became a learned man of the highest reputation at Basra, Iraq. Katada's renowned memory and recall led to his being often consulted on matters of history, genealogy, poetry, and Qur'anic interpretation by both rulers and scholars of his time. Evidently he prized his independence and developed a strong awareness of space and direction; it was recorded that he "used to go from one end of Basra to the other without a guide" (*Ibn Khallikan's Biographical Dictionary* 1842–1871).

—Kumur B. Selim

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KATAKORI

Katakori or *katakori kô* is a condition peculiar to Japan; the name of this condition is somewhat difficult to translate into English, but it comes closes to "pain in the neck." It corresponds generally to a combination of stiffness, tension, or pain in the neck and shoulders. Its etiology is often associated with reduced blood flow to muscle tissue. Some have suggested that it is a physical symptom that allows for medical care in the setting of Japanese stigma against psychological pain. Treatment ranges from anti-inflammatory medications to transcutaneous electrical nerve stimulation (TENS) to acupuncture.

While its history is suggestive of many comparative elements, modern medical researchers have used the status of *katakori* as a cultural-bounded syndrome to identify it and other somatic complaints as markers of depression in Japanese in cross-cultural studies. In popular culture, perhaps not unlike conditions such as anorexia, one can find reflexive affinity for *katakori,* suggested by T-shirts saying, "I ♥ *katakori.*"

—Walton O. Schalick III

See also Cultural Context of Disability; Disability Culture.

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KELLER, HELEN (1880–1968)

American author and lecturer

Helen Keller was born in Tuscumbia, Alabama, on June 27, 1880. At the age of 19 months, she contracted an illness, either scarlet fever or meningitis, that left her totally deaf and blind. In 1887, Anne Sullivan, a recent graduate of the Perkins Institution for the Blind in Boston, joined the Keller household as Helen's teacher. Keller learned to communicate using the manual alphabet for the Deaf. She graduated cum laude from Radcliffe College in 1904. She published nearly a dozen books as well as numerous articles, essays, tracts, and poems. Her work was primarily autobiographical, but she also wrote on such subjects as women's suffrage, women's health issues, the labor movement, and religion. She traveled widely, in the United States and throughout the world, as a lecturer and spokesperson for the American Foundation for the Blind, which she helped to found in the 1920s. She also toured on the vaudeville circuit for two seasons and appeared in several film documentaries on her life. She died at her home in Westport, Connecticut, on June 1, 1968.

For many, Helen Keller's story is the quintessential overcoming narrative. Through the sheer force of will and the self-sacrifice of her devoted teacher, she overcame her disability and serves as an inspiring symbol of the resilience of the human spirit. For this reason, her image appears on the state quarter of Alabama. By contrast, many in the disabled community, both during Keller's lifetime and today, have criticized her for the way she remained aloof from other disability organizations and causes. She angered many in the Deaf community by following the lead of her mentor, Alexander Graham Bell, and supporting auralism rather than Sign. More recently, disability studies scholars have begun to reexamine her life and work in an attempt to separate the myth from reality and gain a better understanding of her legacy.

—*Georgina Kleege*

See also Deafblindedness.

KENNY, SISTER ELIZABETH (1880–1952)

Australian nurse

Sister Elizabeth Kenny, a feisty, opinionated, largely self-educated bush nurse, enraged the Australian medical establishment with her pioneering treatments that significantly alleviated the effects of polio. Her methods, which she developed over several years of treating children with polio and cerebral palsy in Queensland, consisted of hot baths, foments, and mobilization of paralyzed limbs with passive movements to reeducate affected muscles. She passionately asserted that the traditional procedures of splinting and bracing immobilized limbs in metal and plaster casts caused major deformities and were tantamount to torture.

Damned by no less than a royal commission of the Queensland medical fraternity, in 1940 Kenny took her treatments first to the Mayo Clinic in Minnesota and later established the Elizabeth Kenny Training Institute in Minneapolis. Gradually her work gained acceptance and she gained fame and honor throughout the United States, where she resided for 11 years.

Kenny's legacy to the disability community extended far beyond her lifetime and is evident in medical rehabilitation therapies practiced today throughout the world. People with a range of neurological conditions involving some form of paralysis, including spinal cord and head injury, multiple sclerosis, stroke, and cerebral palsy, are indebted to Kenny's vision, common sense, and conviction. Sadly, she is a largely forgotten figure in Australia, but she is still widely revered in the United States.

—*Joan Hume*

See also Polio.

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KERLIN, ISAAC NEWTON

(1834–1893)

American institution administrator

From 1863 until the time of his death in 1893, Isaac Newton Kerlin was the superintendent of the Pennsylvania Training School for Feebleminded Children (better known as the Elwyn Institute), located outside of Philadelphia. Kerlin himself became one of the leaders of the first generation of superintendents for the so-called idiot asylums that were emerging in post–Civil War America. In 1876, in an effort to gain professional status equal to that of the more established leaders of the older insane asylums, Kerlin invited five other fellow superintendents and the prominent educator Edouard Séguin to join him in Philadelphia to found the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons (now known as the American Association on Mental Retardation). Kerlin would serve as the secretary-treasurer of this organization for the next 16 years, actively publishing and disseminating the proceedings of the group's annual meetings. With the deaths of Samuel Howe in 1876 and Edouard Séguin in 1880, Kerlin arguably became the most prominent national expert in the treatment and institutionalization of the feebleminded population and remained so until his death in 1893.

Throughout his career, Kerlin was an aggressive proponent of institutionalization of individuals with intellectual disabilities. He was earlier than many of his colleagues in abandoning the educational optimism that with skilled treatment most feebleminded children could be cured or significantly improved. Even his descriptions of "moral idiocy" (or, in later terms, "moral imbecility" or "juvenile insanity") endorsed the notion of hereditary incurability and the need for custodial institutionalization for those with normal intelligence but a defective "moral sense."

—Philip M. Ferguson

See also Mental Retardation, History of; Edouard Onesimus Séguin.

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KESSLER, HENRY HOWARD

(1896–1978)

American physician

Henry Howard Kessler, a pioneer in the development of comprehensive rehabilitative services for people with physical disabilities, was born in Newark, New Jersey, on April 10, 1896. A 1919 graduate of Cornell University Medical School, Kessler earned a doctorate in social legislation from Columbia University in 1934. Inspired by Dr. Fred H. Albee, an orthopedic surgeon who practiced during World War I, Kessler became a well-recognized orthopedic surgeon, medical administrator, and international advocate for people with disabilities. He is recognized as the developer of the surgical technique of cineplasty for control of artificial arms, as for the pneumatic-operated prosthetic arm.

During his 12-year career in the U.S. Navy, Kessler served as a captain from 1941 to 1945. He was director of the New Jersey Rehabilitation Commission from 1921 to 1941. He founded the nonprofit, nonsectarian Kessler Institute for Rehabilitation in West Orange, New Jersey, in 1949 and served as its director until his death on January 18, 1978, at age 81. He considered the institute, which has long served as a model for centers for physical rehabilitation, his greatest achievement.

Kessler provided consultative services to Newark Beth Israel and Newark City Hospitals and the Federal Office of Vocational Rehabilitation of the Veterans Administration. He also directed the Rehabilitation Unit at Christ Hospital in Jersey City, New Jersey, and was clinical professor at New York Medical College.

He became internationally known for his work as a delegate to the International Congresses of Industrial Accidents and Diseases and as a consultant to the United Nations. Among his many citations and honorary degrees, most noteworthy are the Albert Lasker Award (1954) and the first President's (Truman) Award of the Committee on Employment of the Physically Handicapped (1952). His many publications include *Accidental Injuries* (1931), *Cineplasty* (1947), *Rehabilitation of the Physically Handicapped* (1947), *The Principles and Practices of Physical Rehabilitation* (1950), *Low Back Pain in Industry* (1955), *Peter Stuyvesant and His New York* (1959), and *The Knife Is Not Enough* (1968).

—Joel A. DeLisa

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Henry H. Kessler Foundation, http://www.hhkfdn.org

▣ KHALIL, AL- (CA. 710–787)

Arab scholar and teacher

Al-Khalil ibn Ahmad was a famous grammarian, prosodist, and teacher at Basra, Iraq. His son was impaired in intellect, and Al-Khalil was one of the earliest parents to record some thoughts about this issue. Once, hearing his father scanning a verse by the rules of prosody that he had invented, this lad ran out and told people his father had gone mad. Al-Khalil treated him in a kindly way and exercised patience toward other students who learned slowly or not at all. The learned scholar asked one such student to scan the verse, "If you cannot accomplish a thing, leave it and pass to another which you can accomplish." To his surprise, the student understood the politely coded message and gave up his fruitless studies. Al-Khalil reportedly lived as an impoverished scholar, with mind focused on higher things. He died after crashing into a pillar at the mosque, which he had not noticed as he was thinking about a problem.

—Kumur B. Selim

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

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▣ KHUJJUTTARA

Khujjuttara was the hunchbacked maid of Queen Samavati in ancient India. Converted under the Buddha's teaching, she immediately gave up her practice of stealing the queen's money. As Khujjuttara admitted her earlier thefts to the queen and explained why she had changed her behavior, she was asked to preach to 500 lady courtiers and soon attained a preeminent position as a religious teacher. This unprecedented rise from deformed female servant to teacher of the Law was endorsed by the Buddha. Khujjuttara's life is recorded to illustrate karmic retribution in the morally educational sense. In an earlier birth she had mocked a deformed holy man at Benares, and so earned a "corrective" rebirth as a hunchback herself, so that the progress of her soul should not be impeded by wrong thinking and behavior. Elsewhere, Khujjuttara played a substantial comedy role in one of the Buddha's lives, Kusa Jataka. There she took advantage of her position as royal nanny, locking up her mistress, Pabhavati, and generally throwing her weight around. She was named as Khujjuttara at the close of that story, where the Buddha identified various well-known characters.

—Kumur B. Selim

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KIRKBRIDE, THOMAS S. (1809–1883)

American psychiatrist

Thomas Story Kirkbride was perhaps the most prominent American psychiatrist (or "alienist," as psychiatrists were also called) of the mid-nineteenth century. He is best known as the creator of the "Kirkbride Plan" elaborated in his influential work on asylum design and construction, *On the Construction and Organization of Hospitals for the Insane,* published in 1854. Kirkbride was the first superintendent of the Pennsylvania Hospital for the Insane in Philadelphia, a position he held from its opening in 1841 until his death more than 40 years later in 1883. It was at Kirkbride's invitation that he and 12 of his fellow insane asylum superintendents gathered in Philadelphia in 1844 to found the organization that is now known as the American Psychiatric Association. Kirkbride's famous plan for asylum design and operation called for a linear blueprint with wings added on to a main central building. The plan also called for strict size limitations of no more than 250 residents (a principle honored mainly in the breach), with an ample, open campus surrounded by a large wall. As was the case among his early colleagues (e.g., Isaac Ray, Pliny Earle, Amariah Brigham), Kirkbride's encouragement of congregate care for the insane grew from a strong belief in the curability of the insane if they were given timely, appropriate, and therapeutic treatment.

—Philip M. Ferguson

See also Amariah Brigham; Isaac Ray.

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KNOTT, MARGARET (1918–1978)

American physical therapist

Margaret Knott was born in Oxford, North Carolina, in 1918 and graduated from what is now Appalachian State University in Boone, North Carolina, with a major in physical education. In 1942, she entered Walter Reed Army Hospital to study physical therapy and, on completion of her studies in 1943, was commissioned a second lieutenant in the U.S. Army Medical Corps. After leaving the army, she became affiliated with the Kabat Kaiser Institutes (later the Kaiser Foundation Rehabilitation Center), where she gained her reputation as a physical therapist treating injured mine workers. Knott had a long collaboration with Dr. Herman Kabat as they developed the concepts and approach to patient care called proprioceptive neuromuscular facilitation (PNF), which emphasizes the exercise of muscles in specific movement patterns. The first edition of her book *Proprioceptive Neuromuscular Facilitation: Patterns and Techniques,* was published in 1956. "Maggie" spent most of her professional life in Vallejo, California, where she was a magnet for physical therapists from many nations who came to study with her. She also traveled and lectured the world over.

—Helen J. Hislop and
Suzann K. Campbell

See also Physical Therapy.

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KOREA

See History of Disability: Korea

KŌTŌ, KUZUHARA (1813–1882)

Japanese musician and designer

Kuzuhara Kōtō lost his sight in early childhood. He studied under Kengyō Matsuno at Kyoto and became a renowned regional performer on the *koto* (Japanese zither). He had unusual spatial sense and dexterity, being credited with original designs in origami (the art of folding paper to produce decorative shapes) and living in a house that he himself designed in the city of Kannabe. In later life he made wooden printing blocks of a tactile nature for his own use, and with them he kept a personal diary for more than 30 years. The printing tools and diary are noted in Kannabe as important cultural property that is preserved for posterity.

—Kumur B. Selim

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KRAEPELIN, EMIL (1856–1926)

German professor of psychiatry

Emil Kraepelin, considered to be the founder of modern clinical psychiatry, was born in Neustrelitz, Germany, in 1856 and died in Munich in 1926. He taught in Dorpat from 1886 to 1891, in Heidelberg from 1891 to 1903, and in Munich from 1903 to 1922. His widely distributed textbook on nosology, *Compendium of Psychiatry,* published between 1883 and 1927 in a total of nine revised editions, made the symptomatic diagnosis of clearly delineated illnesses possible.

Even today's classification system, the World Health Organization's International Classification of Diseases, emerged out of the Kraepelin system. Psychiatric illness has, according to Kraepelin, a clear somatic cause; with this thesis, he relied on a psychophysiological parallelism. He did not consider psychosocial reasons, and this made him a proponent of natural scientifically oriented psychiatric doctrine. Consequently, he also subscribed to the popular theory of "degeneration." This was evident in his forensic publications.

Throughout his life, Kraepelin had a pronounced interest in clinical research. As a disciple of Wilhelm Wundt (1832–1920) in Leipzig, and with a focus on experimental psychology, he founded in 1917 the German Research Institute for Psychiatry in Munich. As a cofounder of psychopharmacology, he was influential through the end of the twentieth century.

—Vera Moser

See also Psychiatry.

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KYŌGEN COMEDY

Kyōgen plays emerged in fourteenth-century Japan as brief comedies played between performances of the more serious Noh drama. The repertoire of Kyōgen (literal meaning, "crazy words") grew to about 250 plays recognized in later compilations. They were not standardized texts in the earlier ages. Players worked up outlines in different ways, then continued refining their acts. Disabled characters appeared in some Kyōgen plots, the audience being crudely entertained by their defects, stupidities, and abuse by the world. In Akutagawa, two travelers, each trying to hide his own impairment, gleefully expose each other's defects to mockery. In Kagami Otoko, the bumpkin's naïveté is comically revealed when a peddler sells him a mirror but is exceeded by his wife's imbecility when he presents the mirror to her. She fails to recognize the woman she sees in it, but realizes that her husband must have been dallying with this hussy. He flees before her wrath.

Better known are the Zatō Kyōgen, which are based on blind characters. More than a dozen plays fall into this group—Dachin, Dobu-katchiri, Hakuyō, Inu-hiki, Kawakami, Kikazu zatō, Kiyomizu zatō, Mari-ke zatō, Muma-kari, Nuno-kai, Saru zatō, Tarashi, Tsuki-mi zatō—but some are now obsolete. Among the best known is Tsuki-mi zatō, in which a blind man engages in the refined Japanese custom of viewing the full moon in a field. He is most appreciative of the delightful choir of insects, which he describes aloud. He is joined by a sighted moon viewer from an upper-class area. They engage in polite conversation and share some wine. Then they take their leave, thanking each other for the company. Each feels content, the blind man because he had a pleasant encounter, the sighted man because of his exercise in polite condescension. The audience then hears another thought striking the sighted man: He could exercise his talents further by sneaking back and picking a fight with the blind man, using a disguised voice. He promptly does so, bumping into the blind man, cursing the man's clumsiness, knocking him down, then running away. The irony is heightened as the blind man wails about the contrast between the nice man he met first and the hooligan who knocked him down.

This is the essential Kyōgen as now understood, crazy stuff carrying a sharp message within the slapstick, pinpointing the ambivalence of attitudes, contrasting polite hypocrisy with underlying cruelty. Yet it seems that the early Japanese Zatō Kyōgen portrayed frank ridicule of blind men who suffered farcical tricks to amuse the watchers without any irony. The plays have become more politically correct in recent centuries, with interpreters introducing moralizing elements. Parallels have been drawn with medieval European drama in which serious reenactments of religious and moral themes were relieved by comedy with satire and slapstick. A crude French farce such as the thirteenth-century *Le Garçon et l'aveugle,* about a blind man whose servant plays tricks on him, could readily be adapted to the original Zatō Kyōgen style.

—Kumur B. Selim

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L

LABELING

See Stigma

LAGOVSKY, NIKOLAY MIKHAILOVICH (1862–1933)

Russian educator

Nikolay Mikhailovich Lagovsky was a deaf educator and director of the Mariinskoe school for the deaf in Murzinka village near St. Petersburg, Russia. He organized two boarding schools for the Deaf near Moscow (Aleksandrov, Pererva) and held a position as professor in deaf education of the Moscow State Pedagogical University. He wrote a number of books on deaf education and the history of deaf education, including *Methods of Instruction of the Deaf-Mute* and *St. Petersburg School for the Deaf-Mute.*

—Anna Komarova and
Victor Palenny

LAME, THE

In the twenty-first century, the word *lame* is used primarily as slang for a poor attempt. It is rarely used anymore to refer to human gait. Perhaps this shift in vocabulary reflects the physical landscape of the twenty-first century, in which people with variant gait are increasingly rare as a result of medical technology and aesthetic norm. In contrast, "the lame" were an ordinary part of the ancient human landscape.

The image in the mind's eye of the ancient world is influenced by the legacy of the Renaissance and onward, when scholars and artists depicted perfect Graeco-Roman buildings draped with perfect Graeco-Roman bodies. In fact, any given public gathering place in the ancient world would have included people with a much greater variety of physical conditions than we see in the developed world today. Permanent "lameness" could be acquired at many different stages in one's life. Inadequate nutrition during pregnancy was a significant factor in the ancient world in terms of producing offspring with physical anomalies. Clubfoot is just one example of "lameness" that can be acquired in the womb. Because of the easy corrective procedure available today for this condition, we do not see many people with clubfoot in developed countries, but it was quite common in the ancient world; the Greek god Hephaestus (the Roman Vulcan) himself was portrayed with a condition that matches the description of clubfoot.

Children born without irregular gait could acquire it from a variety of circumstances later in life. The bones of children who are underfed do not have a chance to develop properly. Vitamin deficiencies, especially in combination with swaddling, likely led to such malformations as rickets. A simple accident, such as a fall, could have irreversible consequences for both children and adults in the ancient world. In the developed world, we take for granted that, with medical attention, even the most severe fracture will be undetectably repaired, and we assume that medical attention to a broken bone will result in perfect healing. In the ancient world, a visit from a doctor could have a range of possible results, as doctors' training was not standardized, licensed, or necessarily respected.

However an ancient doctor treated a bone injury, it was not the injured bone but rather the infection that might ensue that was responsible for extreme damage. The bone-injured person would be lucky if the bone simply healed crookedly, because every bone injury was also susceptible to infection. Untreated by antibiotics, an infection can spread throughout surrounding tissues and then the bone itself, attacking even the bone marrow. In addition to injury and infection, disease was responsible for permanent physical impairment, and epidemic diseases could leave whole groups of people with permanent physical handicaps.

Far from the embodiment of the golden mean, the ancient population included a wide variety of somatic configurations. There is no evidence that wheelchairs existed in any form, nor is there evidence that people may have propelled themselves in small carts. People with missing limbs or with other significant mobility impairments probably got around however they could, using crutches as necessary.

—M. Lynn Rose

See also History of Disability: Ancient West.

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LANGE, DOROTHEA
(1895–1965)
American photographer

Dorothea Lange was born in Hoboken, New Jersey, in 1895. She contracted polio at age seven, which resulted in a weakened right lower leg and a visible limp. The changes in her body as a result of polio proved profound and shaped her personality and her later practice as a journalistic photographer. Her most recognized works involve pictures she took of impoverished migrant farmers during the Great Depression era in the United States. She claimed that her noticeable limp allowed her access to her subjects because it made her less threatening as a documenter of exploitation, poverty, and suffering. According to Lange: "I was physically disabled, and no one who hasn't lived the life of a semi-cripple knows how much that means. I think it perhaps was the most important thing that happened to me, and formed me, guided me, instructed me, helped me, and humiliated me" (quoted in Holland 1999). Lange paid a great deal of attention to feet in her work. During 1957, she produced more than a dozen photographs of her own disabled foot and leg.

—David T. Mitchell

See also Polio.

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LANGUAGE OF DISABILITY

In the new global disability universe, perhaps no more contentious debate exists than that surrounding language. Much abuse and harassment of disabled persons occurs as a matter of hate speech even as abusive acts can be covered over with euphemistic expressions and the benevolent rationalizations of professional discourse. Language study thus bears the onus of making visible the contours of disability experiences without erasing the realities behind rhetoric. Particularly since the Enlightenment (1700–1900), many philosophical efforts to explain "reason" as exemplary of what separates humans from animals derive from individuals' assessed competence with linguistic expression. In some frameworks, then, nonspeaking persons or those with communication-based disabilities may be negated as rational human beings out of an apparent lack of verbal fluency that is presumed to equate with an absence of value.

Disability historians sometimes remark that disability today constitutes a densely ramifying totality (see, e.g., Gerber 2000)—the phrase attempts to reckon with the fact that the term *disability* literally consists of conflicting investments among disciplines, sciences, and public cultures. In referencing disability in this manner, we can better understand the varied vocabulary and beliefs that inform our contemporary understanding of disability. This insight is worth picking up, given that so many professional and community interests intersect across the single figure of a disabled individual. Charity interests interpret pathos, pluckiness, tragedy, and deserving vulnerability in disabled persons. Educational interests see the difficult, special, unreachable, or uncontrollable "learner." Medicine approaches disability as a flaw to be conquered and as deviance to be overcome. Rehabilitation recognizes disability as a deficit in need of supplementation and concealment. Everywhere one finds terminology that selects the "cute ones" and conceals or gasps at the "gross ones." Thus, language becomes a barometer of the degree to which a culture openly grapples with the effort to accommodate all capacities or cater to a narrow range of abilities.

Insights from disability studies enter into this discussion in a reflexive manner, prompting us to pay closer attention to the language that filters our perspectives about human differences, particularly as a matter of grappling with the slippery metaphors and allegories that make body predicaments into emblems for cosmic, or simply social, dilemmas. Disability is rarely used to identify the realities of a life of difference—physical, cognitive, or cultural. A common, quite justifiable observation among disability scholars concerns well-placed discontent at having one's body image continually usurped into the expression of a universal motif. Economies are crippled, excuses are lame, a city council is blind to the consequences of some decision. Disability metaphors add combustion and intensity to commentary in any context; they take an expression of concern up a notch in the registers of rhetorical hyperbole. They up the ante on an atmospheric threat so that the strategic placement of a disability-based referent like *crippled* can lend a sentence the quality of an ominous threat. Horror, extremity, and tragedy are the emotions that these metaphoric equations seek—relying for their power on the premise that disability can parlay body differences into an equation with impending doom.

Because of this added punch supplied by the use of disability terminology, one crosscurrent in the field of disability poetics has been a determination to embrace the rhetorically charged references to crippled lives, akimbo limbs, lame figures of speech, cross-eyed stratagems, and limping gaits in poetic traditions. A privilege of being a practitioner of poetics, after all, is that one has permission to investigate language in all its permutations.

Disability poetics, then, assists in demonstrating that the historical language used to define, segregate, and confine people with disabilities is a rich but fraught area for research and interpretation. An encounter with this vast array of historical synonyms for physical, sensory, and cognitive "deviance" demonstrates that while we often seek a less dehumanizing vocabulary to reference disability, such a project proves difficult to achieve. In fact, the multiplicity of ways for referencing disabled lives suggests the degree to which comprehending disability constitutes a central social task in our own historical period. Even the widely accepted term *disability* denotes a form of euphemistic window dressing that cannot successfully exorcise the "barbarism" of previous terminology from which disabled people seek social redress.

Consequently, the battle over self-naming hits at the heart of language struggles themselves. Yet as one disability scholar argues in a discussion of the relationship of linguistic signs to the goals of political reform: "Rather than claiming or disclaiming any set of stigmata (or stigmatizing terminology), a successful poetics of disability would operate from a relentless skepticism of the motives and the truth-value of any sign (marks, names, labels, jargon). . . . Signs have no more an essential, autonomous existence than the categories they represent, and no sign can indelibly mark or irretrievably erase a meaning" (Jeffreys 1997:244). This "relentless skepticism" toward language fixes provides disability poetics with a more dynamic understanding of the politicized notion of language and helps to develop a less naive historical recognition that all terms become contaminated with the very ideas they seek to obliterate or refuse.

The need to develop a more protean sense of language surfaces as disability studies methodologies become increasingly prominent in academic circles. One witnesses numerous examples of critics and educators who refuse to include disability under current work on identity and minority experience. These arguments for exclusion seize on the "biological evidence" of disability as pathology in order to shore up disabled people's "real" difference from other *socially* disenfranchised groups. Within these arguments disabled people are refused a place at the table of social constructionism—they are deviant bodies, whereas other minorities have been unfairly cast as inferior. In such discussions disability poses as less of a linguistic product and more of a literal "flaw" in the mechanisms of living. In the midst of this refusal, medical labels are still assumed to offer up pure diagnostic definitions as opposed to social meanings. Within this rationale other marginal identities—such as gender, race, and sexuality—can be resignified as linguistically defined differences, but no amount of linguistic triage can put the disabled body back together again. Disability becomes a rent in the fabric of being itself rather than an adjudicator of social beliefs about biological differences.

There is a good deal of historical contingency to arguments about the celebratory nature of chosen identities such as blackness, femininity, and other culturally marginalized groupings. The capacity to embrace a historically devalued position takes generations of effort to effect, and one never absolutely arrives at the desired objective: a language free from stigma. Derogatory epithets such as *nigger, hysteric,* and *queer* still surface and, because of language's slippery properties, metamorphose into differently dehumanizing reference systems. They are the residue from historical associations of particular biologies with welfare, criminality, unproductivity, and inferior intelligence. While it proves difficult at some points in history to imagine that a group can effectively take up a despised identity as positive, such efforts are only mitigated by a repetitious history of linguistic dehumanization.

The embrace of formally derogatory language among disability groups is no different—efforts to make disability a matter of social identification rather than "flawed biology" afford an opportunity of semantic *choice* where received definition does not necessarily mean inevitability. While one cannot always choose to extricate oneself from a medicalized notion of abnormalcy projected from the outside, the "disability" rubric provides an opportunity to upend social expectations. The *choice* provided by self-designation flirts with the scandalous political potential of embracing the very identity that others believe to be inherently undesirable.

Counterdiscourse in disability studies sweeps up *crip,* for instance, into an embrace, just as gay, lesbian, and transgender studies came to flaunt *queer.* If one cannot drive away the insults of the playground, then one can take them up and repeat them as a matter of demonstrable fortitude. Such subcultural reclamations emphasize belongingness and chummy verbal communities. The counterdiscursive strategy performs one's place in language and thus exerts a modicum of control over the placement.

Depending on one's cultural location, the usage of *gimp* now results in poetic profit. For instance, the disability comedian Robert deFelice takes up the debasing terminology and turns it into a knowing affectation: "Gimp girls you have consulted with that man [the doctor] many times and look at you!" (in Snyder 1995). Such commentary suggests that strict obeisance to medical regimens of care may not prove helpful to those playfully identified as "gimpy." Likewise, the disabled performance artist Cheryl Marie Wade deploys *gnarly* and *crip* as terms of endearment for her various arts endeavors in Berkeley, California: Gnarly Bones and Wry Crip Productions. These efforts of ironic turnabout by disability performers set audiences into titillating hysteria as they adeptly expose the limits of professional definitions and linguistic assignments. Terms that seem to arrive as unalterably undesirable suddenly become points of community, camaraderie, and knowing mystery exchanged among the like-minded and like-embodied. These ruses of language reveal that labels function not as empirical descriptions of undesirable body types but rather as parameters that restrict meaning where it should be mobile. In the tongues of savvy disability commentators insulting terminology is speedily refashioned for impromptu moments of satirical reclaiming.

In the process of standing language on its head, these efforts not only set language on the run but, perhaps more important, begin to efface a lifetime of hurt for those who have borne the brunt of such abuse in school, in the doctor's office, and in the workplace. Recently a man successfully sued his employer on the basis of the fact that the metal plate in the man's head served as the opportunity for his fellow employees to call him "plate-head." The act of disarming harmful language in this manner ensures the retrieval of the individual's humanity in the face of daily language wars that would argue otherwise. It assists in exposing the violence that so often passes for "good fun" among those who take disability as a "self-evident" sign of an individual's dehumanization. Political correctness wars thus often reference disability in discussion of the ludicrous extremes to which our society will go to deny the obvious; yet, in doing so, these arguments seek to deny the degree to which the language we use shapes perceptions of those who are referenced by such terminology.

Many of today's language pundits spend time ruing the arrival of the "gerrymandering tendencies of linguistic reform movements" by using disability as the absurd example par excellence (Dutton 1996:551). As one prominent commentator argues: "Sooner or later the schoolyard finds out, and *retard* becomes the coinage of value. Everyone ought to deplore the abuse, but it is a delusion to suppose that we alter medical facts by dispensing new names, for *it is the medical condition that is the problem, not the words that describe it"* (Dutton 1996:559). Rather than deny that some persons embody a socially despised biology, the objective of disability studies, disability poetics, and the disability rights movements is to demonstrate that language debases some biologies in order to produce an environment of privilege in the cases of gender, race, sexuality, and ability. Analyses of language usage, consequently, set our sights on the contexts within which some biologies benefit at the expense of others. The object of such efforts is not to deny human difficulties, but rather to critique the idea that the complexity of any lived experience can somehow be confined to the determinism of a pathologizing medical label.

Hence the arrival of one of the more controversial issues in the history of disability language formation: person-first vocabulary. During the 1970s and 1980s, a movement of disability activists forged a social agenda in part around insistence on the phrase *persons with disability* rather than *the handicapped, cripples,* or *disabled person*—labels that were all treated as if they further consigned someone to a nonstandard, unjust future. Within such a linguistic formulation, *disability* would be backloaded as a mere adjective to the personhood of the individual described. In doing so, those who participated in such linguistic adjudications argued that disability would be an aspect of our lives but not an all-encompassing defining feature. In response, others in the same movement argued that placing *disability* last in the chain would amount to a form of denial tantamount to other euphemistic usages such as *physically challenged, special,* and *handicapper.* According to this perspective, *disabled person* is at least as acceptable as *person with disability* in that it overtly claims disability as a point of meaningful difference. Stigma is best combated, argued this language contingent, through an overt embrace of the characteristics directly affecting our lives. In formulating such discussions over appropriate terminology, disabled persons recognized language as one front in the battle for civil rights—it is not merely an adjunct or tangential issue of politically correct language policing.

In this debate, expertise once established by jargon-ridden labels developed by medical, social work, and rehabilitation professionals was challenged and, in some cases, completely overturned. Disability groups made direct claims for the necessity of developing vocabularies that meaningfully grapple with the etiologies and implications of bodily and emotional experiences that differ (or are perceived to differ) from the majority. Whereas "severe" medical vocabularies aspire to neutral description that drives out the last vestiges of freak-show provocations, disabled people deplored the objectification of their bodies that whittled them down to "conditions." Just as late-nineteenth- and early-twentieth-century freak-show performers became exotic spectacles—a man with atrophied legs metamorphosed into "the thinnest man in the world" or "the human skeleton," a woman of Mexican descent with facial hair became "the bearded lady," an African American man with scoliosis transformed into "the missing link"—the complex humanity of persons with disabilities would be usurped by a deterministic feature such as “mental retardation,” “muscular dystrophy,” or “deafness.” The goal here was expediency as opposed to clarity, and the politicized parsing of language was one vehicle of choice.

Yet in many ways some of those attentive to disability language charge that we have not sufficiently attended to the wild card of biology that operates as the point of most disabled people’s ostracization in the current political debates. According to this argument, one of the weaknesses of our current language politics is that people with disabilities cannot afford to overlook the vulnerability and “real” limitations of bodies. Often the problem with medical definitions is not that they pay too much attention to disability, but rather that they prove inaccurate as to the experience of the condition itself. Those with multiple sclerosis, for instance, would argue that a book by Nancy Mairs comes much closer to the nuances of the disorder than any deterministic medical textbook entry. In addition, others have argued that a discussion of disability that fails to take into account the social context of experience references little more than a body shorn of its environment—a corpse posing as a living condition.

Is it necessary to refuse a recognition of biological incapacity in order to establish an effective political movement? Can one not recognize the often very real limitations of the bodies that we inherit or acquire without having to give up on revising the language used to diminish the lives of persons with disabilities? In part, there exists a pressing practicality in this matter; for instance, in research one cannot locate disabled persons in history without searching the keywords by which they would appear in the dehumanizing, medicalizing, segregating, or infantilizing languages of their day. Thus, disability scholars ironically found themselves in a conundrum during the 1990s when the Modern Language Association (the largest humanities-based organization in the world) took it upon itself to excise all instances of debasing disability language from its database search engine. While the gesture proved moving as a safeguard against the use of derogatory speech, it also rendered an enormous amount of historical material invisible. The effect was to erase all written historical materials that relied on terms such as *crippled, demoniac, retarded,* and *gimp*—a sizable cache of materials, as it turned out. In a parallel example, educators might discuss research plans for studies into the future on whether or not sign language should be considered a natural language. For instance, deaf studies scholars have found themselves consternated over the discovery that American Sign Language has been classified under the rubric of “invented languages” alongside the Klingon language created by writers for the television series *Star Trek.*

Like many areas of disability, ideas about language reveal a geography of uneven development. For example, sign language poetry is currently enjoying a creative surge of interest, with international performances, an online journal, and literary prizes. Whereas a history of education for deaf individuals has made sign language usage off limits for deaf students, the effort repressed the idea that signed languages were the first communicative mode of interaction among human communities. In banning signing, then, such educational efforts privileged “voicing” as a preferred communication method in a hearing world. Work to explicitly forbid sign language forced alternative communication modes underground, so to speak, and the revival of sign language poetry attempts to reclaim the power of sign language as a rejection of such prejudicial premises. New ways of integrating the body into linguistic analyses have emerged based largely on the degree to which sign language poetry depends on the body itself as a vehicle of meaning making. The Flying Words Project performer Peter Cook and others have turned their bodies into instruments of communication that outdistance even the most articulate oral talker or writer.

Sign language analysis has also helped to unseat common beliefs that associate articulation with intelligence. Not only deaf people but many with communication-based disabilities have found themselves identified as idiotic, feebleminded, retarded, or delayed, depending on the historical period of their diagnoses. Today, difficulty in oral communication immediately earns an individual placement in special education classes, no matter how fluent he or she may be on paper or computer. Our cognitive sciences have labored long under the erroneous conception that a lack of spoken language acquisition is directly related to insufficient intellectual development where peak performance seems inevitably tied to assessments of oral fluency. To combat this prejudicial assumption, many technologies that facilitate communication have been developed to provide vehicles for communication. Such technologies serve to assist individuals who cannot speak, those whose speech is highly limited, and those who cannot point reliably. These prosthetic enhancements to communications have been widely debated with respect to the degree that they "simulate" the appearance of intelligence rather than reveal the presence of thinking individuals wielding a language of their own. However, such politicized debates only tend to demonstrate the degree to which those who oppose facilitated communication deny humanity to those with speech disorders.

Many prevalent disability clusters form around kinds of language acquisition technologies and assistance that can be readily marketed with payment assurances under different kinds of insurance reimbursement plans. Examples of this phenomenon include hearing-impaired individuals and listening devices (i.e., hearing aids, cochlear implants), people with visual impairments and reading technologies (i.e., Braille, magnification technologies, and so on), those diagnosed with developmental disabilities and various software technologies, and autistic individuals and communication hardware (i.e., portable speech boards, synthesized voicing technologies, and so on). To some extent, one may grow increasingly suspicious at the beginning of the twenty-first century that the technologies are now driving the diagnostic determinations. One will rarely find a disabled individual lacking a closet cache of useless technologies prescribed by one overzealous medical or rehabilitation professional or another. As history has demonstrated, once a technology becomes available human communities find it difficult to resist the ever-present temptation of application.

Finally, this entry will conclude with a discussion of art and advertising, which serve as key contexts for public reception of people with disabilities. The term *enfreakment* has been coined to designate the dire atmosphere of media representation that artificially generates atmospheric strangeness around disabled bodies. The most widely known examples of such phenomena can be found in the sadistic body art of Joel Peter Witkin and the deforming photography of Diane Arbus. In the work of both of these visual portraitists, disabled bodies are transformed into surreal landscapes that tend to emphasize the "grotesquery" of human differences. As one disability scholar argues, their depictions suggest that some impending calamity is about to befall their artistic subjects. Yet, as in the freak-show performances of old, these artistic endeavors consciously seek out the staging of their subjects in ways that artificially exaggerate disabilities as "oddities." Witkin's work slices, dissects, and violates the bodies of his subjects, and Arbus's photography uses alienating props such as Halloween masks, hand grenades, claustrophobic environments, and campy clothing to mock the figures depicted. Such artificial designs trade on the situation of disabled people in bizarre environments where their differences appear out of place and glaring. In all cases, debasing artwork cultivates a visual grammar that encourages viewers to participate actively in the dehumanization of disabled people. Such artwork conjures private language codes that leave art's consumers with little other than extreme emotional responses of distaste, danger, and/or discomfort.

Parallel efforts can be found in the language of charity forums such as telethons and walkathons. In these performance venues disabled people—usually depicted in a perpetually infantilized state as helpless children—are identified as fates-worse-than-death and public contributions promise to eliminate future individuals who might find themselves in the "affected" category. Almost every major disability now has its own charity "organ," and, in the case of the most renowned disabilities—such as muscular dystrophy, cerebral palsy, and "mental retardation"—a plethora of charity organizations have evolved and splintered off from each other. In order to become successful in an industry that has become increasingly competitive, charity organizations participate in the fashioning of severe and pathos-ridden language games in order to top the previous year's contributions. For instance, American telethon barker Jerry Lewis has been recorded as telling disabled people to "stay in their homes" if they do not want to be pitied by others. As this entry's opening discussion of hate speech notes, such aggravated commentary deploys language as a weapon that diminishes disabled people's lives in the midst of encouraging benevolent acts of monetary giving from viewers. Like their scientific partner, genetics, these media displays pursue discourses of prevention as the only appropriate response to unwanted human variations. In doing so, they often manage to avoid efforts at social provisions that would better allow existing disabled people to participate more fully in obstacle-ridden social contexts. Further, in "giving" of their hard-earned dollars, donors are encouraged to feel good about themselves as they contrast their more "fortunate" status with those who are described in terms that mark them as definitively "less fortunate."

By far, linguistic contexts for disability are overdetermined by detrimental ascriptions. Perhaps, as some more pessimistic analysts contend, disability is a difference that cannot be adequately accommodated within the strictures of contemporary vocabularies. At the very least, an examination of disability terminology suggests the degree to which cultures rely on perceptions of extreme human variation to test the outer limits of acceptable humanity. Language is the medium within which all bodies exist; as a result, words create the contexts, the expectations, and the imaginative possibilities for the future cohabitation of disabled and nondisabled bodies. The flexibility of our environments is greatly determined by the language we use to access and construct livable spaces. Let us hope that our language of disability can become as flexible as the bodily variations it references.

—Sharon L. Snyder and
David T. Mitchell

See also Facilitated Communication; Sign Language.

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L'ARCHE

L'Arche is an international federation of communities dedicated to the service of people with intellectual disabilities. It was founded in 1964 in Trosly, a French village north of Paris, by Jean Vanier (son of General Georges Vanier, former governor general of Canada), who was born in 1928. L'Arche emerged as one individual's reaction to and attempt to address the dismal living conditions in institutions for the developmentally disabled at the time.

L'Arche began when Vanier welcomed two persons with disabilities to live with him in a small home. His desire to share his life as a brother with these individuals, Raphael and Philippe, attracted others, and soon a community of several homes and workshops grew in the same village. Later, some of those living in Trosly left to begin similar communities in other parts of the world, at the same time maintaining strong links of friendship and support with one another. In 1972, L'Arche was constituted, and by the beginning of the twenty-first century it included more than 113 communities in 30 countries around the world. The organization's name, French for "The Ark," is taken from the Old Testament story of Noah. It signifies a place of refuge, of salvation from the flood. The name was at first applied to the original home begun by Vanier; it was later given to that first community he founded.

L'Arche is distinctive in that its style of community living is based on relationships, wherein the people with disabilities, called "core members," and people without disabilities, "assistants," live in an atmosphere of trust, security, and mutual affection. The core members are valued and accepted for who they are and the gifts they bring. The people with disabilities are not viewed as "residents" cared for by "staff." Assistants do not view their role as only that of caregiver, but rather as one of sharing life *with* people with disabilities. Assistants usually commit to live in a L'Arche community for one year. Many stay longer, and some assistants have chosen to live in L'Arche communities as a life vocation.

L'Arche communities are faith based, Christian in origin, and welcome people of all faiths and religions. The communities vary in size within and among the countries around the world, having from one to eight homes per community, and they are located in both urban and rural areas. L'Arche communities celebrate each person as being of unique and sacred value and strive to create homes where faithful relationships are nurtured, based on forgiveness and celebration. The same sense of communion unites the various L'Arche communities throughout the world. Bound together by solidarity and mutual commitment, they form a worldwide family.

Although L'Arche has experienced tremendous growth over the past 40 years, this growth has been primarily organic. L'Arche does not seek to expand greatly; rather, it seeks to serve as a sign of hope to society in a divided world.

—Clarissa Schoenberg

See also Community Living and Group Homes.

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LARYNGECTOMY

Theodore Billroth of Vienna performed the first successful laryngectomy in 1873. Laryngectomy is a surgical procedure to remove the larynx (voice box), which is situated above the trachea (windpipe) and in front of the esophagus (gullet or food pipe). This procedure is often done to treat larynx cancer if chemotherapy is unsuccessful. Laryngectomies may also be performed on people with gunshot wounds, severe fractures, or other trauma.

A laryngectomy may be partial or total. In a *partial laryngectomy,* only a portion of larynx or the surrounding muscles is removed. Although the voice is not lost and the individual may retain his or her usual patterns of speech and swallowing, the voice may sound weak or hoarse. The larynx is completely removed in *total laryngectomy,* which alters breathing and communication. A permanent opening (stoma) in the front of the neck allows the individual to breathe, but speech is altered. People who have had laryngectomies are known as laryngectomees; some refer to themselves as "larries."

Laryngectomees are taught one of three alternative ways of talking to restore communication: esophageal speech, tracheoesophageal speech, and electronic speech. The goal is to learn a new speaking technique that is most comfortable for the individual.

Esophageal speech is the oldest method of voice restoration, having been used for more than 100 years. In this technique, the individual draws in air through the mouth and forces the air into the esophagus by locking the tongue. The process is similar to a controlled burp. Esophageal speech is less costly than other methods because it requires no equipment or surgery; however, the vocal phrasing and low volume of the speech that results may make it difficult for others to understand the individual.

Tracheoesophageal speech is similar to esophageal speech, but the individual uses a device to redirect air from the trachea into the esophagus. The device is inserted at the stoma site with a *tracheoesophageal puncture* (TEP): A small shunt is placed through an opening between the trachea and esophagus. A small one-way valve placed into this opening allows the laryngectomee to force air from the lungs into the mouth. This method results in a more natural voice than does esophageal speech, and voice restoration occurs within two weeks of surgery.

Electronic speech involves the use of an electronic or artificial larynx, a device first developed by Johann

Czermak in 1859 to create a clearer voice and increase vocal volume. There are two types of artificial larynxes. The *extraoral type* looks like a flashlight; it has batteries in the handle and a vibrating disk on the end that the laryngectomee presses against the outside of the upper neck. The *intraoral type* consists of a shirt-pocket-sized battery pack connected to a sound emitter by a small wire that is held in the palm of the hand.

Following laryngectomy, some people experience depression and social withdrawal due to the changes in their voices and reactions of others. A number of support groups have been established for laryngectomees (e.g., WebWhispers Nu-Voice Club, the International Association of Laryngectomees), and many find that joining such groups is beneficial. Most laryngectomees successfully return to their jobs and resume most of their usual activities.

—*Kelly Hsieh*

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LATINO HEALTH

LATINO ETHNICITY AND IMMIGRATION

The terms *Latino* and *Hispanic* refer to people who are of Latin American or Spanish descent. There is a great degree of heterogeneity among Latinos, as this group is made up of people from many different races, cultures, and countries of origin. Within the U.S. population, the number of Latinos is currently growing. The majority of U.S. Latinos are of Mexican descent, and most live in the southwestern region of the country. In addition, many people of Central American and Puerto Rican descent live on the U.S. East Coast and many of Cuban descent live in Florida. Growing numbers of Latinos are also immigrating to many midwestern and southern states. The majority of Latinos who migrate to the United States do so in search of jobs that will allow them to support their families, both in the United States and in their countries of origin.

INTERNATIONAL LATINO HEALTH AND DISABILITY

A major cause of underdevelopment in many countries is repeated episodes of illness and long-term disability. Poor health and disability among Latino groups in developing countries are often the consequences of infectious diseases and noncommunicable conditions such as malnutrition, perinatal conditions, mental illness, diabetes, cancer, and cardiovascular diseases. Malnutrition and the spread of infectious diseases are the results of inadequate sanitation, lack of immunization, and poverty. Poor nutrition, lack of prenatal care, and environmental toxins cause perinatal conditions. Chronic diseases such as cardiovascular diseases and diabetes are increasingly becoming major contributors to disability and mortality, both within the United States and internationally. Latinos in Latin American countries and in the United States are at increased risk for these diseases due to a sedentary lifestyle, high-fat/calorie diet, hypertension, high cholesterol, and obesity.

U.S. LATINO HEALTH AND DISABILITY

According to the U.S. Census, 15.9 percent, more than 11 million, Latinos age five years and older have some kind of disability. Data from the mid-1980s indicate that the highest rates of anencephaly, spina bifida without anencephaly, and Down syndrome in the United States occurred among Latinos. Chronic conditions are major causes of disability among Latinos living in the United States. Most often, disabled

Latinos are of school or working age. Furthermore, the U.S. population of Latinos includes 1.6 million people age 65 and older. The Hispanic elderly population is the second-fastest-growing aging population. As the population ages, the number of Latino with disabilities will grow as well. The leading causes of disability among older adults include Alzheimer's disease, arthritis, cancer, cardiovascular disease, and diabetes. More Latinos have arthritis, the leading cause of disability in the United States, and activity limitations from arthritis than do non-Hispanic Whites. The prevalence of type 2 diabetes is 10.2 percent among Latinos in the United States, a rate that is two to five times greater than that among non-Hispanic Whites, and many disabling secondary diabetes-related conditions affect Hispanics as well. Another cause of disability among Latinos is occupational injuries. It is estimated that there are more than 3 million migrant and seasonal farmworkers in the United States, the majority of whom are Latino, and large numbers of Latinos work in high-risk industrial settings as well, such as animal processing plants. Occupational injuries are not uncommon, and many Latinos do not seek treatment for fear of facing questions about their immigrant status and perhaps losing their jobs.

Prevention and Treatment

Compared with non-Hispanic Whites, Latinos in the United States are less likely to engage in preventive practices and to obtain screenings to detect chronic disease risk factors and signs of disease. That is, they are less likely to regularly obtain routine checkups, to undergo blood pressure and blood cholesterol screening, or to be screened for colon, prostate, cervical, and breast cancer. There is also evidence that rehabilitation outcomes are less successful among Latinos than among any other ethnic groups. Many social, economic, and cultural factors influence the preventive and screening health practices of Latinos.

Factors Affecting Health and Disability among Latinos

It is well established that low income, low level of education, and lack of access to health care are associated with chronic disease risk factors and mortality. Latinos in general are poorer, less educated, and less likely to have health care coverage than are members of other ethnic groups in the United States. In 1999, the per capita income for all people 16 years of age and older in the United States was $21,587, whereas among Latinos it was almost half that ($12,111). About 45 percent of Mexican Americans working full-time reported earning less than $15,000 a year. Just over half of Latinos have at least a high school diploma, whereas just over 85 percent of non-Hispanic Whites have at least a high school diploma. Latinos also have less access to health care: More than 33 percent of Latinos in the United States do not have health care coverage. Research has also shown that Latinos are less likely than members of other ethnic groups to use public aid, even if they are eligible, for reasons of pride, fear of questions about their immigrant status, and lack of awareness of the system. The negative effects of lack of resources and access are compounded for Latinos with disabilities, who experience even more difficulty with access to health care and obtaining employment. They also experience difficulty in accessing public facilities and transportation. Language barriers and cultural differences among Latinos with disabilities may also impede their access to health care, their ability to obtain assistance from service agencies, and their ability to obtain employment. In addition, it is estimated that 10,000 Mexicans cross the border into the United States every day, and little is known about the prevalence of disability among recent immigrants or about the potential barriers that those with disabilities face.

CULTURAL BELIEFS AND VALUES

Cultural values about health and disability have been shown to affect the lifestyle choices that people make, decisions to access health care, and the services that people with disabilities seek out. It is important to note that among Latinos in the United States there is a great deal of heterogeneity in cultural beliefs and values. Differences in ethnicity, national origin, gender, income, and education, as well as in religion and level of acculturation (defined as the process of adopting the beliefs, behaviors, and values of the dominant culture), all influence cultural beliefs and values.

Religion plays an important role in Latino cultures, as it does in most cultures. Religious beliefs may influence individuals' views of and attitudes toward illness and disability. Latinos may see disability or illness as a test from God, as God's will, or as a punishment. Religious beliefs can also provide a positive framework through which to view disability and illness. Many Latinos believe that prayer, pilgrimages to holy sites, and vows can aid in curing or ameliorating symptoms, and many who are ill or disabled find sources of support in faith and in organized religion. Religious leaders and fellow parishioners provide everything from emotional support to instrumental support. Research has shown that faith in God provides a higher level of support than does religion as an institution. It is common for an individual to experience an increase in faith with the onset of an illness or disability, but disability or illness may also contribute to a loss of faith.

Latino cultures in general are collectivist. They are guided by duties to the group rather than to the individual, and collectivist norms influence how Latinos perceive health and disability. The value of placing the needs of the family above those of the individual influences Latinos' view of the world. Close extended families are more commonplace among Hispanics than they are among non-Hispanic White Americans. Latinos often turn to family members for social support and advice about health. A family's beliefs and knowledge about preventing and controlling disease shape the individual members' health beliefs and behaviors.

Familial roles also influence conceptualization of disability. For example, if a person with a disability is able to fulfill his or her traditional family roles, other family members may not think of that person as having a disability. The idea of being "normal" can be related more to being able to fulfill roles and expectations than to having an illness or being impaired. A person with an impairment may be considered a unique individual rather than described as disabled. Expectations related to gender roles also influence attitudes and behaviors related to disability and illness. For example, women may deny the impact of illness or disability because of a cultural expectation of *aguantar* (a verb meaning "to endure"). *Machismo* among men may contribute to denial of disability or illness and may cause them to avoid seeking services.

Beliefs about Causes of Disability and Illness

The beliefs of Latinos vary in respect to the causes and treatment of disability, the perception of the severity of disability, and the impact of disability on life. Latinos living in the United States hold varying degrees of both medical and folk beliefs about the causes and treatment of illnesses and disability. Medical beliefs about causality are related to genetics and accidents at birth or in childhood. Folk beliefs about the causes of disability and illness include such elements as imbalance between hot and cold, flies in a home, the evil eye (*mal de ojo*), and dreams during pregnancy. Bad air, germs, and poverty are blamed for symptoms and illnesses. Psychological states such as worry, fear (*susto*), anger, and envy may be labeled as causes of symptoms and disease, as well as turmoil in the family, amorality, and ethical violations. Faith in God, fatalism (a belief that disease onset is a result of fate, and thus individuals have little or no hope of preventing or controlling disease), and *personalismo* (personal relationships) both influence health conceptualization and lead Latinos to avoid or put off seeking treatment. Some Latinos use home remedies involving herbs, purification rituals involving holy water or candles, and the services of spiritual healers to treat illness or disability before or in place of seeking medical help. One study on the cultural norms related to Latinos' delayed use of medical care when chronic disease–related symptoms are present found that the factor with the most pronounced effect on care seeking was the perceived seriousness of the symptoms.

Cultural Competence

Health professionals in the United States are increasingly recognizing that they need to be aware of the social and cultural factors that influence how Latinos perceive health and disability. To improve the health and well-being of Latinos with disabilities, research is needed to examine the diverse health-related beliefs among various Latino groups. Although it is important to be sensitive to cultural beliefs, health professionals should avoid assuming that every Latino has traditional beliefs. Culturally competent and bilingual service providers are also needed to serve this population effectively.

—Janine M. Jurkowski

See also Cultural Context of Disability.

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LAVATER, JOHANN KASPAR

(1741–1801)

Swiss scientist and poet

Johann Kaspar Lavater was a Swiss scientist and poet who wrote in German. Lavater developed an influential science of physiognomy that linked facial countenance and bodily appearance with moral disposition. While physiognomy itself was not new—some scholars place aspects of this belief as far back as the writings of the ancient Greeks—Lavater's system sought to formalize a common practice as empirical method. His most famous book, *Art to Know the Men by the Aspect: The Physiognomy* (1775–1778), was a two-volume work that included silhouettes and illustrations of faces in profile exemplary of character traits such as greed, criminality, melancholy, miserliness, and virtue. He also included his own profile as well as those of celebrated individuals of his time whom he admired. The basis of his system of physiognomy was Lavater's belief that the body communicates the nature of the soul. Along these lines, he once argued, "Action, looks, words, steps, form the alphabet by which you may spell character." Significantly, several prominent disabled people of the eighteenth and nineteenth centuries opposed Lavater's theory on the basis of its prejudicial relation to disabled bodies. Disabled critics of this theory included the "hunchbacked" German mathematician Georg Christoff Lichtenberg (1742–1799), who mocked Lavater and other physiognomists of his time by explaining that they took their own bodies as the barometer of morality. According to Lichtenberg, "God created man in His own image, says the Bible; philosophers reverse the process: they create God in theirs."

—David T. Mitchell

See also Georg Christoff Lichtenberg.

LEADERSHIP

The term *leadership* is used to represent an office or position of leader or the ability to guide, direct, or influence people. By definition, leadership involves the holding of an elevated office or position—that is, leaders have a higher status than do those whom they are leading. Further, definitions of leadership stress that leadership is a group process that involves interaction between at least two persons as they work toward a common goal. In this way most directly, leadership has done much for the field of disability. This entry discusses types of disability leadership and their effects, which include advances for both leaders themselves and the general disability community.

TYPES OF DISABILITY LEADERSHIP

Specific to the field of disability, leadership has taken three major forms: leadership by persons with disabilities; leadership by parents, family members, and caretakers of persons with disabilities; and leadership of policy makers surrounding disability-related issues.

First, many people with disabilities have taken leadership roles themselves in a number of capacities, including in large organizations such as the American Association of People with Disabilities as well as in smaller grassroots community groups. As one example, the centers for independent living (CIL) movement began in the 1960s and 1970s due in large part to the leadership of Ed Roberts, an individual with an extensive physical disability as the result of contracting polio as a child. Roberts's leadership experience began with his advocating for his own equal access to an education and moved on to include his advocating for the rights of people with disabilities all over the United States. Another example is Deng Pufang, himself a wheelchair user, who founded the China Disabled Persons' Federation (CDPF) in 1988. The CDPF works to protect the human rights of persons with disabilities as well as promote their equal participation in society. In 2003, Deng Pufang was acknowledged with the UN Prize in the Field of Human Rights for the extensive work he has done for people with disabilities in China through legislation, programs, and activities.

Along these lines, much has been done to encourage the leadership of people with disabilities, including a number of national and local conferences that have chosen as a major theme the leadership of people with disabilities. In addition, a variety of disability leadership forums and training programs exist across the United States and the larger international community, including in places such as Illinois, Massachusetts, Michigan, Oregon, and Thailand. The majority of these projects have been designed to help youth or adults with disabilities uncover or further develop their leadership skills, sometimes in relation to a specific area, such as independent living.

Second, parents, other family members, and caretakers of persons with disabilities have also participated as leaders in the disability community. Parents of children and adults with disabilities have been responsible for beginning many support organizations, including United Cerebral Palsy, as well as networks such as the Parents Exchange, an informational, referral, and advocacy organization. Another example is the Kennedy Foundation, which grew in part out of Eunice Kennedy Shriver's experiences with her sister Rosemary's intellectual disability and continues to provide supports to serve those with mental retardation. These groups are essential to supporting people with disabilities as well as educating the able-bodied community regarding the strengths and needs of individuals with disabilities. Similar trends have been evidenced internationally. For example, in the United Kingdom a group of parents of children with disabilities formed the National Autistic Society in order to provide information and support to other family members of individuals with autism.

The third form of leadership in the area of disability has been that provided by policy makers and government agencies. For example, the National Institute on Disability and Rehabilitation Research (NIDRR) has been a strong leader in advocating for the rights of and equal services for individuals with disabilities. NIDRR has developed funding priorities that, among others, promote leadership training for people with disabilities. These priorities continue to ensure that disability remains an integral part of the research agenda in the United States. Another example of leadership by government agencies occurred in Australia during the early 1970s, when a larger community health movement took place. Under the Whitlam administration, local community health projects were made directly accountable to the communities they served. There was community involvement at every level of service development and delivery, which allowed channels of communication to open up among service providers, government officials, and consumers in areas such as disability and mental illness (among others). These types of policy initiatives provide a framework for both national and local organizations to strive to meet the needs of individuals with disabilities more effectively.

EFFECTS OF DISABILITY LEADERSHIP

Positive effects of disability leadership can be seen both in leaders themselves and in the broader disability community. First, serving as leaders can benefit leaders themselves. Much general research conducted across a variety of populations has found that helping others can have a positive impact on the person providing the help. Specific to disability, serving as a leader may benefit the leader in terms of self-determination, power, and control. For example, leadership training has been used to promote recovery in persons with psychiatric disabilities. Such training may lead to decreases in psychiatric symptoms as well as increases in self-efficacy, community living skills, and empowerment. Similarly, serving as a peer leader has been found to facilitate adjustment to a new disability among individuals with spinal cord injury. Leadership training can also open the door to further career opportunities. For example, in one leadership training program, graduating leaders had the opportunity to join local advocacy organizations on a formal basis as speakers who would advocate for effective supports for people with disabilities.

Second, leadership can also benefit the broader disability community in terms of advancements in the area of equal access and equal rights, as a catalyst toward person-directed services, and as a way to build a solid sense of disability community and identity. Perhaps the most significant impact that leadership in the disability community has had is seen in the passage of the Americans with Disabilities Act (ADA) in 1990. The development of leadership in the disability community in the United States led to the passage of the ADA, and in turn the ADA has raised the quality of life for many people with disabilities. Changes such as better access to employment, transportation, housing, education, communications systems, and public facilities for people with disabilities have all resulted from leadership in the disability community. Moreover, the passage of the ADA in the United States foreshadowed growing interest in disability rights legislation in other countries, such as Australia and Colombia.

Another example of the broader community impact of leadership is the CIL movement, which is dedicated to helping people with disabilities live independently and become productive, fully participating members of society. The National Council on Independent Living (NCIL), which was formed in 1982 in the United States, provides an excellent example of leadership for people with disabilities, by people with disabilities. The NCIL has been a leader in the disability community in terms of building local community bases as well as advocating nationally for disability rights.

Community impacts can also be seen on a smaller scale. For example, leadership training programs often foster the development of networks of individuals who have strong leadership skills. Such networks can then be effective tools for outreach and education of other people with and without disabilities about disability rights in the community.

In all of the examples presented above, leadership has facilitated the building of empowerment in the general community, which can also help new people develop as leaders in their communities, creating a solid feedback loop. Leadership serves as an effective and essential tool to effect change and advocate for a variety of rights for people with disabilities.

—Erin Hayes and
Jose Mendez

See also Advocacy; Advocacy, International; Advocacy Movements: France; Advocacy Movements: Germany; Empowerment and Emancipation; International Disability Organizations; Peer Support; Roberts, Ed.

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LEAGUE OF THE PHYSICALLY HANDICAPPED

The League of the Physically Handicapped was a grassroots organization of disabled activists that operated in New York from 1935 to 1938. In 1935, in the depths of the Great Depression, President Roosevelt established the Works Progress Administration (WPA) to provide jobs for the unemployed. However, among the groups considered "unemployable"—and thus ineligible for WPA jobs—were people with disabilities. In response to this policy, six young people with disabilities held a sit-in at the offices of New York City's Emergency Relief Bureau. At first merely aiming to speak with the bureau's director, they escalated their demands as the sit-in continued. An ongoing picket line of supporters at times swelled to hundreds, with thousands of onlookers. Six days later, when those sitting in finally met with the bureau director, the nascent group was demanding jobs in unsegregated environments and explicitly rejecting charity.

The League grew from this core of activists. Focused on employment rights, the organization engaged in picketing, public education, and meetings—often confrontational—with public officials. The group also wrote a 10-page "Thesis on Conditions of Physically Handicapped." Prefiguring later thinking, this work asserted that discrimination is the cause of disabled people's unemployment and critiqued the charity model, especially sheltered workshops.

—Anne Finger

See also Activism.

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LEARNING DISABILITY

Coming to agreement on the definition of learning disability (LD) has been a challenge since the 1960s. Various groups, such as the Learning Disability Association (LDA), provide their own definitions. However, the most widely used definition in the United States is that provided by the U.S. Department of Education under the regulations of the Individuals with Disabilities Education Act (IDEA) of 1997. According to the IDEA, the term *learning disabilities* refers to a group of neurological disorders that impact one or more of the brain's basic functions used to understand and interpret language, symbols, and gestures; such disorders are typically identified during the elementary school years. The manifestation of these neurologically based conditions can be observed in an individual's difficulty with reading, writing, listening, speaking, completing mathematical functions, fine motor skills, and even interpreting social cues and gestures. The term *specific learning disability* (SLD), which is sometimes used instead of the more general term *learning disability,* refers to a severe difficulty with one area of life and learning without any accompanying difficulty with others. For example, someone with an SLD in reading may experience great difficulty with written print but be able to complete complex mathematical computations and manipulate objects that require great dexterity.

Historically, three conditions have been considered in identifying a learning disability: (a) the presence of a discrepancy between potential and achievement, (b) the presence of intraindividual differences, and (c) the presence of average to above-average intelligence. These conditions pose a problem for professionals working in the area of LD. Most notably, procedures for determining whether a discrepancy exists are a source of great debate that centers on issues related to IQ testing and performance measures. As a result, the IDEA, the federal legislation in the U.S. that is designed to ensure that individuals up to the age 21 receive free appropriate public education that meets their needs, calls for a comprehensive, interdisciplinary assessment of strengths and needs for any student thought to have an LD. One critical factor to rule out in making a diagnosis of LD is that the problems themselves are a result of LD and not due to other disabilities or societal factors. However, LDs can coexist with nonintellectual disabilities, and in many schools it is common to find students with both LDs and emotional behavioral disorders.

More than 50 percent of individuals in U.S. schools who receive special education services have some type of LD. Adults who have learning disabilities may also go undiagnosed and thus experience great difficulties. Their undetected LDs may have negative impacts on their ability to work, engage in social relationships, and experience success. Because LDs are invisible, they pose some interesting challenges for individuals with LDs as well as their families, professionals working with them, and their peers and coworkers. An LD can affect every domain of an individual's life, and, as such, interventions designed to support success may vary greatly for different individuals.

Specific LD disorders include dyslexia, dyscalculia, dysgraphia, dysnomia, and dyspraxia, and in recent years the growing category of attention deficit disorder (ADD) has been included on this list. Individuals with the best-known type of LD, *dyslexia,* experience great difficulty understanding language and using various language-related skills, most commonly reading, writing, spelling, and speaking. This condition at times affects an individual's ability to interpret mathematical symbols to determine operations and may also influence the ability to interpret social cues (e.g., facial expressions). The next most common form of LD is *dyscalculia,* which has the same effect on an individual's learning and understanding of mathematical concepts and operations. Although the impact of this LD on a person who is in school is significant, it does not end once the individual exits the school setting. It can be observed in disorganization with balancing a checkbook, poor money management (e.g., late payments), and scheduling errors. *Dysgraphia* affects an individual's ability to develop written language and use it as a mode of communication. *Dysnomia* refers to difficulty experienced with the recollection of names, places, or specific object words. This form of LD can have a negative impact on children and youth, but it has a greater influence on adults as they attempt to communicate with coworkers, supervisors, clients, and related groups. *Dyspraxia,* the least common of the learning disabilities, is related to the manipulation of fine motor skills; it limits the individual's ability to engage in handwriting, drawing, typing, sequencing, and even daily self-care.

According to the Learning Disability Association, ADD and brain injury also fall under the category of learning disability. ADD affects an individual's ability to focus attention for any prolonged period of time; if hyperactivity is also observed, attention deficit/hyperactivity disorder (ADHD) may be diagnosed. In recent years, ADD and ADHD have become increasingly recognized. Until about 20 or 30 years ago, young people with similar behaviors were identified as hyperactive, impulsive, or disobedient. Now there is greater understanding of how this condition becomes or creates a learning disability. Given that brain injury affects an individual's neurological development, it is also considered a learning disability.

Since the 1990s, a new group of individuals has been considered as having a learning disability: individuals who are simultaneously gifted. Gifted LD individuals do not typically fit the criteria of experiencing failure, but they do meet the criteria for the presence of a discrepancy. In other words, individuals who are gifted LD may easily use their intellectual potential to compensate for their learning disabilities.

While the above description of LD conditions provides an outline of the various learning characteristics of individuals identified as having LDs, intervention options also need to be considered. Once a learning disability exists, it will not go away or be "cured" as an individual matures. The goal of intervention is to teach skills to address the challenges that are presented by the LD. Teaching the use of multiple learning modalities—visual, tactile, auditory, and kinesthetic—helps to "educate the brain," the source of this neurologically based disability. The use of assistive technology devices is becoming increasingly common among educators and employers for supporting individuals with LD. The technology that allows assistive devices to convert speech to written print, predict words, and/or read text is advancing daily. Such devices can open doors for individuals who may not be able to read or write but have excellent comprehension. They can make the difference in whether an individual with LD can access postsecondary education, participate in competitive high-level employment, and in other ways demonstrate his or her full potential.

Brain research demonstrates the neurological basis for learning disabilities and their impact on information processing, memory, and performance. However, symptoms associated with a learning disability can also be observed as a result of gaps in learning and of biased evaluations rather than the presence of a neurological condition. Consequently, there has historically been an overrepresentation of ethnic minority individuals identified as having LDs, as a result of both cultural bias and language bias. For example, professionals can easily misinterpret the characteristics of a potentially English-proficient student during the emergence of a second language as a language learning disability. However, if individuals go undiagnosed, they may experience great difficulties as adults living with undetected LDs that have the potential to limit their success in many ways.

The term *learning disability,* and the concept to which it refers, is relatively new. Learning disability was identified as a specific condition in the 1960s by a group of parents and advocates who observed unique learning styles in their children. The children in question had at least average intelligence and did not have physical or sensory disabilities. Professionals were at a loss to provide effective educational interventions for these individuals. Since that time, the recognition of this condition as a disability has extended beyond the United States and is now recognized internationally through brain research.

As with other disabilities, the presence of a learning disability has a significant impact on an individual for life. Unlike other disabilities, LDs are misunderstood as a result of their invisible nature and broad scope. Changes in the wording of legislation and subtle differences in definitions, whether theoretical or operational, can affect the diagnosis of LD. Students with LD are protected under the IDEA in the United States, but adults must use the protections of the 1990 Americans with Disabilities Act. Because of the ADA definition of disability, individuals with LD may not actually be protected unless they can prove that their disability has a negative impact on at least one major life function. In school, at workplaces, and in their communities, individuals with any type of LD are constantly pressured to perform actions that are in direct contradiction to their disability. Therefore, greater understanding of both the neurological basis for a learning disability and its vulnerability to the impacts of curriculum, poor education, and cultural bias is crucial.

—Teresa Garate

See also Dyslexia.

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LEONARD CHESHIRE

Leonard Cheshire is the largest charitable supplier of services for disabled people in the United Kingdom. It also operates globally. Founded by the World War II bomber pilot and war hero Leonard Cheshire, VC, in 1948, it greatly influenced the pattern of social care provision made for disabled people in the second half of the twentieth century internationally. This was particularly based on group living in residential institutions, which greatly restricted disabled people's opportunities to shape their own lives.

In the 1960s, the resistance of disabled people who lived in one Leonard Cheshire home, Le Court, played a major role in establishing the British disabled people's movement and the development of disability emancipatory research. The introduction of "community care" legislation in the early 1990s in Britain was intended to support disabled people to live in their own homes and neighborhoods.

In the late 1990s, the Leonard Cheshire organization established the Disabled People's Forum, which is run by disabled people and works within the organization to support disabled people's involvement and empowerment. The process of democratizing the organization, increasing the control of disabled people, improving the quality of services, and enabling disabled people to live independently, is still proving problematic, however. Leonard Cheshire's experience highlights some of the difficulties of making change from within traditional charitable organizations for disabled people.

—Peter Beresford and
Fran Branfield

See also Community Living and Group Homes; Empowerment and Emancipation; Independent Living.

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LEPROSY

Leprosy is increasingly known by the less offensive name of Hansen's disease (HD). It was the first chronic disease to be attributed to a bacterial cause, when the Norwegian physician Gerhard Armauer Hansen identified the bacillus *Mycobacterium leprae* in 1873. There still is no clear understanding of the transmission of the causative agent, which appears to require long-term exposure and has a long incubation period. Efforts to grow the organism in a cell culture, which is prerequisite to the development of a vaccine, remain unsuccessful. Divided into localized (tuberculoid) and generalized (lepromatous) forms, the disease manifests first in skin discoloration and then in nodules, lesions, and topical anesthesia. If unchecked, it gradually spreads over the entire body, attacks the soft tissue of the nose and throat, impairs vision, and damages the nervous system. Ultimately, extremities become deformed and paralyzed, and may fall off after repeated but unperceived injuries.

The intrinsic seriousness and disfiguring effects of leprosy and, in the West, an accumulation of misnomers and misconceptions related to the disease have triggered irrational reactions that have proven difficult to overcome. Fateful changes in nomenclature began in late antiquity. The Greek category of "scaliness" (*λέπρα*), which covered a wide range of skin conditions, and the analogous Hebrew *zarã'at,* which biblical law termed unclean and cause for ritual isolation, merged into the Latin term *lepra.* The most ominous confusion ensued when the term became interchangeable with *elephantia* centuries after the Romans noted this disease as new, foreign, and presenting symptoms matching those of HD; they reported that it caused horror and that they feared the transmission of this evil.

Horror and revulsion interacted with the belief that physical deformity implied moral perversity. Deep fear persisted as long as infectiousness was misconstrued as contagiousness. The highly visible effects of the disease, together with its endemic and frequently clustered incidence, led observers—and historians—to overestimate the epidemic dimensions beyond the maximum documented ratio of patients to population. The tendency of the disease to occur in families and to strike children was confused with heredity. The steady advance of symptoms, obscuring the secondary infections that actually were the lethal threats to the weakened body, led to the assumption that death was the natural and inevitable outcome of leprosy and that, therefore, patients were beyond medical help.

The abandonment of patients found its most dramatic expression in a funeral rite that accompanied their ejection in some areas of medieval Europe, but it did not preclude continued efforts at palliative care. Similarly, in most societies, public stigmatization and exclusion coexisted with the protectiveness of families. Even official banishment failed to eliminate the victims from communal life and consciousness. HD patients have been the objects of effusive charity and the subjects of stories of miraculous healing and of heroic missionaries from the twelfth-century foundation of numerous leprosaria to the current activities of global aid movements. Nevertheless, they must still contend with discrimination and assaults on their self-esteem in addition to the physical disabilities they incurred before receiving medical treatment. After ages of unproven remedies, in which snake meat figured prominently, and high but vain expectations for chaulmoogra oil in the early twentieth century, the introduction of dapsone in 1941 brought the first effective therapy. The drug takes a toll on the kidneys, which may cause some patients to forgo their medication and others to die when dialysis is not available. In addition, emerging drug-resistant strains of *M. leprae* have necessitated multidrug therapies. These carry more side effects, and their expense impedes application in the areas of the world with both the lowest prosperity and the highest incidence. Endemic leprosy declined markedly in early modern Europe, and currently no industrialized country has more than a hundred HD patients. In the developing world, however, hundreds of thousands of new cases are diagnosed each year.

—Luke E. Demaitre

See also Institutionalization and Segregation; Stigma.

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LEUPOLT, JANE (1812–1894)

British missionary and educator

Jane Leupolt, née Jane Chambers Jones, went to India in 1835 with the Society for the Promotion of Female Education in the East as a trained infants teacher. She married the Reverend Charles Leupolt in 1839 and for many years concerned herself with the education of blind children in the Orphan Institution at Sigra, Benares (Varanasi), and with local blind adults. After living in England, where she saw Moon's embossed reading materials, she returned to India in 1860 and organized formal literacy teaching of blind children with Mrs. Amalie Fuchs, a fellow missionary. By 1864 their efforts convinced the government to fund teachers for blind children. Using adapted Moon characters, Jane Leupolt succeeded in printing readers in Hindi. Light industrial work was also begun at Benares with blind youths at Raja Kali Shankar Ghosal's Asylum in this period, and Jane Leupolt's embossed books were used there from 1868 by Indian teachers whom she trained in their use. Although some earlier literacy work had begun in India with Lucas's script, Jane Leupolt was the first to organize the teaching of blind people on a larger scale and to gain government recognition. Before leaving India in 1872, the Leupolts passed the materials to the Reverend John Erhardt at Secundra Orphanage to add to the facilities of its famous printing house.

—Kumur B. Selim

See also William Moon.

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LEWIN, KURT (1890–1947)

German-American psychologist

Kurt Lewin was a German-American psychologist who profoundly influenced many fields. Lewin's environmental/contextual approaches to studying behavior and his integration of science and social change serve as cornerstones for contemporary conceptions of disability, disability research, and policy. Born in Prussia, Lewin studied and taught at the University of Berlin. In 1933, he emigrated to the United States to work at Cornell University, moving to the University of Iowa in 1935 and then to the Massachusetts Institute of Technology with the 1944 launching of the Center for Group Dynamics.

Lewin conceptualized behavior (B) as a function of the person (P) and the environment (E), expressed mathematically as B = f(P, E). Person-environment interaction is key to the social definition of disability.

Lewin melded research and social intervention. His oft-quoted statement "There is nothing so practical as a good theory" characterizes his view that science and social change should be achieved simultaneously. Lewin called this combination "action research," and this approach is often used today in disability studies.

Much of Lewin's work dealt with reducing prejudice. Lewin demonstrated that nondiscriminatory policy led to decreased prejudice in mixed-race housing projects. Blacks and whites living as equals came to view each other as friends, a concept on which the inclusion efforts of disability advocates are based.

—Willi Horner-Johnson

See also Translating Theory and Research into Practice.

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LICHTENBERG, GEORG CHRISTOPH (1742–1799)

German physicist and philosopher

Georg Christoph Lichtenberg was born on July 1, 1742, in Ober-Ramstadt in Darmstadt, Germany, and died on February 24, 1799, in Göttingen. His father, who was a minister, wrote in the church register after Lichtenberg's birth: "birth'd son who despite weakness I baptized." From the age of eight, Lichtenberg suffered from a spinal deformation combined with a hunchback that was probably caused by rachitis. With the help of a governmental scholarship, he was able to attend university. In 1769, Lichtenberg was appointed professor of physics in Göttingen. It is said that Lichtenberg could write his lectures on the board without turning his back—that is, his hump—to the audience.

For a time, Lichtenberg lived with a flower girl, Maria Dorothea Stechardt. She was his housekeeper and lover, but she died at an early age. Soon thereafter he took in a new young housekeeper, Margarete Elisabeth Kellner, who also became his lover. She bore Lichtenberg six children, and late in his life he married her.

Lichtenberg, although fond of the monarchy, was not only an outstanding physicist but also a representative of Enlightenment philosophy. He became the father of the German aphorism. Many of his witty ideas, familiar quotations, and flashes of thought—or "penny truths," as he liked to call them—were connected with his life. These can be found in his so-called *Sudelbücher* (mess books), which remained unpublished during his lifetime and became available widely only at the beginning of the twentieth century. In some of his most famous aphorisms he addressed the philosophy of disability and physical impairment. Lichtenberg's fear of people was paired with the gift for observation concerning human behavior. This also generated his polemic "Über Physiognomik; wider die Physiognomen" ("On Physiognomics; against Physiognomy"), which was published in 1778.

In 1983, an exhumation of Lichtenberg's skeleton proved that in fact no smallness in stature or "misshapenness" could be ascertained. His impairment, although descriptions of it have been handed down by his contemporaries, seems to have vanished into the air. One could take this finding as an ironic commentary on the controversies among Lichtenberg's biographers. Even today, discussions arise as to whether the philosopher endured his suffering with patience or with humor, or whether he simply went about his daily life, feeling indifferent about his disability.

—Christian Mürner

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LILIANE FOUNDATION

The Liliane Foundation, located in the Netherlands, is committed to doing justice to children with disabilities in developing countries by giving them access to rehabilitation. In 1980, the Liliane Foundation started by assisting 14 children. In 2002, the foundation helped 31,982 children spread over 80 countries. As of that year, the total number of applications allocated and justified since the organization started its activities amounted to exactly 249,792.

Characteristic of the Liliane Foundation's assistance are direct contact with the child within the home situation and attention to the personal growth and happiness of the child. The key feature is "tailor-made" assistance—that is, assistance that varies according to the personality and the situation of each individual child. The guideline in the rehabilitation process is the child's individual rehabilitation plan, which sets out specific goals and describes the desired results. The final objective of the rehabilitation is the child's integration and participation in society.

The Liliane Foundation directs its efforts primarily toward children with disabilities living at home. From the start, the parents are closely involved in the rehabilitation process; this involvement (also in a material sense) is extremely important for the success of the rehabilitation.

The small-scale, direct, and person-centered assistance that is typical of the Liliane Foundation is made possible in practice through the foundation's collaboration with a worldwide network of "mediators" (local contact persons). Only representatives of nongovernmental or religious organizations can become mediators. The Liliane Foundation pursues its policy of strengthening the mediator network structurally by entering into partnership agreements with these organizations. The partnership agreements place the responsibility for the functioning and financial control of the mediators, as well as for the continuity of the work done, with the organizations.

Many mediators are social workers, physiotherapists, or nurses who work in the slums of big cities or in rural areas, where people often hardly know that rehabilitation is possible. Mediators or their coworkers arrange for the rehabilitation of the children with disabilities they come across in their work, requesting that the Liliane Foundation provide partial funding of the rehabilitation interventions needed. Because mediators and their coworkers have direct contact with these children and their families, they know the children's needs and the particulars of the local situation. They are aware of what kinds of assistance the children need most to cope better in their specific surroundings and circumstances.

The Liliane Foundation uses as many local facilities for rehabilitation as possible. Children who need surgery undergo it in the hospitals nearest to where they live and receive aftercare in the vicinity as well. Physiotherapy is provided in the children's homes or in nearby facilities, and any needed appliances are obtained locally. Children also receive education and vocational training in locations as close to their families' homes as possible.

—Patrick Devlieger

Websites

Liliane Foundation, http://www.lilianefonds.nl

▣ LITERATURE, FOLLY

Folly literature is mainly a phenomenon of sixteenth-century Europe. Although the term *Narr* (fool) was used by earlier authors, it achieved its broad circulation only when Sebastian Brant (1457–1521) published the moral fiction *Narrenschiff* (*Ship of Fools*) in 1494. Shortly after the appearance of its first German edition, this book was translated into Latin, English, French, and Dutch. The passengers on the "Ship of Fools"—including the narrator himself—were fools because they were not able to conform to moral, religious, and ethical norms. The author not only criticized human sins and vices, such as drunkenness, adultery, and lavishness, but also condemned minor deviations such as the dislike of planning one's future. Brant's book became a best-seller and was a hallmark in Renaissance literature. It influenced many other pieces such as Erasmus von Rotterdam's *Encomium moriae* (*Praise of Folly*).

Besides their evident importance to moral fiction, fools played important roles in carnival plays and jest books. However, natural fools, being the main objects of interest from the disability studies perspective, were hardly ever mentioned in the *Ship of Fools* and similar fiction. In his sermons about the *Ship of Fools* in 1498 and 1499, the famous Strasburg preacher Geiler von Kaysersberg (1445–1510) explained that natural fools were fools without sins. They did not deliberately behave in deviant ways and therefore were not suitable to illustrate violations of moral, religious, and ethical norms. Instead, during the Middle Ages and Renaissance natural folly simply described a condition of essential mental difference. Natural fools were understood as differing not only from the normal but also from the mentally ill, since their condition was not a temporary, but a permanent one.

Although natural fools can be found in Renaissance literature even before the *Ship of Fools* was published, printed pieces about natural fools made up only a small segment of literature. For instance, in Wolfram von Eschenbach's thirteenth-century epic poem "Parzival," the protagonist's mother dressed his son as a fool to prevent him from becoming a knight. In doing so, the mother hoped that Parzival would return home quickly as soon as he was badly treated at court. However, as natural folly depended not only on a special costume, Parzival's princely origin could not be disregarded. In contrast, in Gottfried von Straßburg's epic thirteenth-century poem "Tristan," the hero voluntarily dressed as a natural fool when he met Queen Isolde. In this disguise, it was even possible for him to sleep at the door of his secret love. However, as natural folly was linked with asexuality, he could stick to his folly role only as long as he was not seen in bed with Isolde. Having betrayed his secret, Tristan had to escape. This plot serves as an example of high medieval German literature in which natural folly often offered a chance and disguise and dissembling.

In sixteenth-century Europe, jest books were another genre that collected anecdotes about all kind of fools. A good example of a jest book is *Schimpf und Ernst* (*Jests and Lessons*) by Johannes Pauli (c. 1450–c. 1520). Three main approaches to natural fools can be differentiated in folly literature. First, actions of natural fools were said to evoke laughter. Second, natural fools were shown as divine beings bearing messages from God. Third, natural fools were used as positive didactic examples. They were laughed at for their deviant behavior. For example, a popular anecdote told of a natural fool discovering a foal standing next to the fool's stud. The fool started to beat his horse for being a whore, and comforted the foal.

These anecdotes often had a closing statement that aimed at making the general audience laugh. The authors also understood the natural fools' deviance as divine intervention, and consequently interpreted their behavior as foretelling signs. It was Martin Luther (1483–1546) who related the anecdote about natural fool Claus Narr, who asked for water that would help him to extinguish a fire while at the same time in the distance a castle was burning. Other authors interpreted not only single episodes of a fool's life but the whole foolish behavior as a sign of prophecy or wise telling. These authors used natural folly as a didactic example for moral, religious, and ethic norms.

The German collection of 627 anecdotes of Claus Narr by Wolfgang Büttner is a prominent piece of this type of didacticism. The book was printed under the title *Sechs hundert/sieben und zwantzig Historien/Von Claus Narren. Feine schimpffliche wort und Reden/die Erbare Ehrenleut Clausen abgemerckt/und nachgesagt haben/Zur Bürgerlichen und Christlichen Lere [. . .] (Six hundred and twenty-seven anecdotes of Claus Narr. Fine and funny words and talks which honorable men noticed and retold. For civilian and Christian lessons [. . .]).* One anecdote in this book went like this: When Claus Narr saw a painted bird, he tried in vain to chase it away. Büttner interpreted this episode in a moral sense as a lesson that guests should not stay too long. Not only in everyday life, but also in the theological debates of sixteenth-century Europe, Claus Narr was presented as a model for true faith in God. For example, at one occasion he was asked about Martin Luther's future. Claus Narr answered that he was sure that the Reformation would prevail but added that his shoes and clothes became worse and worse. In his moralizing conclusion, Büttner called the fool a wise man as he foretold the continuation of the Reformation.

Until the end of the eighteenth century, Wolfgang Büttner's book was often reprinted. Other collections of jests and folly anecdotes quoted this source and continued to use the fool as a didactic example. Besides Claus Narr, who was a main source of reference in the sixteenth- and seventeenth-century folly literature, other natural fools became subjects of literature. In 1619, the Protestant preacher Philipp Cradelius printed a sermon for a natural fool's funeral. The life of the fool Hans Miesko was interpreted by him less as a sign of God but more as an object of pity. In that respect, Cradelius's sermon showed a slightly different approach to natural folly.

The various perceptions of natural folly remained in existence until the end of the eighteenth century. Until the Enlightenment, natural folly remained an object of laughter, of admiration, and of pity. At the beginning of the nineteenth century, however, the view of natural fools changed completely. They came to be classified as mentally ill. Consequently, books about natural fools such as *Claus Narr* were no longer read or understood. It is significant that in contrast to other examples of folly literature such as the *Ship of Fools* or the *Dyl Ulenspiegel,* Büttner's *Claus Narr* was not reprinted again. In the nineteenth century, the mental difference of natural fools became an object of medical and pedagogical institutions.

Literature about natural fools draws our attention to the fact that the concept of mental difference varies in history. It is therefore a fruitful source for disability studies as it serves to show the diverse constructions and functions once applied to mentally impaired people.

—Ruth von Bernuth

See also Fools.

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▣ LOBBYING

Lobbying is relatively easy to define but less easy to explain, carrying as it does many negative connotations as well as a fairly high capacity for being misunderstood. This entry provides a definition of lobbying, a discussion of lobbying restrictions imposed by U.S. federal legislation as well as IRS regulations, and an illustration of lobbying taken from the 1998 reauthorization of a major disability law.

DEFINITION OF LOBBYING

The term *lobbying* refers to engaging in activities directed toward public officials for the purpose of influencing legislation and/or policy. Three factors are involved in a lobbying activity:

- *The government activity being targeted:* "Legislation and/or policy" in the above definition refers to an array of federal, state, and local governmental activities, such as preparation and passage of laws; adoption and implementation of rules, regulations, and policies; awarding and administration of grants and contracts; and confirmation of individuals nominated for official positions (Lobbying Disclosure Act, sec. 1602, defs. [8]).
- *The public officials being lobbied:* The title of "public official" covers a range of government-affiliated positions in the executive and legislative branches, including legislators and staff, and department and agency administrators and employees (U.S. Department of Education n.d.).
- *The method being used to lobby:* Lobbying activities include not only in-person exchanges but also written communication and background work, such as the planning of lobbying strategies, analysis of bills, and preparation of position papers (U.S. Senate n.d., sec. 3).

In essence, all attempts to influence government action, to persuade public officials of the rightness of one's position, are defined as lobbying.

LOBBYING REGULATIONS AND RESTRICTIONS

Lobbying has had a prominent presence in American government since the nation's earliest days. (In the late 1700s, veterans of the Revolutionary War petitioned Congress for reimbursement of personal funds expended on the war effort. See Byrd 1989.) As citizens of a representative government, Americans have the right to let their legislators know how they feel about laws, bills, policies, and nominees for positions in government.

That said, lobbying carries what one historian has called a "somewhat sinister and pejorative connotation" (Maskell 2001, sec. 2). Of course, this connotation has to do with improper behavior between lobbyists and public officials. Regrettably, lobbying holds a great potential to result in preferential treatment. Impropriety in lobbying has been described in the most severe of terms, including unsavory, corrupt and contaminated, and reprehensible.[1] Certainly, records provide ample documentation of lobbying abuses, describing the frequently tawdry, occasionally startling, and too-often-successful attempts of lobbyists to win favor with legislators and other public officials (Byrd 1989).

The Lobbying Disclosure Act

The U.S. Congress's answer to lobbying corruption has consistently been regulation, with the first attempt instituted in 1876 (Byrd 1989). The most recent overhaul of lobbying regulations occurred in 1995 with passage of the Lobbying Disclosure Act. This law requires lobbyists to register, disclosing such information as the organization(s) they represent and the issues they are addressing. In addition, twice a year lobbyists must file reports updating this information and adding estimates of how much money they will spend. An organization that engages in lobbying—whether using members of its staff or board of directors as its lobbyists or employing lobbying consultants—may be exempted from registration if it meets minimum thresholds related to money expended, time invested, and number of lobbying contacts made with public officials. Lobbying, it should be noted, requires serious record keeping, whether registration is necessary or not.

IRS Restrictions on Nonprofits

> This topic [lobbying by nonprofit organizations] often results in two extreme actions—some people warn that if your organization does any lobbying you risk losing your tax-exempt status with the IRS. Other people don't exercise enough caution and do put their organization at risk with the IRS because they don't understand the restrictions on lobbying that pertain to their non-profit. So what is the answer? Can we or can't we lobby? The answer lies somewhere in the middle. (Community Health Assistance Resource Team n.d.)

As the above quotation shows, lobbying by nonprofit organizations is an area in which there is much confusion and misinformation, especially for small nonprofits without the funds to hire professional lobbyists. For example, the staff at the Independent Living Research Utilization Program in Houston, Texas, have been providing technical assistance in the field of independent living for nearly 30 years, and one question they have been asked innumerable times is, "Can a center for independent living do lobbying?" One can easily replace "center for independent living" in this question with descriptions of other kinds of organizations, such as a counselor association, parent group, university, physical therapist organization, or hospital. The answer is always the same: "Yes, of course, but . . . ." And this is followed by the advice, "Be sure to run your plan of action by an attorney who specializes in lobbying."

A careful reading of the IRS rules pertaining to lobbying activities by nonprofits may reduce the confusion and misinformation to some degree. The rules make it clear that lobbying is entirely appropriate, given certain caveats such as the following:

- Federal funds may not be used for lobbying (Office of Management and Budget n.d.).
- A 501(c)(3) organization may not be involved in political campaigns (such an organization is "absolutely prohibited" from either direct or indirect participation) (Internal Revenue Service 2004).
- The lobbying activities of a nonprofit must not constitute a "substantial" portion of its total activities (Internal Revenue Service 2004).

The penalties for violating these restrictions are severe: An organization may lose its tax-exempt status, its income may be subject to tax, and penalties may be imposed against the organization's officers having complicity (Internal Revenue Service 2004).

Are there conditions under which the IRS considers it acceptable for a nonprofit to advocate strongly for its beliefs? Yes, as specified in this IRS (2004) statement:

> Organizations may, however, involve themselves in issues of public policy without the activity being considered as lobbying. For example, organizations may conduct educational meetings, prepare and distribute educational materials, or otherwise consider public policy issues in an educational manner without jeopardizing their tax-exempt status.

A POSITIVE LOOK AT LOBBYING

Much of this entry has covered the negative aspects of lobbying—as action that is morally corrupt or as action that jeopardizes the existence of an organization. There is another side to lobbying, however; lobbying is often a laudable activity undertaken by people committed to improving our way of life. The following illustration, taken from the arena of disability rights during the 1998 reauthorization of the Rehabilitation Act,[2] is provided to show how lobbying has been used to improve law, to expand opportunities for consumers with disabilities to live more independently, and to protect the civil rights of these consumers.

Background. In 1986, Section 508 was added to the Rehabilitation Act. It requires governmental departments and agencies to use accessible equipment when creating, duplicating, and sending information. This includes computers, copiers, faxes, telephones, and just about everything used in a modern office. The problem, as seen by disability rights advocates, was that Section 508 had no enforcement provisions, making it nonbinding, and compliance was not overwhelming (Association of Tech Acts Projects n.d.).

Desired changes. Members of a number of organizations active in the disability rights movement wanted to take advantage of the Rehabilitation Act's 1998 reauthorization to have Section 508 strengthened in three respects: by requiring development of standards of accessibility that all equipment must meet, by permitting individuals to file complaints and lawsuits against noncompliant departments and agencies, and by applying these two conditions to state governments.

Government activity addressed. Disability rights advocates wanted very badly to influence the writing of the law so that Section 508 would be enforceable. And just as ardently, they wanted to influence the procedure by which the compliance standards would be prepared so that the access needs of people with visual impairments, mobility impairments, and cognitive impairments would be met. And, because members of the entity given responsibility for preparing the standards (the U.S. Architectural and Transportation Barriers Compliance Board) were presidential appointees, they wanted to influence who was nominated for membership so that people who truly understood accessibility barriers would be selected.

Outcome. Under the principle of "win some, lose some," Section 508 was strengthened through the inclusion of enforcement provisions and establishment of sound access standards; however, its enforcement coverage was extended only as far as the federal government and not to state governments as disability advocates had wanted.

At the same time lobbying activity was being undertaken to address Section 508, other organizations of people affected by and/or working in the disability and rehabilitation fields were taking action to address *other* sections and titles of the Rehabilitation Act. For instance, it is likely that associations of rehabilitation counselors wanted to increase training programs under Title III, that advocates of supported employment wanted to strengthen and ensure continuation of that program under Title VI, and that researchers wanted to increase funding under Title II. (The National Council on Independent Living, for example, had its excellent reauthorization position paper written and circulated among legislators more than a year in advance.) This is the American system of lobbying at its best.

IN CLOSING: LOBBYING AND ONE'S DUTY

When considering lobbying, Americans need to remember that lobbyists are exercising rights that are guaranteed to all persons living in the United States, particularly those rights assured under the First

Amendment regarding speech and petition (Maskell 2001). Nearly a hundred years ago, the 11th edition of the *Encyclopedia Britannica* included a discussion of citizens' involvement in lobbying, observing that "people who are most intimately concerned naturally have a right to appear before the legislature or its representatives, the committee in charge of the bill, and present their side of the case." Indeed, who better to advise Congress on legislation, policies, and programs that increase opportunities for people with disabilities than those who have spent a lifetime in support of disability rights? It is the right, privilege, and, some would say, the duty of citizens to take part in the development of public policy.

—Laurel Richards and
Lex Frieden

See also Advocacy.

Notes

The authors are indebted to Bob Michaels (1998) for his study of lobbying regulations and their application to centers for independent living.

1. Sources for these descriptions are, respectively, the *Columbia Encyclopedia* (6th edition), Maskell (2001), and the 1911 edition of the *Encyclopedia Britannica*.

2. When the Rehabilitation Act was amended in 1998, it was incorporated into the Workforce Investment Act as Title IV. Until that time, it had been a stand-alone law.

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LOHSE-WÄCHTLER, ELFRIEDE (1899–1940)

German painter

Struggles, crises, and catastrophes characterize the biography of painter Elfriede Lohse-Wächtler, whose work the Nazis condemned as degenerate in 1937 and was first rediscovered at the end of the 1990s. Born on December 4, 1899, in Dresden, Elfriede Wächtler grew up in a lower-middle-class family. During her studies at the renowned Dresdner Königliche Kunstgewerbeschule (Dresden Royal Art Academy) in the department of fashion and applied graphic arts, she moved into a studio in 1915 that became one of the main meeting spots for modern artists in Dresden. There she began to paint and draw using a variety of techniques—the beginning of work that spanned expressionism, verism, and New Functionalism. She could not survive off the income from her artwork alone, as it earned her only little money. In 1921, she married the painter and singer Kurt Lohse, and in 1925 she moved to Hamburg to be with him. The marriage was marked by frequent moves, economic difficulties, and Lohse's infidelity. The definitive break came in 1929, with the divorce occurring at Lohse's instigation in 1935 "due to incurable mental illness."

The years 1925–1931 were Lohse-Wächtler's most intense creative period and included a few public exhibitions. At the same time, her health grew increasingly worse. In 1929, she was admitted to the psychiatric state institution in Hamburg-Friedrichsberg for two months because of paranoia. After her release, she showed her portraits of fellow inmates in a successful exhibition titled Friedrichsberger Köpfe (Heads of Friedrichsberg). Isolated and impoverished to the point of homelessness, she created primarily (self-)portraits, nude studies, and milieu studies in 1930 and 1931. Without means and exhausted, she returned to her parents' house in 1931, and her father subsequently had her admitted to the regional psychiatric institution in Arnsdorf. There she was diagnosed with schizophrenia, a diagnosis that is disputed today. Although her confinement left her in a state of despair, Lohse-Wächtler continued her artistic work until she was forcefully sterilized on December 20, 1935, despite her own and her family's enraged resistance. On July 31, 1940, Elfriede Lohse-Wächtler was "transferred" out of Arnsdorf to the NS-"Euthanasia" Institution in Pirna-Sonnenstein, where she was murdered.

—Petra Lutz

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LÜ K'UN (1536–1618)

Chinese scholar and administrator

Lü K'un was a forward-thinking senior administrator in Northern China who worked to establish institutions that would relieve poverty and encourage self-help among aged or disabled people: "For those among the last who were not too young nor too old he prescribed training in skills like basketry or the braiding of mats" (Goodrich and Fang 1976). Lü also invested time and effort in didactic writing and publication to guide the masses toward better health and improved agriculture. He encouraged careful record keeping by physicians and government officials, so as to improve their practice. His particular concern for blind people arose from his mother's many years of blindness. "Lü ordered the officials of each city to train the blind in a profession such as music, singing, storytelling, and fortune telling" (Goodrich and Fang 1976). He had no personal faith in fortune-telling, yet he "compiled a simple textbook from which the younger people among the blind might be orally taught" (Goodrich and Fang 1976). These were innovative attitudes and practices in his time, with some parallels to contemporaneous social thinking in Western Europe.

—Kumur B. Selim

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LUTHER, MARTIN (1483–1546)

German church reformer and scholar

Martin Luther, the German church reformer, polemicist, scholar, and pastor, is linked in some disability literature with an oral suggestion about killing a severely disabled boy who was considered not human but a changeling—that is, a devil exchanged for a child (LW 54:397). The report comes from a source notorious for editing and altering some of Luther's conversations (LW 54:ix–xxiii), yet Luther's writings do underline his belief in satanic powers of deception (LW 3:244; 24:74–75; 26:190). The "changeling" idea may derive from academic constructions, mistakenly attributed to folklore. Luther's much-loved personal assistant through most of his working life was a man with mild disabilities, Wolf Sieberger. Luther strongly advocated the inclusion of deaf or disabled people in church life. He believed that their spiritual qualities are in no way impeded by their physical condition (LW 30; 54:460; 35:110–111; 45). An overview of evidence suggests that Luther's attitudes and practices toward disabled persons were largely positive, although some of his views may seem strange in the twenty-first century.

—Kumur B. Selim

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LUXEMBURG, ROSA (1871–1919)

German revolutionary and journalist

The German socialist, revolutionary, and journalist Rosa Luxemburg was born on March 5, 1871, in the province of Zamosc in Russian-occupied Poland. She came from a Jewish family. After acquiring an illness at age five, she walked with a limp. In addition, she was noticeably small. Even as a young student, Luxemburg was active in politics. After fleeing Poland, she studied economics in Zurich and received a doctorate in political science. In Zurich she also became acquainted with Leo Jogiches, who became her lifelong companion. She obtained German citizenship through a sham marriage with another man.

From 1898 on, Luxemburg lived in Berlin, where she quickly became one of the most important politicians of the Social Democratic Party of Germany (SPD) and the left-wing party's leading representative. In spite of her disability, she undertook exhaustive election campaigning, gave rousing speeches, lectured at the party school, and positioned herself as an outstanding journalist, uncompromising—although her work was eventually futile—in her stances against war and for international solidarity. During this time she was the subject of numerous personal attacks. Her opponents—as well as members of her own party—attacked her heritage and her appearance, reviling her as a "small, ugly Jew." Luxemburg spent the majority of the World War I period in prison, with her feelings fluctuating between resignation and hope. Deeply disappointed with the SPD, in 1918 she became one of the founders of the German Communist Party (KPD). Right-wing Freikorps officers murdered Luxemburg (together with her fellow KPD member Karl Liebknecht) on January 15, 1919, in Berlin during the height of revolutionary unrest. Her corpse was first discovered months later in a Berlin canal and was buried in June 1919 at the behest of a highly sympathetic populace. Perhaps the most-often quoted statement from Luxemburg's work is this: "Freedom is always and exclusively freedom for the one who thinks differently."

—Hedwig Kaster-Bieker

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M

▣ MACE, RONALD L. (1942–1998)

American architect

Ronald L. Mace was a design visionary whose life as a disabled person influenced the focus of his life's work and shaped the genius of his architecture and product designs. He was a driving force behind the creation of the first accessible state building code in the United States (in North Carolina) in 1973 and in the drafting of national accessibility codes and standards. He later coined the term *universal design* to capture and promote his expanded philosophy of "design for all ages and abilities," which applies to all aspects of design—architecture, landscape, graphic, and product design.

Mace contracted polio at the age of nine and subsequently used a wheelchair for mobility; he personally experienced how inaccessible environments limit a person's ability to participate in the world. After graduating from North Carolina State University School of Design in 1966, he was the first to put a human face on access guidelines by using well-rendered, human-centered illustrations. Mace and his consulting firm, Barrier Free Environments, did pioneering work in accessible, or barrier-free, design focused on improving accessibility in the built environment so that disabled people could participate in the life of their communities. In 1988, Mace was named a Fellow of the American Institute of Architects for that groundbreaking work. He was also influential in drafting the 1988 Fair Housing Amendments Act and the 1990 Architectural Guidelines of the Americans with Disabilities Act, which require basic accessibility in the built environment for future generations. In 1992, he was honored with the Distinguished Service Award of the President of the United States for promoting the dignity, equality, independence, and employment of disabled people.

In his training of architects and designers around the United States, Mace emphasized that accessible designs make life easier for everyone—curb cuts being his favorite example. As his vision expanded, the North Carolina State University Center for Accessible Housing, founded in 1989, became the Center for Universal Design to reflect its expanded work in promoting the integration of the principles of universal design into all aspects of the design profession. Shortly before Mace's death on June 28, 1998, on the occasion of the first international conference on universal design, he was honored by designers from all over the world who had embraced his vision of designing for all people.

—*Joy E. Weeber*

See also Accessibility; Accessibility Codes and Standards.

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MACKENZIE, CLUTHA (1895–1966)

New Zealander blind activist

Clutha Nantes Mackenzie spent his youth in New Zealand as a farmhand and sailor, though his father was a senior politician and diplomat. Clutha lost his sight in 1915 during a World War I battle in Turkey. He went to St. Dunstan's in England for rehabilitation and practiced writing and magazine editing. His future wife, Doris, was a St. Dunstan's volunteer. Clutha returned to Auckland, New Zealand, and worked from 1923 to 1938 managing the Jubilee Institute for the Blind, fund-raising and campaigning for blind people to live independently. His autocratic style caused some problems, but his work was successful and he was knighted in 1935. His international career included lecturing and fund-raising across the United States, then six years in India, where he opened St. Dunstan's Center at Dehra Dun in 1943. He held a special government post to study and report on blind education and employment, and engaged in battles to determine which form of Braille would be adopted in India and internationally. In 1947, he toured China, producing a substantial report on blind people there. He advised other Asian countries, reported on blindness in Turkey in 1952, and a few years later was mobilizing services for blind people in East Africa. Clutha retired to New Zealand in 1958.

—*Kumur B. Selim*

See also Blind, History of the; Experience of Disability: India.

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MADNESS AND MENTAL DISTRESS

While Western understandings of disability have been subjected to fundamental reassessment in recent years, the medicalized individual model of "mental illness" continues to dominate mental health policy and practice internationally. It still shapes public understandings of "mental health" and governs the lives and experience of many mental health service users. In contrast, mental health service users/survivors and their organizations are increasingly expressing their concerns about medicalized individual models of "mental illness" and framing their experience in different terms. Yet traditional "mental illness" understandings of their experience seem, if anything, to be gaining ground. They have been exported to the majority world. They have been reinforced by the introduction of a new "recovery" model for mental health services developed in the United States.

THE MAINTENANCE OF MEDICAL DOMINANCE

The number and range of psychiatric diagnostic categories continues to mushroom. These increasingly cast broad socially related issues in medicalized terms, for example, attention deficit/hyperactivity disorder (ADHD) and posttraumatic stress disorder (PTSD). The needs of a growing range of groups, notably children and young people and older people, are being framed in psychiatric terms. While making clear that it cannot "treat" them, psychiatry has also categorized a growing range of people and behaviors under the heading of "personality disorder." Some of these are closely associated with violence and homicide. This has reinforced traditional associations of mental health service users with dangerousness, which has resulted in pressure for increasing restrictions on their rights, most notably in North America and the United Kingdom.

A growing focus on and recent developments in genetics, the neurosciences, and pharmacology seem to have confirmed the ascendancy of the natural sciences in this field as the key source for understanding, interpretation, and "treatment" of "mental disorder." Doctors are still the most powerful professionals operating in this area. Understanding mental disorder in terms of physical processes fits with the large-scale use of drugs as the main and routine response to people's difficulties.

One of the consequences of the development of organizations and movements of mental health service users/psychiatric system survivors since the 1980s has been the emergence of new challenges to and new critiques of conventional medicalized understandings of "mental health." These have been qualitatively different from previous critiques of the dominant paradigm, such as "antipsychiatry" and the "social constructionism" of sociologists, which have tended to come from dissident professionals, competing professions (e.g., psychology), and related academic analysts. These new challenges have been based primarily on service users'/survivors' understandings of their own experience—their experiential knowledge.

It is important to emphasize, however, that so far, no equivalent of the social model of disability has been developed among mental health service users/survivors that could provide a systematic and philosophical basis for their activities. While it is still a focus for much debate and controversy, the social model of disability has offered disabled people just such a coherent basis for their philosophy, self-organization, and collective action, reflected in their focus on rights and independent living. The social model of disability, however, has not as yet adequately been extended to address and explain the related, but also distinct, issues facing mental health service users/survivors. Thus, while "mental health" issues and the situation of mental health service users/survivors have sometimes been incorporated in the social model of disability by its proponents, so far this model has not been accepted widely by mental health service users/survivors as providing a satisfactory conceptual framework for their experience.

It is not clear why, as yet, mental health service users/survivors and their organizations have not developed a coherent alternative to the medicalized model of "mental illness." While the latter may be the only model for understanding with which many mental health service users/survivors are familiar, there also seems to be an unwillingness on the part of many activists to develop an explicit alternative. One view is that this may be linked with fears that to do so would be interpreted from outside as an attempt to deny their difficulties or difference and lead to their being further marginalized as lacking in insight and rationality.

Mental health service user activists have tended not to challenge the dominant medicalized framework explicitly. They have themselves frequently continued to operate within a framework of terms such as *mental health, mental health problems, difficulties,* and *issues.* However, they have also shown a growing unease with the traditional medicalized model, particularly as it has been linked with an increasing emphasis on social control and the extension of restrictions on mental health service users' rights and freedom.

For a growing number of mental health service user activists, the inherent problem with a medicalized approach to "mental health"—even the descriptor is itself medicalized and value laden—is that it is based on a *pathologizing* construct. The underlying construct that dominates "mental health" policy, provision, practice, and service users is one of "psychopathology." It is possible to be persuaded that this is not the case, because terms such as *mental illness, mental disorder,* and *psychopathology* are less often and less explicitly used nowadays. But the origins and meanings of the terminology remain unchanged. The legal base that operates tends to be the same. Law and policy rest on the premise that there is something "wrong" with the person. He or she is "ill." The individual's experience, behavior, perceptions—the person *him-* or *herself*—is pathologized. This is how people also come to understand themselves as mental health service users.

DEVELOPING ALTERNATIVE APPROACHES

The lack of a clear and agreed-upon conceptual framework has not stopped mental health service users and their organizations from developing their own alternative culture, discourses, and schemes for support. These have generally been based on nonmedicalized models, highlighting a holistic, complementary approach to providing support for mental health service users/survivors. Such schemes have placed an emphasis on peer and self-advocacy, self-defined needs, self-education, self-management, and self-support. They have led to the development of self-run crisis houses and refuges, survivor-led supported housing schemes, environmentally friendly employment, training and skill exchange schemes, programs employing mental health service users as mental health workers, crisis cards and advance directives, mutual aid and self-help support groups, and peer counseling. However, the lack of a clear and agreed-upon philosophy underpinning these developments has sometimes made it difficult for service users/survivors and their organizations to avoid being co-opted and their goals and ideas subverted by dominant medicalized service systems and their agendas, with which they have frequently worked in close association.

Mental health service users/survivors and their organizations have also developed their own alternative terminology, framed in terms of "madness" and "mental distress" rather than "mental health" or "mental illness." Survivors' use of terms such as *mad* and *distress* seems to reflect a desire both to move beyond the medicalized individual understanding of their situation and experience and, in the case of *mad,* also to reclaim language that continues to be used to marginalize and demean them. *Mad* is just one of a constellation of pejorative terms used to describe mental health service users and the behaviors associated with them—a constellation that includes terms like *loony, crazy,* and *nuts.* Such terms are also still used widely in popular discussion to mean weird, frightening, outlandish, unpredictable, and irrational.

MADNESS AND DISTRESS

In different cultures and historically, madness has been interpreted and understood in many different ways. It has been associated with magical powers, the supernatural, divine intervention, possession by the devil, violence, irrationality, spirituality, and special gifts and insight. It has been seen in both negative and positive terms. If once it was treated in the West as a condition of the whole person—body, mind, and spirit—more recently it has generally been diagnosed as a disorder of the brain. Responses have been spiritual, secular, and morally based, according to the society in which madness is identified, based on both superstition and elaborate theories. It has also long had a parallel embodiment in the law, in terms of "insanity," "incapacity," and "lack of responsibility." Such legal status has served both as a basis for taking control of people's money, goods, and affairs and for the imposition of "treatment" regimes, including confinement, restriction of rights, and compulsory "treatment."

Mental health service users/survivors have yet to develop their own clear and agreed-upon definitions of *mad* and *distress,* although the terms have come to be widely used within their movement. Members of Mad Pride, a U.K. survivor network that organizes events and direct action and also produces publications, highlight their pride in being mad. This pride may be in being different, in surviving madness, in surviving the mental health system, in having unusual sensitivities or capacities, in having capacities to an unusual degree, or in having a different way of life or approach to life—an approach that may be unconventional or anarchic, open to a wider range of experiences, or experienced more intensely.

Madness can be viewed as an equivalent of "psychosis," although not all survivors would be happy with the concept's being appropriated in this way. As mental health service users/survivors discuss it, madness may have many expressions. It may be a one-off experience, episodic, or long-term. In all these cases, people may report positive aspects of their madness. They may value their experience and perceptions, discovering helpful aspects, for example, to hearing voices or learning how to live with them. They may feel that their positive qualities and abilities are linked with and inextricable from the fact that they experience madness. Such experience, however, may also be negative and costly, restricting what people can do, linked with difficult and painful thoughts and feelings and associated with crises and problems.

Mental health service users talk about both "mental" and "emotional" distress. Such distress is associated with pain, sorrow, and anguish. It is difficult to conceive of distress as a positive, although it may be seen as part of a learning process, or as a predictable human response, for example, to loss and bereavement. Anxiety and depression are two common expressions of such mental distress. Distress may be a short-term/crisis event or a long-term state. People may also experience physical distress. A distinction may need to be drawn between mental and physical distress, but it is also possible that one may be interlinked with the other.

Mental health service users/survivors have a tendency to combine the two terms *madness* and *distress* when they are seeking to offer their own conceptualizations of their identity and situation. This seems to relate to a sense that neither term adequately carries the full range of experience and meanings that they wish to convey (and that are associated with being on the receiving end of mental health services). Just as distress may not always be "maddening," so madness may not always be distressing. Thus, "madness and distress" may represent a single construct rather than two. It is important to take account of this, because there is some tendency to treat "madness" and "distress" as mirroring traditional medicalized psychiatric and psychoanalytic concepts of psychosis and neurosis.

Treating the two sets of terms as interchangeable in this way is unlikely to be helpful or accurate. One of the aims of survivors in developing new language has been to challenge rather than retain traditional categories. Treating "madness" and "distress" as distinct and separate categories is likely to reinforce existing (unhelpful) distinctions between the worried well ("us") and the mad ("them" and "other"). The terminology of mental health service users/survivors is intended to be inclusive rather than divisive. In this, it reflects the same concern as that expressed by many members of the disabled people's movement, to avoid being "impairment specific," or, in this case, to privilege diagnostic categories and to focus instead on shared concerns and common processing.

It is also questionable whether there are clear boundaries between ideas of "madness" and "distress" or "distress" and "madness" that could demarcate a distinct group of mad people or madness. The boundaries are likely to be as imprecise and socially constructed as those that relate to perceptions of physical and sensory impairment. It is also helpful to remember that the terminology of mental health service users has an underlying political purpose. The term *psychiatric system survivor* highlights this. It was developed to emphasize that what individuals in this group have in common is primarily their (frequently oppressive) experience and (hopefully) survival of the psychiatric system.

THE EMERGENCE OF A NEW SOCIAL MODEL

Mental health service users/survivors and their organizations are showing increasing interest in the social model of disability. This seems to relate to their growing focus on the barriers and restrictions to their rights they currently face. These do not seem to be diminishing significantly and in some cases are experienced as increasing. Mental health service users/survivors experience disproportionately high levels of poverty, unemployment, homelessness, and social isolation. They are subject to high levels of stigma, institutionalization, and imprisonment. In Western societies, black and minority ethnic mental health service users/survivors face additional discrimination and disadvantage. Policies of psychiatric decarceration (without the provision of adequate alternative support services) have led to political pressure internationally for the extension of restrictions on mental health service users'/survivors' rights and compulsory "treatment." This provides the context for their growing interest in a "social model of madness and distress."

The terminology of "madness and distress" provides a helpful nonmedicalized framework for a social model. Such a social oppression/barriers approach to understanding "mental health" represents a break with traditional social approaches. These have tended to focus on social factors in the generation and conceptualization of "mental health problems" rather than on social oppression. Discussion of a social model of madness and distress is still at a relatively early stage, but it has already highlighted two issues that need to be addressed. First, some mental health service users/survivors do not see themselves as having any kind of "impairment" or equivalent. They may not accept the idea of "madness" as a discrete, objective state, or they may reject the idea of it as a negative or a problem. Instead, they interpret madness as essentially a consequence of societal responses to particular people, perceptions, or situations. The view of some disabled commentators that impairment may most helpfully be understood (like disability) as socially constructed—as *perceived* impairment—may offer a helpful way of taking account of this viewpoint.

Second, some mental health service users/survivors have emphasized that psychiatric labels and diagnostic categories have traditionally been attached not only to people whose behavior is seen as pathological, defective, or different but also to those whose behavior, perceptions, or attitudes are defined as deviant, dissident, or nonconformist. Demonstrating compliance (rather than resistance) continues to be an effective way for service users to be seen as getting "better" or "recovering." It is important to note, for example, that some women's sexual behavior and the sexuality of gay men, lesbians, and bisexuals have until recently been formally and specifically identified and "treated" in the West as forms of psychopathology. This had an extreme expression in the former Soviet Union, where political dissidents were consigned to the psychiatric system.

Thinking about a social model or approach to madness and distress is still at an early stage, and it would be wrong to suggest that as yet any clear or agreed-upon definitions have been developed. Such discussion is, however, developing. Such a social model is likely to be located within the framework of a social model of disability that is extended to accommodate it. Its increased adoption is likely to have at least three significant effects. First, judging from the experience of the social model of disability, such a social approach to understanding is likely to alter the focus in mental health policy and practice and among mental health service users/survivors. It is likely to shift it from a preoccupation with individual deficiency and blame to broader social concerns. It will draw attention to restrictions imposed on mental health service users' rights and the barriers and discrimination they face—which medicalized responses have generally failed to do. It is also likely to encourage reconsideration of "mental health" issues in terms of (ongoing) support and "independent living" rather than in terms of "treatment," "cure," and "recovery."

It is also to be expected that if it is possible to develop such a social model, which carries credibility and consensus among mental health service users/survivors, it will offer them (in the same ways as the social model of disability has helped disabled people) a clearer and more consistent philosophical basis for their activities and resources. This is important given the limits of such resources and the resistance of the psychiatric system to reforming its tendency to incorporate and tokenize the efforts of service users/survivors working in partnership with it. A social model of madness and distress is also likely to strengthen links and understandings between mental health service users/survivors and other disabled people, as well as increase the sensitivity of mental health policy to social model–based disability policy. On this basis, the concept of madness and distress can be expected to have increasing currency and significance.

—Peter Beresford and Peter Campbell

See also Mental Health; Mental Health: Law and Policy; Mental Illness; Psychiatric Survivor Movement.

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MAINSTREAMING

The term *mainstreaming* emerged within the educational jargon associated with the 1975 Education for All Handicapped Children Act (EHA, P.L. 94-142), the early U.S. legislation subsequently reauthorized as the Individuals with Disabilities Education Act (IDEA) in 1990. Mainstreaming was a component of the principle of the least restrictive environment (LRE) clause of the EHA, which aimed to promote the social acceptance of students identified for special educational services. However, the context was one in which students identified as needing special education services were typically removed from the general education classroom and, depending on need, reassigned to resource rooms for 21 to 60 percent of the school day or to disability-specific classrooms when student needs exceeded placement for more than 60 percent of the school day. Students with mental retardation were placed in an MR class, those classified with educable mental retardation were assigned to an EMR class, those with emotional disturbance (as per the vernacular of that era) were assigned to an ED class, those with health impairments were placed in an OHI class, and so forth. These labels—*Resource, MR, EMR, ED, OHI*—were affixed to classroom doors in much the same way other doors read *First Grade, Second Grade, Library,* and so on. In turn, this context normalized practices such as placing students beside placards that read "Resource Class," "MR Class," "OHI Class," and the like when they posed for their annual class pictures. Likewise, students became known as LD, MR, or ED students. Despite early warnings by a handful of special educators about the negative effects of the overuse of labels, most general and special educators seemingly viewed the labels as nothing more than benign markers—mere terminology formulated through the legislation of the EHA.

Decades would pass before the critical insights of scholars exposed the language of special education as a powerful mechanism that enforced subjectivities associated with assigned labels and the presumption of stigma. Although touted as a policy that guaranteed all students would have access to the least restrictive environment, this naive interpretation of the law became a controversial and contested practice by both general and special educators.

AIMS AND INTENTIONS

The vexed meaning of mainstreaming was compounded by the ambiguities of the EHA and the subsequent state and local interpretations that followed. Moreover, the EHA had unwittingly authorized the creation of two separate systems of education (which continue today), each with its own funding structures, policy and practice standards, and, most critically, distinct teacher preparation programs. In practice, the aims and intentions of mainstreaming were difficult to articulate as the goals that were established quickly proved antithetical to the everyday demands of schooling. Special education advocates urged a three-pronged approach to mainstreaming in which physical, social, and academic considerations would be merged. Thus, a disabled student would have access to receive his or her education in proximity to the *place* where other students received their education—regardless of the child's disability. *Place* was clarified as meaning the same building and same neighborhood school, regardless of its population as a preschool, elementary school, junior high school, middle school, high school, or technical school. *Social* suggested participation in the common social activities of the school in nonacademic settings, including interactions in the hallways, cafeteria, library, and playground—that is, interactions within the general social milieu of the school. The third prong of mainstreaming was specific to instruction and the general curriculum. During the 1970s, the general education curriculum was less restricted by mandates for standardization of instruction and educational outcomes than is the current curricular context. It was argued then that because students in regular classes are not all taught the same things at the same time, modification of the nature, method, rate, and procedures was commonplace for all students, and, hence, it was equally an option for students identified with special needs.

In practice, general educators rarely considered these integrative criteria, as mainstreaming proved antithetical to the everyday demands of schooling. Instead, the return of special education students to the general education setting was authorized only on the condition that the students demonstrate the "right" to return. The motivation for this approach to mainstreaming was bureaucratically driven—it was a means to ensure that general education teachers would not be stressed by the demands of disabled students who, as a consequence of mainstreaming, might jeopardize the learning of nondisabled students. A rights discourse soon emerged, but it was one that pitted the rights of the general education students against those of special education students. Fear led to educators' claims of "injustice" and imagined harm inflicted on the rest of their students as a consequence of the perceived negative impact of mainstreamed students. Moreover, citing the lack of credentials, general education teachers claimed they were ill prepared and actually unable to accept disabled students back into their mainstream classrooms. Arguing to these same ends, professional teachers' organizations warned their members to be on guard against the "hazards" of mainstreaming. In 1975, the same year the EHA was authorized by Congress, the president of the National Education Association described the "plight" of a teacher who is "suddenly and for the first time presented with a blind child, a spastic, an emotionally disturbed child—or even all three—as additions to the 40 'normal' students" (quoted in "NEA Warns" 1975). The NEA urged its members to support mainstreaming only if the plans in their districts met several specifications that guaranteed a "favorable" learning experience for both handicapped and nonhandicapped students.

Implicit within this debate was the belief that the learning problems of disabled children stemmed from individual pathology rather than from instructional or institutional pathology. For the most part, general educators held firm to the belief that despite procedural safeguards, the general education setting was not an appropriate place for disabled students, arguing, "If they can't do the work, they don't belong here."

PROCEDURES AND PRACTICES

Mainstreaming proved to be one of the many paradoxes associated with the implementation of the EHA. Because special education was mandate driven, policy heavy, and procedure intensive—and thus a highly bureaucratized approach to education—legislation, litigation, and fiscal concerns easily diverted its educational aims. Compliance with the law focused on the formulation of paper trails to document adherence to the letter of the law. Meanwhile, the spirit of the law became increasingly more illusory. Mainstreaming was a sort of no-man's land, ill defined and poorly articulated by both general and special educators, in which neither would agree to assume responsibility for the mainstreamed student. After a tremendous investment of effort toward the identification, assessment, referral, and placement of students into special education, neither general nor special education teachers were persuaded by the logic of orchestrating these students' return to general education. Once a student was identified with special education needs, he or she was removed from the general education classroom in order to receive "specialized" instruction in separate self-contained classrooms with specially trained teachers. The processes of identification, assessment, referral, and placement, although hailed within a rights discourse of "hard-won educational access," in fact often resulted in restricted access to general education. It was paradoxical that once a student was physically relocated to special education, his or her "right" to return to general education was authorized only on the condition that the student demonstrate the ability to meet the existing academic goals in place for nondisabled students.

Another related paradox emerged as educators questioned why a student would want to return to general education if his or her academic success was all but ensured in special education through the development of an individualized education program (IEP). Identified students received their education in what was often characterized in the special education literature as a "learning-intensive environment." The norm for this setting included small class sizes, specialized instruction, paraprofessional support, modified curriculum, and prescriptive technology targeted to meet individual student needs. This learner-centered setting stood in opposition to the teacher-centered general education classroom, which was neither intimate nor individualized. In fact, this was a persuasive selling point, both for the recruitment of special educators and for the parents of identified students, who tended to overlook the isolation their children would experience in separate self-contained classrooms. Moreover, because instructional remediation was predicated on a positivist approach to intervention, with treatment aligned to a medical model, it was assumed that this more "scientific" and "prescriptive" approach to learning would promote "individual" gains in ways uncommon to general education.

Indeed, the approach to learning in special education was one in which tasks were broken down into various component parts, each of which was then indexed in a hierarchy of simple to complex learning objectives. Students moved through the learning of bits of discrete knowledge on the assumption that more complete learning would result from this incremental approach. Exclusively behavioral models for learning—including task analysis, direct instruction, drill and practice, and rote memorization—formed the core of special education instruction. Accompanied by the use of reward systems and token economies, these practices reinforced the view that student learning in bits and pieces took precedence over contextualized learning within a broader holistic and emancipatory framework. The pedagogy, methodology, and learning context in special education and that common to the mainstream setting proved to be worlds apart.

Government-sponsored research on effective educational practices was another legitimating force that helped to shape the chasm between general and special education. Federal dollars allocated to university researchers privileged positivist methods over integrated and holistic approaches to learning, which in turn advanced a reductionist approach to learning and prompted calls for even greater specialization among professionals. Unwittingly, this government-sponsored research reified the belief that a "highly qualified teacher" is most capable of educating disabled students. Curiously, the link between the university-based researchers and their institutions' agendas specific to the expansion of their own teacher training programs was never questioned as a conflict of interest. The long-term effect of an overreliance on the traditional empirical research generated by many of the nation's largest academic programs in special education was the reinforcement of the beliefs that some students really *do not belong* in regular education and that some, but *not all,* teachers are responsible for all learners.

In time, this research fed the deeply entrenched attitudes that continue to divide general and special educators today. It is a belief that has proven to be one of the greatest obstacles to the inclusion of disabled students in public education. Ultimately, the goal of successfully mainstreaming identified students proved increasingly more difficult to realize as these students fell further and further behind their general education peers on both social and academic measures. The initial belief that identified students might eventually rejoin the mainstream when their learning deficits had been remediated was all but extinguished by shifting attitudes relative to who does and does not *belong* in the mainstream classroom.

—Linda Ware

See also Education, Primary and Secondary; Education and Disability; Race, Disability, and Special Education; Special Education.

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MANAGED CARE

For persons with physical and mental disabilities, managed care presents both a threat and an opportunity. Persons with disabilities have much to gain from truly and responsively integrated managed care health delivery systems. However, persons with disabilities also bring atypical, complex, and, in many cases, long-term service needs that managed care organizations may be reluctant to address because of the increased clinical and financial risks these needs represent.

The origins of managed care can be traced to the late nineteenth century, when a small number of physicians in several U.S. cities agreed to provide prepaid medical care to members of fraternal orders, unions, and other associations of workers. The physicians gave the members of these organizations unlimited access to the health care services they provided in exchange for a small annual fee per member. In the early twentieth century, railroad, mining, and lumber companies organized their own medical services or contracted with medical groups to provide care for their workers. During the Great Depression of the 1930s, prepaid contracts between employers and employee associations were relatively common. Starting in the 1970s, the federal government and many large private companies began encouraging their workers to join prepaid forms of health care groups. Despite this encouragement, however, prepaid group practice grew slowly. In the mid-1980s, employers increasingly turned to managed care to contain the spiraling cost of providing health care benefits to workers. During the 1990s, managed care enrollments soared. Today, the vast majority of privately insured Americans, and a sizable fraction of those in the government-sponsored Medicare and Medicaid programs, are covered by some form of managed care.

Despite the large number of persons enrolled in managed care programs, it is difficult to define precisely what managed care is. The definition of managed care has changed significantly through time as the concept of managed care has evolved. Currently, managed care can be broadly defined as any organized system of health care that attempts to reduce or eliminate services that system representatives deem ineffective or unnecessary in order to hold down costs while at the same time maintaining high-quality health care. Most managed care is carried out in one of two basic types of health care organizations: health maintenance organizations (HMOs) or preferred provider organizations (PPOs).

Managed care organizations use a variety of methods of financing and organizing the delivery of health care to control costs. Specifically, managed care relies primarily on three strategies for success: selective contracting, innovative economic incentives, and utilization review.

To develop selective contracts, managed care organizations use health care claims data to compare the prices that different hospitals and physicians charge for the same treatments in order to identify the lowest-priced providers. In highly competitive health care markets with many providers, large managed care organizations with hundreds of thousands of enrollees can selectively contract with individual hospitals and physicians and receive substantial discounts for the provision of health care to their members. The providers are willing to give deep discounts to these organizations to avoid losing large numbers of patients. Providers also can retain or build a greater market share by giving these discounts.

Managed care organizations frequently provide innovative economic incentives to patients and physicians to encourage them to select less costly forms of health care. For example, organizations may require patients to obtain preauthorization before using hospital emergency rooms to receive care for specific conditions. They also may discourage patients from using higher-priced health care institutions such as costly teaching hospitals for routine care. To control costs, some managed care organizations, such as HMOs, put their physicians on fixed salaries. They can then adjust the salaries up or down annually based on performance, rewarding those physicians who contain costs and punishing those who do not.

To conduct utilization reviews, many managed care organizations have established their own sophisticated internal computer information systems that monitor provider prices and the quality of health care received by their enrollees. Many have also developed a variety of utilization review programs that include such elements as preadmission screenings (to determine whether a patient should enter a hospital or receive treatment elsewhere), surgical second opinions, and ongoing reviews of high-cost cases (such as patients with HIV/AIDS and those receiving complex cancer care).

Of the three strategies described above, the evidence to date clearly shows that selective contracting has been the most effective in lowering costs for managed care organizations. The evidence on innovative economic incentives is weaker, and evidence on the effectiveness of utilization review is virtually nonexistent.

Initially, managed care organizations targeted generally healthy populations, placing emphasis on maintaining health and preventing disease. Recently, however, managed care has moved into less traditional markets, including managing health care for individuals with chronic illnesses and various disabilities.

Managed care has the potential to be of great benefit to people with disabilities in comparison with traditional fee-for-service systems or typical government-sponsored programs. By its very nature, managed care tends to decrease or eliminate individuals' incentives to overuse services. It generally reduces patient out-of-pocket expenses and other financial barriers to health care. Managed care also has the potential to achieve better coordination of patient services. Given that most managed care organizations use the primary care physician to direct and structure the patient's total treatment, in theory the services provided should be more logical, customized, and prompt than they would be under other systems. Thus, under managed care, persons with disabilities should experience less frustration and confusion from splintered service provision, which can be commonplace in public programs. Managed care, through its use of internal computer information systems, also has the potential to monitor the quality of care and assess the performance of both individual patients and their physicians more efficiently. Finally, some managed care organizations provide transportation services for patients between their homes and the facilities where they receive care. These services may be vital for patients with major disabilities, especially those who live in areas without any public transportation.

Managed care also poses a number of formidable problems for people with disabilities, however. For example, managed care organizations may design and direct their marketing programs to attract only generally healthy populations. They may overtly and covertly discourage enrollment of individuals who are likely to be users of costly health care services. Because patients with disabilities may be frequent users of specialists and other high-cost medical services, managed care organizations may view them as undesirable patients.

As noted above, managed care organizations typically use primary care physicians as "gatekeepers" to control access to care. These physicians may not have the necessary experience or expertise to address the unique needs of people with diverse physical and mental disabilities. Further, they may not have the time or inclination to provide care to such patients.

With their emphasis on primary care and cost containment, managed care organizations may not provide people with disabilities adequate access to needed specialists who are qualified to diagnose and treat their special health care conditions. For example, managed care organizations may stop referrals to psychiatrists, who tend to provide more comprehensive treatment than other mental health professionals. In addition, the complexity of managed care organizations' referral procedures and complaint and grievance processes, and the materials that describe these aspects of managed care, may create tremendous barriers for individuals with cognitive or learning disabilities.

Because managed care organizations deal primarily with the needs of healthy people, they may use definitions of "medical necessity" that work against people with disabilities. For example, they may apply criteria that call for "substantial improvement" or "restoration of function" as conditions for the authorization of treatment, medication, or medical equipment. This may discriminate against individuals with certain types of physical or mental disabilities who cannot meet these standards.

Managed care organizations may have narrow short-term business perspectives that ultimately may result in decisions that harm people with disabilities. Because many of these organizations operate on a for-profit basis and so must generate an appropriate return on equity to their owners or shareholders, administrators may be under great pressure to hold down short-run costs. To do so, they may deny patients access to ongoing ancillary services, such as speech, physical, and occupational therapies, or they may withhold costly medical equipment from individuals with disabilities who truly need them. These patients may suffer in the long term because of these shortsighted decisions.

To date, no rigorous scientific evaluations have conclusively demonstrated that managed care has improved the quality of life or the health outcomes of persons with disabilities.

—*Ross M. Mullner and Kyusuk Chung*

See also Health Care Systems; Health Management Systems; Political Economy.

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MARTHA'S VINEYARD

See Deafness, on Martha's Vineyard

MATERNAL IMAGINATION

Maternal imagination is the concept that oddities in infants occur as the result of thoughts by the mother during parturition. Although the interpretation of maternal imagination as a root cause for birth anomalies does not wholly refute the idea of supernatural causation, it does signal a move toward scientific formulations of the etiologies for congenital disabilities. Any kind of parental blame spells difficulty for disabled persons, who may thus have their lives less welcomed than those of others. Maternal imagination is different, however, from the perception that corporeal differences are signs from a supernatural realm or harbingers of danger.

The theory of maternal imagination hinges on an understanding of women's bodies as highly susceptible to powerful external events, and tales about such susceptibility abound in the literature. According to such stories, a pregnant woman exposed to traumatic or highly sensitive stimuli can translate those impressions to the developing fetus. A pregnant woman who is startled by a frog, for instance, could imprint her impression onto the body of her child; that is, her child's body might manifest physical evidence of the event, such as webbed toes or fingers or a froglike head. A woman who gazes too obsessively at a portrait of Christ might be shown her excess by giving birth to a bearded child. Thus, perceived corporeal strangeness in the infant also reflects back to the mother a “lesson” concerning her affect and demeanor. Contemporary scholars discuss how explanations based in maternal imagination theory nonetheless bestow on mothers an extreme amount of control over the plasticity, form, and shape of their children's bodies. While the theory holds woman culpable for the appearance of congenital disability, it does usurp a small aspect of the patriarchal belief in the supremacy of male seed in the gestation process.

This early etiological theory of disability was most influential during the early European Enlightenment, which occurred from the late sixteenth to the early eighteenth century. Nonetheless, one can find similar theories of women's impact on parturition across histories and cultures. The early Latin story of Marulla and Cinna, who gave birth to seven monstrous children, provides a prime example of the adulterous mischief of mothers reflected in the strange aspects of their children, but it is not a matter of the sensibility or emotional experiences of a mother imprinting themselves onto a life-form. Instead, Cinna bears the blame for producing strange children by deliberately cavorting with one who is a “natural” and “black” or “red” children by crossing codes of color conformity: “Two sisters, one black, the other red, are Crotus the flautist's and Carpus the bailiff's. You would now have a troop as numerous as Niobe's, if Coresus and Dindymus had not been eunuchs.”

Debates about the prevention of birth defects continue to emphasize the behavior and habits of the mother during pregnancy. Many environmental causes or congenital properties are assigned to maternal habits and modes of existence; for example, low birth weight in newborns is now frequently determined to result from maternal stress. Babies that are deemed to mix skin tones in racially polarized societies can be held out as a matter of maternal impropriety. In Third Reich Germany, German mothers of *mischling* children, whose fathers might be African, Jewish, or Romany, were publicly shamed and punished. The children themselves were frequently sent to institutions that participated in genocidal "cleansing" of the German "race."

Throughout the Renaissance and premodern period, "monstrous births" were often attributed to maternal imagination, although they were sometimes linked to other "mechanical causes," such as a narrow uterus or inappropriate sitting positions of gestating mothers. The stuff of bawdy songs and legend, such births were sensationally cataloged in publications called "wonder books." Fortuno's *Monstrum* (Italian, 1646) and Pare's *Of Monsters and Marvels* (French, 1585) contain well-known and quite remarkable examples. The wonder book collected instances of strange and unnatural occurrences for prurient audience interests in observing disability. These early Enlightenment books served to mediate between more metaphysical systems of disability interpretation implied by ideas about divine or satanic intervention in fetal developmental processes. While fanciful to a viewer from the twenty-first century, they indeed anchor developing empirical systems of medical observation. Wonder books served as transitional texts between supernatural explanations and more "naturalistic" explanations for what we recognize as congenital disability today, while unsure of any belief for supernatural purposes.

One perspective always absent from the wonder book was that of the "monstrous" individual—instead, each figured as a "marvelous" specimen. We can start to piece together a tradition of voiced commentary by subjects in dramatic and poetic traditions. In Shakespeare's *Richard III,* the protagonist contemplates his own birth predicament as "scarce half made-up." Abandoned at birth, Quasimodo, the title character in Victor Hugo's classic novel *The Hunchback of Notre Dame,* is sealed off from contact with other townspeople. In a journalistic interlude quoted verbatim by William Carlos Williams in his epic poem *Paterson,* George Washington visited a man with severe hydrocephaly to trade quips on late-eighteenth-century American politics. In each of these instances, an individual deemed a "monstrous birth" begins to give voice to a nuanced, self-reflexive perspective. Such entries in the Western literary canon also forward these perspectives as disruptive moments to competitive versions of the normalcy of a national "stock" in which early modern nations, with census taking of disabled persons, engaged.

The debate over maternal imagination as a reliable, scientific barometer for birth anomalies largely circulated around medical theorizing about the degree to which fathers could be held culpable for "disastrous" births. Marie-Helene Huet discusses these issues in detail in her book *Monstrous Imagination* (1993). If the theory of the supremacy of male seed provided masculinity with a controlling role in the course of pregnancy, then such an emphasis helped make male partners more central to procreation itself. However, such centrality in the reproductive process came with its own costs. If the birth of a disabled child was viewed as a "failure" or developmental mishap, to what degree did the male partner share the blame in such an event? Maternal imagination has been discussed as a desperate resolution to this conundrum without relinquishing men's centrality in pregnancy. A mother's influence over extreme birthing results would expand only during instances of congenital disability. In fact, as in contemporary examples of the births of disabled children, fathers often abandoned households after the births of children with medically remarkable distinctions. In this context, then, the idea of maternal imagination might be exculpatory for fathers in order to dissuade them from abandonment.

However, there have also been efforts—particularly among feminist critics—to interpret maternal imagination as an opportunity for reading women's expanding agency in their own reproductive lives. For instance, a value in the idea of inherited traits could go astray for a woman who gave birth to a child in whom a family resemblance was not forceful. This might be the situation, for instance, in cases of Caucasian women giving birth to racially mixed children or in cases of severe disability. In order to distance themselves from the social opprobrium of sex outside of marriage, women sometimes actively sought refuge in claims to maternal imagination. For instance, in one famous case, Marjorie Sheldrake, who gave birth to a "severely deformed" child in England in the mid-eighteenth century, argued against the charge that she had had intercourse with a man other than her husband by claiming maternal imagination. Given that she was scheduled to go on a trip to Australia after giving birth, Sheldrake claimed that images of kangaroos and other exotic scenes that she contemplated during pregnancy directly influenced the development of what would have been an otherwise paternally mimetic infant. While such recourse to the influence of exotic cultures may seem fraught with racial and cultural anxieties about difference, such arguments provided women with access to less severe forms of public disapproval and familial suspicion.

At root, the theory of maternal imagination developed as a reaction to widespread patriarchal suspicions that women's sexuality was untrustworthy. Because femininity's association with irrationality and embodiment led to explanations of female volatility, maternal imagination functioned as a symptom of many superficial ascriptions. An equation of failed differentiation informed these explanations. Whereas male subjectivity relies on perceptions of bodies as whole, coherent, and autonomous, women's bodies, in their many sexed differences, often appear unstable by contrast. Power structures, such as patriarchy, may directly define women's bodies as excessive, or as what Julia Kristeva (1987) has theorized as abject. Abjection is a compulsive rejection of body types that are determined to exceed acceptable mandated standards for participation in social life. They appear to espouse a refusal of normative boundaries and strict cultural assignment.

A gender theory of body difference can also be critical for assessing the different reactions to disabled bodies in culture insofar as cognitively, physically, and sensorially impaired bodies, by definition, resist normative classifications. The classic 1896 textbook *Anomalies and Curiosities of Medicine* begins with a section devoted to menstruation as the matter of a medical anomaly. Many bodies present radical challenges to Euro-American investments in the myth of a narrow bodily spectrum of variation. In this sense, maternal imagination and the often radically divergent bodies that result threaten to expose premises of bodily integrity that inform models of standardized embodiment. Pregnancy itself, harboring multiple bodies and presenting quickly growing elements, challenges boundaries of singularity and body life. Indeed, arguments about the modifications of environments that best suit pregnant bodies abound. A famous contemporary account of maternal imagining during the experience of inhabiting a multiplying can be found in Julia Kristeva's "Stabat Mater" (1987).

—*Sharon L. Snyder*

See also Family; Gender; Models.

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MAUGHAM, W. SOMERSET

(1874–1965)

British novelist and playwright

W. Somerset Maugham was born in Paris in 1874, the sixth and youngest son of the solicitor to the British embassy. His mother died when he was 10 years old, and he was sent to live with an uncle in England. After attending university, Maugham studied medicine for six years in London, qualifying in 1897 as doctor from St. Thomas' Medical School, but he abandoned medicine after the success of his first novels and plays. Maugham had considerable success first as a playwright and satirist and later as a novelist and short story writer.

Loss and disability strongly influenced Maugham's work. He had a severe stammer that left him afraid to speak. He led a double life both in sexuality and, for a brief while, occupation. He continued for many years both his marriage and his affair with an American man; he also worked as a British intelligence agent during World War I. Perhaps the most profound life event he experienced was the death of his mother when he was a child, an event from which he claimed he had not recovered some 50 years later. Themes of disability and uncontrollable longing are vividly portrayed in his classic novel *Of Human Bondage,* which was published in 1915. The protagonist, Phillip Carey, is a medical student who is embarrassed and publicly humiliated by his professors and fellow students because of his clubfoot. Carey conducts an ill-fated relationship with a selfish waitress who reappears at the end of the novel with all the signs of tertiary syphilis. The mixing of sexuality, disability, and subcultures is more clearly developed in this novel than in the works of other authors using similar themes.

—Joseph A. Flaherty

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McDONALD, ANNE (1961–)

Australian disability activist

Anne McDonald was born with athetoid cerebral palsy and was originally diagnosed as having profound intellectual impairment. She is unable to walk, talk, or use her hands effectively. At the age of three she was placed in St. Nicholas Hospital in Melbourne, Australia, a government institution for people with severe intellectual disabilities; she stayed there for 14 years. She later wrote:

> The hospital was the state garbage bin. Very young children were taken into permanent care, regardless of their intelligence. If they were disfigured, distorted or disturbed then the world should not have to see or acknowledge them. You knew that you had failed to measure up to the standard expected of babies. You were expected to die. . . .
>
> Nurses were discouraged from cuddling children. A crying child needed to be punished for its own good, so it would learn to accept the absence of affection and be happy. Punishment consisted of locking the crying child in a small dark storeroom. The hospital defined a happy child as a quiet child. Silence was not only golden but sullen; the nurses never saw the looks we gave them when a child was put away. (Crossley & McDonald 1980:16)

In 1977, when McDonald was 16 years old, Rosemary Crossley taught her to read and to communicate by spelling. Because of her severe physical disability McDonald needed someone to support her arm while she pointed at letters on an alphabet board. Once she was able to make her wishes known, she sought her discharge from St. Nicholas. The hospital authorities denied her request on the grounds that the reality of her communication had not been established. McDonald instructed a lawyer to take an action for habeas corpus in the Victorian Supreme Court. She won the case and was released from the hospital in 1979. In 1980, she and Crossley coauthored a best-selling book, *Annie's Coming Out,* which was made into an award-winning film of the same title (released in the United States as *Test of Love*). She later graduated from Deakin University.

McDonald's story contributed greatly to the move to community care for people with disabilities, which started with the closure of St. Nicholas Hospital in 1985 and subsequently spread throughout Australia. McDonald has been a notable campaigner for the rights of people with expressive communication impairments, helping to establish the Communication Aid User Society, the world's first organization founded by people without speech, in 1981. Her 1993 statement on the right to communicate has been adopted by the U.S. organization TASH (the Association for Severe Handicaps):

> The right to communicate is both a basic human right and the means by which all other rights are realized. All people communicate. In the name of fully realising the guarantee of individual rights, we must ensure
>
> - that all people have the means of communication which allows their fullest participation in the wider world;
> - that people can communicate using their chosen method, and
> - that their communication is heeded by others.
>
> Where people lack an adequate communication system they deserve to have others try with them to discover and secure an appropriate system. No person should have this right denied because they have been diagnosed as having a particular disability. Access to an effective means of communication is a free speech issue. (pp. 21–22)

In a 1992 address to TASH, McDonald said:

> For people without speech, talking is often dependent on the generosity of others, either in providing interpretation or facilitation or in giving up time to listen. While this is inevitable, there needs to be an irreducible right to make one's opinions known on issues concerning your future well-being. At the moment social conversation and medical consent are equal in the sight of the law, both depending on the accidental availability of communication partners with the necessary skills and commitment.
>
> There is no right to be heard. There is no right to an interpreter. There is no obligation to listen.
>
> While social interactions will always be dependent on the politeness and tolerance of individuals, it should be possible to legislate for a right to communicate in formal situations such as courts, hospitals and schools. Without such legally enforceable rights, people without speech are at the mercy of decision-makers who can arbitrarily decide to disallow communication.
>
> Communication falls into the same category as food, drink and shelter—it is essential for life, and without it life becomes worthless.

—Chris Borthwick

See also Activism; Advocacy.

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MCMILLAN, MARY L. (1880–1959)

American physical therapist

Mary Livingstone McMillan, "Molly" to her friends, was the founder and first president of the American Women's Physical Therapeutic Association, which is today known as the American Physical Therapy Association (APTA). Born in Hyde Park, Massachusetts, McMillan was raised by cousins in Liverpool, England, and graduated from Liverpool University in 1905. Her interest was attracted by the new field of physical culture and corrective exercise, which she studied along with such medical subjects as neurology and anatomy. After several years of working with polio and scoliosis patients as well as patients living with the aftereffects of industrial accidents, McMillan returned to the United States, where in 1918 she became the first volunteer to respond to the U.S. surgeon general's call for reconstruction aides to work with injured veterans at Walter Reed Army General Hospital. Later in 1918, she was asked to move to Reed College in Portland, Oregon, to organize three-month training programs for 200 new reconstruction aides needed for the war effort. This successful effort led to her recall to Walter Reed to establish an army-based education program. (The fact that she worked at the two "Reeds" has led to much confusion about McMillan's efforts and which of the two programs she founded was the first.)

After World War I, McMillan was the driving force behind the formation of a professional organization for physiotherapists. Following a meeting of some 20 women and a few physicians at Keen's Chop House in New York City, the forerunner of the APTA was founded with McMillan as its first president. The organization's structure was similar to that of the British Chartered Society of Trained Masseuses, and standards for training and ethics were important elements of the fledgling association. Along with guiding the new organization, McMillan published her book *Massage and Therapeutic Exercise* in 1921. She went on to teach at Harvard University until 1932, when she went to Peking Union Medical College to become director of physical therapy under the auspices of the Rockefeller Foundation. Caught in Manila at the outbreak of World War II, McMillan was interned at the Santo Tomas prisoner of war camp. While there, she set up clinics to treat the wounds and disabilities of combatants with whatever was on hand. Like many others, she developed severe nutritional deficiencies during her stay in the camp. Later she was transferred to the Chapei prison camp near Shanghai, where she remained until 1944, when she was repatriated on the Swedish American ocean liner *Gripsholm.*

At her death in 1959, McMillan left a large part of her estate to fund a scholarship program for all levels of education for physical therapy students. The program is administered by the APTA, which has also honored her memory with the establishment of the Mary McMillan Lectureship, which began in 1964.

—Helen J. Hislop and
Suzann K. Campbell

See also Physical Therapy.

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▣ MEDICAL FUTILITY

Medical futility is a term used to describe situations in which medical investigations and treatments have little or no beneficial effect on a patient. A futile treatment is one that will not cure the patient's illness or improve the patient's quality of life. When treatments are said to be futile, health professionals owe no duty to provide them to patients, and, it is argued by some, doctors can refuse to provide such treatments even when patients or substitute decision makers request them. *Medical futility* is therefore an extremely controversial term, primarily because health professionals can use it as a way of closing the debate about treatment provision and resource allocation. It is also controversial because it has proven extremely difficult to define.

ETHICAL UNDERPINNINGS OF MEDICAL FUTILITY

Concepts of futility can be found in the earliest writings on medical ethics. In the Hippocratic corpus, physicians were encouraged not to treat patients who were overmastered by disease. Similarly, in Catholic bioethics, physicians are not bound to provide "heroic" or "extraordinary" treatments—that is, treatments that are rare and expensive, that offer little hope of benefit and involve significant pain or inconvenience to the patient.

The term *extraordinary treatment* has also found its way into legislation. For example, in the Northern Territory of Australia, the Natural Death Act 1988 (NT) states that

> "extraordinary" treatment means medical or surgical measures that prolong life, or are intended to prolong life, by supplanting or maintaining the operation of bodily functions that are temporarily or permanently incapable of independent operation.

However, in the past two decades, the terms *heroic* and *extraordinary treatment* have been used with decreasing frequency. By the 1980s and 1990s, commentators began to rely more often on the term *medical futility.*

APPROACHES TO DEFINING FUTILITY

There are two main approaches to defining medical futility. One is the *quantitative* approach, by which a treatment is judged to be futile when it fails (or is known to fail) to achieve certain physiological goals. This could also include those treatments that have a very poor probability of success or that will fail to postpone the onset of death. Second is the *qualitative* approach, which looks not only at physiological success but at quality-of-life factors, such as comfort, well-being, and cognition. The simplest definition of futility using this approach is treatment that cannot return a patient to consciousness or that cannot end the patient's dependence on intensive medical care. Included in this assessment would be treatments that may have success in prolonging life but do so at a great cost to the patient's quality of life, for example, by inflicting enormous pain and discomfort. The qualitative approach therefore focuses on the ends or goals of medicine, those being primarily the absence of disease or disability. If a treatment will not be able to achieve these ends, then it can be considered futile.

PROBLEMS WITH MEDICAL FUTILITY

Clinical Uncertainty

The first problem with the concept of medical futility is that all assessments of quantitative futility are uncertain. While evidence-based medicine has improved our understanding of the success of treatments across populations of patients, it remains extremely difficult to judge the possible outcomes of treatment for individuals. Additionally, there is no consensus as to when the probability of a treatment's success will be low enough for the treatment to be classed as futile. As Kerridge, Mitchell, and McPhee (1997) point out, some doctors might think a treatment is futile when it has zero chance of success, whereas others might make the same judgment when the treatment has a 10 percent chance of success.

Discourse That Disguises Value-Laden Judgments

The assessment of medical futility, particularly of qualitative futility, is laden with value judgments about the quality of a patient's life. Physicians consider factors such as the pain that will be caused by a treatment, the level of awareness of the patient, and the patient's age. The ethical integrity of the medical profession may not provide a sufficient safeguard to prevent improper discrimination in this context.

Problems of hidden values are exacerbated in the end-of-life context, particularly in regard to decisions concerning the artificial feeding and hydration of patients in permanent vegetative states. If a person is in a permanent vegetative state, it might be argued that it is futile to continue artificial feeding and hydration because such treatment will not return the patient to sensate awareness. Nevertheless, it can equally be argued that the treatment is not futile (and in fact works extremely well) because it continues to keep the patient alive, even after the death of the higher brain. This example illustrates the fact that applying the term *futility* does not by itself resolve the underlying conflict about whether such treatment should be provided. Other considerations, such as the best interests of the patient or substituted judgment, are determinative.

Universally, common-law courts have found that artificial feeding in such circumstances is futile and have authorized its withdrawal. For example, the Supreme Court of California said such feeding was futile in *Barber v. Superior Court of the State of California* (1983). Similarly, the House of Lords found in *Airedale Trust v. Bland* (1993) that the continued artificial feeding of a patient in a permanent vegetative state served "no therapeutic purpose of any kind" and that it is the "futility of treatment that justifies its termination." Critics of these decisions have argued that the language of futility has shifted impermissibly from an examination of futility of treatment to consideration of whether the lives of the patients are futile.

RESOLVING DISPUTES ABOUT FUTILITY

Given that a purely objective and noncontroversial definition of futility does not seem to be possible, it is logical to assume that disputes about futility will continue. How are such disputes to be resolved?

If the determination of futility were limited to qualitative knowledge of medical probabilities, it might be arguable that debates about futility should be confined within the medical profession. Conversely, if the definition of futility includes consideration of factors of quality of life, medical professionals should be the only people to contribute to the debate.

Increasingly, it appears that the courts are being asked to resolve disputes about whether treatment should be provided to patients when health professionals have deemed that such treatment is futile. In the United States, much commentary was generated by the case *In the Matter of Baby K* (1994), which involved a decision by a hospital not to resuscitate a baby born with anencephaly (a congenital malformation where the upper brain, skull, and scalp are missing). The child had frequent presentations to the hospital (from the nursing home where it resided) because of breathing difficulties. The hospital believed that respiratory therapies were futile given the baby's inability ever to achieve cognition or awareness. The child's mother disagreed and insisted on treatment for the child. The court found that the hospital's decision breached the Emergency Medical Treatment and Active Labor Act, a statute aimed at ending the practice of patient dumping; the act requires hospitals to stabilize patients before moving them to other institutions.

Some commentators have seen the *Baby K* decision as an unnecessary expansion of patients' rights, so that patients (or their representatives) can demand and receive unnecessary, expensive, and unethical treatment. Others have argued that the decision is limited in scope, noting that it focuses on the narrow question of statutory interpretation and has not always been followed in later decisions.

Similar cases have arisen elsewhere. In the United Kingdom, futility arguments were raised in the case of *Glass v. The United Kingdom* (2004). In this case, doctors had decided to enter a not-for-resuscitation order on the chart of a disabled child without the consent of the child's mother. The child was also given diamorphine against the mother's wishes. The child had been treated for complications arising from surgery, and the doctors believed that resuscitation and aggressive respiratory treatment were futile. The mother disagreed with the doctors' assessment. After a fracas between the child's relatives and medical staff, the child was resuscitated and, eventually, discharged from the hospital. After the Court of Appeal of England and Wales refused to review the hospital's decision, the mother successfully sued the U.K. government in the European Court of Human Rights. That court found that the doctors' failure to gain consent from the mother or from a court meant that the family life rights of the patient and his mother had been breached. This case clearly demonstrates the problems with both quantitative (given the boy's survival) and qualitative (given the dispute between the family and the doctors about the child's quality of life) approaches to judging medical futility.

THE WAY FORWARD?

Given the failure to find an acceptable definition of medical futility, some commentators have suggested that what is needed is a process whereby disputes can be mediated and consensus can be achieved regarding the meaning of whether a particular treatment is futile. This approach has been adopted by the American Medical Association's Council on Ethical and Judicial Affairs and has also been legislatively recognized. For example, the Texas Advance Directives Act of 1999 provides for a process of ethical review of futility determinations that includes dispute resolution services when doctors and families cannot agree about whether treatment is futile.

—Cameron Stewart

See also Consent to Treatment; Refusal of Life-Sustaining Treatment.

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MEDICAL MODELS

See Models

MEDICAL THEATER

The term *medical theater* refers literally to the operating room—the operating theater. More broadly, the term is also used to refer to the places and practices that surround demonstration as a method of dissemination of medical knowledge. By drawing attention to theatricality, the term *medical theater* brings into view the different agendas and power positions that criss-cross medical environments.

Medical practices are not fixed; they are subject to historical changes, and they have not always been aligned with issues of visibility. In *Discipline and Punish,* Michel Foucault (1977) describes the changes in machinery and practices that influenced the hospital's move from a place of thick walls and shelter, as a place apart and out of public view, to a place characterized by a regime of visibility that allowed observation of patients, complete with theatrical spaces created specifically to allow doctors to view patients and to instruct trainees. This new regime of visibility allowed for physicians' engagement with individual patients at the same time the patients themselves became site—places within which and on which symptoms could be observed. In the history of disability representations, psychologist Jean-Martin Charcot and his performances of hysteria in the Salpêtrière in the 1870s can illustrate this point. Charcot investigated women diagnosed with hysteria, fainting attacks, or spontaneous paralyses, parading them around his amphitheater. By presenting that these women were not consciously in control, that they were not faking their attacks, Charcot established the legitimacy of psychological conditions and their effects on the physical body. The price paid for this achievement, however, was the further disempowerment of these women, who became puppets with disheveled clothes in a male-dominated theater of stares.

The original medical theaters where dissections were publicly performed were amphitheaters, architectural forms that echoed the Greek theater tradition. The architecture also echoed Greek concerns of the public sphere: knowledge circulated from the staging area to the benches, and back—the patient's body was the scene of the action, but not the action itself.

The transformation of individual bodies into "data," or into forms of knowledge, is the economy initiated in this theater. The individual patient becomes a barrier breached, the patient's life a collection of data: heartbeat, blood pressure, lines on computer monitors, relations of blood chemicals, lung capacity. These disembodied data as representations of a patient's life are familiar from medical television shows and films. In *Flatliners* (1990), for instance, the resting green luminescent line of the heart monitor signifying death becomes the central metaphor of the film. Successful television shows such as *CSI: Crime Scene Investigation* offer a narrative of the anatomy theater and dissection in stylish images, bright colors, and clean arrangements. In *CSI,* the body on display is broken down, anatomized, atomized, into microsites of narratives. Bullets are tracked through flesh; a burst vein fills the screen, zoomed into by computer graphics; skin appears under the microscope, dramatizing the story that happened outside on the streets of Las Vegas anew in the confines of the medical theater and its laboratory stages.

Within this economy of the medical theater as medical practice, the "ideal" body becomes the object of knowledge: The symptoms of the bodies on display within this theater are interesting insofar as they shed light on the general body, the nonspecific body, the universal or "normal" body. Statistics set boundaries and norms within which the body in the medical theater is aligned. In some instances, these statistical demands and their effect on aesthetics and "proper bodies" lead to strange acts: medical practices that invade bodies, often of disabled people, in order to normalize. Thus, limbs are straightened or lengthened, often under excruciating pain; ears are repositioned, fat sucked, breasts enhanced.

In art practices, the boundaries between the "diseased" and the "normal" can become unstable and can be queried. The film *Crash* (1996), directed by David Cronenberg, reconceptualizes the medical theater. In the film, which is based on J. G. Ballard's novel by the same title, traffic accidents and the unhealed flesh of survivors become eroticized. New alignments between metal and body, unnatural openings into previously "whole" bodies become the focus of the camera, identified with the central character's desirous gaze. Within the medical setting, in the hospital bed—with its paraphernalia of bandages, metal cages, and blinking instruments—sex is used as a counterpoint to death. The medical theater here is the liminal space. But disability remains negative in this economy of eroticized wounded bodies; it is the fluidity of bodies that is valued, their ability to be wounded and to heal. For disability politics, the film offers a different vision of fetishized flesh, but not a pathway to a rethinking of disability as lived reality.

The medical theater is not without an audience—Charcot's pupils eagerly drank in the sight of their powerful professor handling fainting women. In *CSI,* detectives follow action with bated breath as the stage machinery of the medical theater distills "evidence" out of the wounded and dead bodies. Historical studies of anatomy practice discuss the growing public attraction of these spectacles of medical display, and history of medicine scholars have excavated the extravagant and (to modern sensibilities) strange practices surrounding medicine in the seventeenth and eighteenth centuries. For instance, Gonzalez-Crussi (1995) describes the Bolognese amphitheater in the seventeenth century as a site of theatrical spectacle, decked out magnificently for the occasion. In these rites of knowledge and bodies, the professors appeared in long crimson robes, flanked by assistants, to take up a position on the stage next to the cadaver. In contemporary displays of the rites of the medical theater, the clothing and procession are less extravagant, but TV series such as *ER* have educated the public to the less ponderous but still strictly followed fashions and practices of the medical theater today. Within disability history, the various dramatizations of the life of the "Elephant Man" hinge on the display of John Merrick—first by the freak show and then by the medical establishment. Bernard Pomerance's play *The Elephant Man* (1979) presents the problems of seeing beyond the roles of doctor and patient, of achieving human contact within the machineries of hospitals, fund-raising, and differing class demands and life paths.

Disability culture has also embraced the medical theater as an important site of political artwork, criticism, and revolt. Many of the skits and stand-up comedy routines performed at disability arts cabarets include references to encounters between medical personnel and disabled people in the medical theater. The medical theater here becomes a performance form that is highly aware of the power differentials, the "genres," the stories and the predetermined performance scripts that surround the doctor-patient encounter. Most disabled people have intimate knowledge of these visual and performative practices of the medical theater. In particular, if they have rare congenital impairments, they might have been required to undress in front of doctors and medical students; photos might have been taken, and demonstrations held over their mute, or even their protesting, bodies.

Traditionally, the diagnostic gaze of the medical practitioner can roam freely across the displayed bodies of patients, and only rarely are its intrusive and objectifying powers acknowledged in the everyday encounter. In disability culture's revision of the medical theater, the object of the gaze speaks back or subverts the agency and power of the scrutinizing gaze. Performers such as Bob Flanagan, Mat Fraser, Angela Ellsworth, Victoria Halford, Ron Athey, and Greg Walloch have used the encounters between doctors and patients as well as the paraphernalia of the medical environment as starting points for their explorations.

—Petra Kuppers

See also Disability Culture.

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MEDICINE

MODELS OF DISABILITY

In the medical and rehabilitation sciences, various models of disability have been proposed. These models help in the conceptualization of the medical aspects of disability and serve to guide research and educational efforts in rehabilitation medicine. In the United States, the Institute of Medicine of the National Academy of Science and the National Institutes of Health make use of a model that defines the development of a disability as a four-step path with three transitions. The process begins with the *pathophysiology* of the condition—that is, the basic disturbance at the level of molecules, cells, or tissues that results in clinical manifestations of disease. The presence of the disturbance itself may not result in disability and in fact may not be manifested clinically all the time. Modern medical sciences have made significant advances in understanding disease at this level, as illustrated, for example, by research into the genetic basis of disease.

When molecular and cellular alterations reach a certain threshold, the person may develop *impairment*—that is, the inability of a physiological or body system to perform the function for which it was designed. Thus, an impairment of the neuromuscular system may be manifested by muscle atrophy and weakness, and a loss of joint range of motion is a sign of an impaired skeletal system. Along the same lines, diabetics who cannot control and regulate their blood sugar levels have impaired metabolic and endocrine systems. When the impairment limits the person's ability to perform basic functional activities, such as climbing stairs, running, or jumping, a *functional loss* has occurred. Individuals need to be able to perform many functional tasks in order to be independent at home, perform the duties of a parent, work, and function in society. If a functional loss is severe enough and limits the person's ability to do such tasks, a *disability* has developed. Obviously, disability cannot be looked at from a medical or biological point of view only. In this model, disability is the final outcome, and it is defined not only by the biology of the disease or injury but, more important, by the interaction between the biology and the environment surrounding the person as well as the demands of the social and occupational activities of the person. In other words, an impairment or functional loss may not become a disability if the environment facilitates the task at hand (for example, by removing barriers to mobility) or reduces occupational demands (for example, by allowing the person to work from home). Disability is not necessarily permanent; it can be reversed if its determinants can be altered.

The elimination or treatment of factors that convert a functional loss into a disability or an impairment into a functional loss may result directly from medical intervention that limits tissue damage (e.g., thrombolysis in acute stroke) or replaces damaged tissue (e.g., joint replacement surgery). The latter, for example, eliminates pain and damaged tissue, restores joint integrity, and allows for physical therapy for the restoration of muscle strength and endurance. Thus, the functional losses and impairments are eliminated or minimized. This illustrates that the current conceptual model of disability is dynamic, and we should not assume that nothing can be done about the problem.

In this context, it is important to highlight the role that assistive technology, used in centers for rehabilitation medicine, can play in the conversion of a disability to a functional loss or in reversing a functional loss to the level of impairment. Assistive devices include mobility aids, computers to enhance communication and cognitive functions, and memory aids that can replace biological or mental functions and at least partially restore activity and participation. For example, when a person with muscular dystrophy loses muscle mass and the ability to walk, he or she may use a wheelchair to participate in community activities. In this case, the use of a device to assist in mobility replaces the functional loss and minimizes the disability.

A more recent model of disability, favored by some authors and adopted by the World Health Organization, is also based on various levels or steps but begins with the *person* as the central element. This level is roughly equivalent to the level of pathophysiology in the model described above. The person depends on having biological, physical, and psychological integrity to perform *activities* (a level roughly equivalent to the impairment and functional loss levels of the previously discussed model combined). One example of the importance of activity for disability is the beneficial effect of physical activity (e.g., walking, running) on a variety of chronic diseases. Well-conducted studies have shown that the regular practice of physical activity or exercise is associated with reduction in the incidence of heart disease, stroke, some types of cancer, diabetes, obesity, depression, and other conditions. Further, regular exercise of moderate intensity reduces mortality from many of these conditions in both men and women and, more important, delays the development of disability by several years.

Finally, it is not enough for the person to be capable of being active; rather, the ultimate objective is for the person to be a *participant* in his or her community and in society in general (i.e., for the individual to interact with the environment in performing certain tasks). Although there are important similarities between the two models, the latter model is less medically oriented and is characterized by a more holistic, participatory approach.

Independent of the model used, the important issue is that, in the practice of medicine, we need to understand the factors, biological and otherwise, that contribute to the development of disability. Medical and rehabilitative interventions must be based on this knowledge and understanding. Many of these factors are not biological or medical, and therefore many interventions must include other aspects of health.

THE INTERSECTION BETWEEN MEDICINE AND DISABILITY

An analysis of the relationship between disability and medicine is relevant for several reasons. Most obvious is the fact that the road to disability often begins with an acute illness (e.g., a stroke), injury (e.g., traumatic brain injury), or the development of symptoms and signs of a chronic illness (e.g., rheumatoid arthritis). In all of these situations, the affected person is likely to need the services of a medical professional. For many young and healthy individuals, this could be their first experience as hospital patients. Further, even those who have permanent but stable disabilities are likely to require medical services at different points in their lives. For example, disabling conditions resulting from spinal cord injury (e.g., tetraplegia and paraplegia) are associated with a high incidence of such medical complications as infections of the urinary tract, pressure sores, osteoporosis below the level of the injury, and pulmonary diseases. Persons with these conditions become regular users of the medical services available in their communities and develop relationships with health care providers. Another example is the patient with peripheral vascular disease and poor circulation who undergoes an amputation below the knee. Such a patient requires rehabilitation, including the use of an artificial limb, but also careful medical monitoring of the condition of the nonamputated leg, because many such patients develop complications during 5 to 10 years postamputation.

In any of these instances, various medical professionals with different areas of specialization evaluate the patient, establish a diagnosis, and initiate treatment and rehabilitation. These are important encounters, because medical interventions represent one of the first opportunities to control or reverse the physical and psychological conditions that, if left unattended, may lead to the development of a new disability or the worsening of an existing one. In addition, these critical opportunities represent times when professional medicine can display shortcomings. Although many medical specialists do not necessarily recognize the fact, acute therapeutic interventions can alter significantly, either positively or negatively, the pathway to disability. In other words, limiting tissue damage and disease activity in the early stages is the first step in the restoration of form and function. Medical professionals' failure to recognize this principle has led to undesirable outcomes and been the source of much criticism of the medical model of disability. On the other hand, inappropriate medical interventions can also contribute to a problem by delaying tissue healing and by imposing unnecessary restrictions on a patient's activity and community participation. History reveals many instances in which medical interventions, although well-intentioned, did more harm than good. In this context, one of the most noticeable weaknesses of the medical approach to disability has been the failure to recognize the importance of the environment as well as the psychosocial forces that define disability.

Two factors that have contributed to an increase in the prevalence of disability in recent years are worthy of attention. One of these is the success of the health care system in providing advanced medical interventions and using modern technology in acute settings. Advances in science and medicine have been published at an unprecedented rate since the middle of the twentieth century. These developments have resulted in a reduction in mortality associated with accidents, injuries, and acute and chronic illnesses. Paradoxically, the increase in survival rates, a positive outcome in and of itself, may have contributed to an increase in the incidence of disability, given that many patients now survive life-threatening injuries and diseases associated with permanent impairments and functional losses. This increased prevalence of disabling conditions requires a change in our medical practice, better educational programs for medical students and residents (postgraduate trainees), and novel research programs to generate new knowledge and successful interventions. Some of these needs are not being met, and the medical profession must make an effort to fulfill them if it intends to serve well an increasingly large segment of the population.

The dramatic demographic changes registered during the late twentieth and early twenty-first centuries have also contributed to an increase in the prevalence of disability. Increasing numbers of people survive to advanced adult age, and life expectancy is significantly longer today than in the past in all continents of the world with the exception of Africa. The World Health Organization has predicted that the aging of the world's population will continue for the next few decades, resulting in an increase in the number of people in the older age groups, particularly those older than 85, including centenarians. Further, the incidence of functional losses and disability increases with advanced age in both men and women. This is in part due to age-related physiological losses but also to the increased incidence of chronic illness in the elderly. The elderly seek health care services more than do the members of any other age group, bringing to the attention of their physicians, primary care doctors, and specialists not only their medical needs but also their functional limitations. Studies have shown that the elderly fear functional dependence more than death. This preference expressed by patients is a strong statement against the traditional medical approach of treating symptoms and diseases in isolation, without considering their functional consequences. A change in paradigm is needed to place the person's ability to participate in society at the forefront of medical interventions and to integrate the environment in the analysis of the health care and medical needs of patients.

TEACHING MEDICAL STUDENTS AND SPECIALISTS ABOUT DISABILITY

The changes mentioned above highlight the need for a health care system that is knowledgeable about and accessible to persons with disabilities. Although many medical specialties (e.g., developmental pediatrics, geriatrics, neurology, neurosurgery, oncology, orthopedics, and psychiatry) have developed an interest in disability, the only medical specialty that has included disability as a central theme in its philosophy of care, mission, educational and training programs, research agenda, and clinical services is the specialty of physical medicine and rehabilitation (PM&R, also known as physical and rehabilitation medicine, rehabilitation medicine, or physiatry). In fact, PM&R was born, to a very significant extent, out of the needs of patients with permanent disabilities caused by war-related injuries, because the other medical specialties available at the time did not offer effective therapeutic alternatives after the acute stage.

In the United States, physicians specializing in PM&R (physiatrists) must complete four years of postgraduate residency training. They learn to evaluate, treat, and rehabilitate people with disabilities using a holistic approach and are trained to pay particular attention to the restoration of form, function, and freedom to the patient. Thus, the specialty is defined by its comprehensive approach and interest in function and not by the need to attend diseases of a specific organ or body system. Furthermore, in addition to attending to the biological and physical needs of the patient, physiatrists place special emphasis on psychosocial, emotional, and vocational issues that may be important determinants of the level of disability. It is interesting that the consequent lack of identification with a specific organ or body system (unlike the identification of cardiology with the heart and ophthalmology with the eye, for example) has made the process of communicating the nature of the specialty more difficult. For those without disabilities, the concept of function may not be all too obvious.

Unfortunately, the specialty of physical medicine and rehabilitation is not very popular among medical students and is usually not included as part of the regular curriculum in most medical schools. Furthermore, conceptualization of function and disability is poorly disseminated within the field of medicine in general. Thus, standard medical textbooks such as *Harrison's Principles of Internal Medicine* do not include disability in their indexes. More frequently, disability awareness comes from firsthand experience. It is not unusual to find students whose interest in the specialty of PM&R resulted from their having lived with relatives with disabilities. Medical students interested in the field have to use some of their elective time to do special rotations in physiatry in order to learn more about it. It could be argued that this deficiency of information and knowledge about disability and rehabilitation, characteristic of many medical school graduates, explains the lack of appreciation and understanding that many physicians have in relation to disability issues. Further, more often than not, postgraduate residency training in many medical specialties fails to provide students with practical experiences in the diagnosis, treatment, and rehabilitation of disabling conditions. Nevertheless, recent data indicate that, despite the above-mentioned limitations, the medical specialty of PM&R is growing in many countries and regions of the world. Currently, there are approximately 8,000 board-certified physiatrists in the United States and 15,000 physiatrists in Europe. In addition, the numbers of medical graduates enrolled in PM&R residency training programs in the United States and Europe are 1,200 and 2,000, respectively. Greater availability of well-trained medical professionals could significantly enhance access to quality services focused on disability issues.

Another opportunity to educate physicians and other health care professionals has resulted from recent changes in the financing and management of health care systems. These changes may have the unintended consequence of enhancing the general understanding of disability and rehabilitation issues among health care providers outside the world of rehabilitation. Financial concerns with the cost of health care have forced acute care hospitals to reduce the length of the hospitalization for many diseases and surgical cases. To accomplish this goal, hospitals have begun transferring patients to other, lower-cost, facilities as soon as their medical conditions are stable enough to permit continuation of their treatment and recovery elsewhere. As a consequence, rehabilitation facilities have become important providers of subacute medical and rehabilitative care much earlier in the recovery (postinjury or postsurgery) process, and physicians and administrators in acute care facilities have been forced to learn more about the needs of people with conditions that require rehabilitation and patients with disabilities, particularly in the early stages of episodes of care.

HEALTH CARE SERVICES FOR PEOPLE WITH DISABILITIES

Modern health care systems are multicomponent organizations that integrate different levels of care across geographically separated campuses. Many patients needing multiple levels of care are transferred from one location to another, and then another, and so on. Most of the services for people with disabilities have been consolidated in entities known as *nonacute, postacute,* or *continuing care* health care systems. These systems have important distinguishing features that should be understood.

Acute medical services, including the acute hospital, an emergency room, operating rooms, ancillary services such as radiology and clinical laboratory services, and outpatient clinics, are usually available all on one campus. On the other hand, nonacute health care systems organized with the rehabilitation continuum in mind may provide services on multiple campuses, including the rehabilitation unit or hospital, nursing homes, day hospitals, and outpatient clinics, as well as in patients' homes. Acute care facilities provide important services for people with disabilities. The presence of a disability and the rehabilitation needs of the patient are sometimes important determinants of the nature and success of the intervention in the acute hospital, but most of the time they are not the center of attention. In the acute care hospital, more often than not, the need to restore form and function is a secondary consideration. The opposite is true in the various levels and facilities of care that form part of the nonacute system. In the majority of cases, people with disabilities access services in the nonacute system because of the disability, and the health care professionals make the disability and its determinants the center of attention and clinical activity. The need to include the home of the patient as a component of the system is a formal recognition of its important role in the final outcome.

An important difference between a typical acute medical intervention and treatment received in the medical rehabilitation context is the emphasis that the latter places on the interdisciplinary team. Although recently many medical specialties have begun to develop and implement versions of the team concept, medical care for people with disabilities in rehabilitation settings has always been characterized by the interrelatedness of the interventions of a large group of health care professionals. The team approach is one of the central tenets in the practice of clinical rehabilitation and the delivery of medical services for the disabled. In addition to the physician, the rehabilitation team may include individuals in all or some of the following health professions: occupational therapy, physical therapy, speech language pathology, psychology, neuropsychology, recreational therapy, rehabilitation nursing, nutrition, and social work. Fragmented medical care in which multiple specialists intervene with a patient without coordinating their services has no place in rehabilitation medicine clinics and centers or in medical programs for the disabled. The coordination of services takes place not only through daily communication among the members of the team but also through formal team meetings in which members discuss the goals and progress of the patient. In a very real sense, the patient and his or her family are also part of the team, and family meetings are held to discuss the patient's progress and to get family members' opinions on issues confronting the patient. Although some of these interactions and activities take place also in the acute care setting, they are more formally planned and executed in the rehabilitation setting.

Two of the main objectives of the rehabilitation process are the return of the person to his or her home and, if possible, the return of the person to his or her previous level of employment. To meet these objectives, medical professionals must develop a good understanding of the social and occupational environments of the patient. Such understanding may not be necessary in acute care settings, but it is almost always required in nonacute health care systems. For example, many of the rehabilitative and therapeutic interventions may have to take into consideration the architecture and physical barriers of the patient's house and the physical and psychological demands of the patient's job. Again, disability is defined by the interaction between the biological and physical domains and the environment, and even in the case of static and permanent biological dysfunctions, alterations in the environment can reduce negative impacts on function and lessen the degree of disability. In this context, it could be said that therapeutic and rehabilitative interventions should be directed toward the environment: enhancing the person's ability to overcome environmental barriers or reducing the magnitude of the barriers themselves.

THE MEDICAL RESEARCH AGENDA AND DISABILITY

Research is needed to generate new knowledge that medical professionals could use to understand the natural world and apply to the solution of clinical problems. In medicine, new knowledge is generated through research studies that can be divided into three general categories: basic science research, clinical research (including clinical trials and outcomes research), and health services research.

The goal of basic medical science research is to increase understanding of health and disease at the mechanistic level. Important basic science questions address how the human body works and what happens when a disease develops at the molecular and cellular levels. Many of these questions are relevant to a variety of clinical issues and help us understand problems at a very fundamental level even though they do not address or test immediate solutions to clinical issues.

Clinical research, on the other hand, is designed to test ideas with the potential to treat or cure disease in humans. Thus, researchers test drugs, new surgical interventions, and new technologies to assess their value in preventing illness, treating disease, and alleviating pain and suffering. This type of research is unique in that it requires the voluntary participation of human subjects. The patient or person with a disability has an opportunity to be part of the process and contribute to a better outcome. The clinical research enterprise has a solid base in areas such as cardiovascular disease and cancer but is not well developed in rehabilitation medicine. Advances in the rehabilitation of people with disabilities will depend on the establishment of a clinical trials network, so that new treatments can be tested on large numbers of individuals.

Finally, health services research deals primarily with issues related to the delivery of health care and the factors that determine the efficiency and effectiveness of health care systems. Current health services delivery models may not be adequate for people with disabilities, and more creative ways of providing services are needed. For example, new technologies such as tele-rehabilitation could help medical professionals to deliver services in patients' homes and reduce dependence on clinic and home visits.

In many ways, all of these types of research are important for persons with disabilities because many of the treatments developed in the context of acute care interventions might find application in rehabilitation centers. For example, understanding the basic events leading to brain damage after an injury or stroke could help with the development of ways to protect healthy tissue surrounding the affected area. Further, tissue engineering could potentially be used to replace tissue that has been damaged or lost due to illness or injury, as in degenerative arthritis. Stem cells that have the capability to differentiate into different types of cells represent another potential source of "new tissue."

Clearly, significant efforts in basic science are needed to accomplish these goals. Further, no discovery is incorporated in standard medical practice until appropriate clinical trials have been conducted to prove the safety and effectiveness of treatment based on the discovery. Therefore, clinical trials and outcomes research studies must also be part of the research agenda addressing disability issues. New pharmacological agents developed using this model could be effective in treating medical complications that are frequently seen in association with disabling conditions such as spasticity (a velocity-dependent increase in muscle tone) in stroke survivors and tetraplegics. Advanced prosthetic (artificial limbs) and orthotic (braces) devices for those with mobility problems and amputations, which clearly benefit consumers, are developed and tested using this approach.

Finally, the organization of a system of care for people with disabilities should take into consideration the special needs of this population; therefore, health services research is needed to help define the characteristics of such a system. This concept has been tested in the Model Spinal Cord Injury System, a network of centers in the United States dedicated to the care of patients with spinal cord injuries. These centers provide and coordinate emergency and acute medical care, rehabilitation services, psychosocial and community reintegration programs, and long-term follow-up focusing on the special needs of patients after spinal cord injury. During the past 35 years, researchers have developed and tested each of these levels of care and special programs with the needs of persons with spinal cord injury in mind. It is worth noting that these centers must integrate not only different levels of care (e.g., acute neurosurgical interventions with rehabilitation goals) but also administrative, research, and educational efforts for health care professionals, patients, and patients' families.

In general, the medical research agenda does not include enough research initiatives that have at their centers the purpose of ameliorating disability. Traditional medical research models used, for example, in acute care hospital settings are more oriented toward the biological and physical aspects of disease. These are clearly important, but in the future, the roles of environmental and psychosocial factors will have to be integrated with these two aspects. An example of this integration is the proposed future agenda for the Model Spinal Cord Injury System, which includes attempting to integrate basic science, clinical research, and health services research. This agenda, with minor modifications, could serve as an example for research agendas concerning other disabling conditions. It has been proposed that the Model

Spinal Cord Injury System centers conduct research related to the following general areas:

- Neuroscience and nerve regeneration
- Pharmacological interventions, including randomized controlled clinical trials
- Biotechnology interface projects
- Preventive health and wellness
- Subjective well-being and consumer satisfaction
- Bioethics
- Health care models
- Bioinformatics, collaborative patient, and research databases

This proposed new research agenda will take advantage of the dramatic advances in science recorded in the twentieth and twenty-first centuries and apply this new knowledge to the enhancement of the quality of life of people with disabilities. Disability should not be defined by medicine; instead, the medical profession should be considered an important partner capable of making a significant contribution to the understanding and transformation of disability.

—*Walter R. Frontera*

See also Health; Health Care and Disability; Models; Professions.

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MEDITATION

See Mindfulness Meditation

MELANCHOLY

The word *melancholy,* which refers to a state of low spirits, sadness, and anxiety, comes from the Greek terms *melas* (black) and *chole* (bile). The historical meaning of the concept of melancholy has been superseded by modern terms such as *depression;* whereas *melancholy* is now used to refer to a state of lingering sadness, from antiquity to the development of prepsychiatric medicine the term was used to describe a medical condition.

In antiquity, the word *melancholy* referred to a medical disturbance of the mind and the soul that was contrasted with other states of madness, such as *mania,* a chronic mental disorder without fever, and *phrenitis,* an inflammation of the brain with fever. The specificity of melancholy was believed to be related to its cause in the body: black bile. Like the three other bodily humors—blood, yellow bile, and phlegm—black bile was understood to affect the body as well as the soul; in excess, it was seen as the cause not only of melancholy but also of cancer, elephantiasis, and hemorrhoids.

The Hippocratic corpus mentions black bile, but melancholy is not prominent. One of the *Aphorisms* (6.23) states that "if sadness and fear last for a long time, the state is melancholic." A treatise from the Aristotelian tradition, *Problem XXX,* which connects the melancholic state to exceptional men, was very influential. In the treatise *On Black Bile,* Galen focuses on the physiological aspects of this humor. The twofold nature of black bile—that it is both necessary to life and yet in excess so potent that it is able cause anthrax, elephantiasis, and melancholy—is clear in this text. The cure for melancholy aims at reducing black bile through purgation with white hellebore. Other authors show more doubts about the possibility of a cure. Aretaeus of Cappadocia (1856) gives a vivid account of persons suffering from melancholy:

> And they also become peevish, dispirited, sleepless, and start up from a disturbed sleep. Unreasonable fear also seizes them, if the disease tend to increase, when their dreams are true, terrifying, and clear: for whatever, when awake, they have an aversion to, as being an evil, rushes upon their visions in sleep. They are prone to change their mind readily; to become base, mean-spirited, illiberal, and in a little time, perhaps, simple, extravagant, munificent, not from any virtue of the soul, but from the changeableness of the disease. But if the illness become more urgent, hatred, avoidance of the haunts of men, vain lamentations; they complain of life, and desire to die. (pp. 299–300)

On the physical side, the skin of melancholics was said to become green-black, and they were said to have great appetites while remaining emaciated.

During the Middle Ages, the whole theory of the bodily humors was systematized, and the melancholic emerged as one of the four temperaments—that is, a type of person with characteristics, both physical and mental, determined by the melancholic humor. Robert Burton's *Anatomy of Melancholy,* first published in 1621, is emblematic for the Renaissance: The author organizes the classical sources about melancholy around scrutiny of himself. Although alternative ideas concerning the treatment of melancholy were put forward, the ancient theories were influential well into the nineteenth century.

—Anne-France Morand

See also Humors, Theory of.

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MENTAL HEALTH

The concept of mental health has changed radically in the past decade. Mental health disabilities are no longer perceived as chronic, disabling conditions; rather, they are seen as limitations in the quality of life of affected individuals. In some nations, public policy legislation—such as the Americans with Disabilities Act (ADA) of 1990—has favored this reconceptualization of mental disability.

Despite these new perspectives in the understanding of mental disabilities, some dilemmas still are observed in this matter. In some countries and sectors of society, a disparity still exists between the perception and approaches to the management of chronic illnesses. In this regard, some chronic medical illnesses, such as diabetes and epilepsy, are treated intensively and acutely at every relapse; in contrast, this approach is not always afforded to certain chronic psychiatric disorders, such as schizophrenia. This type of discriminatory practice is also observed among countries, including the United States, where no parity exists between medical/surgical illnesses and psychiatric illnesses with respect to medical insurance coverage.

This dilemma, of course, is related to stigma, fear, and ignorance. It may not be the patient but society at large that discriminates, fears unknown illness, and feels guilty of conditions that still are not well-known. This is what has also happened in the past vis-à-vis epilepsy, leprosy, plague, and other similar conditions. Incidentally, this situation is similar to the one observed when people from different races, ethnicities, and cultures interface with people from the majority culture. In general, persons tend to be afraid of those who differ from them in religion, economic ideology, skin color, language, or culture. This type of phenomenon leads to fears, persecution, discrimination, racism, oppression, and even wars in some instances.

During the past two decades, major research advances have taken place in the field of psychiatry and behavioral sciences, particularly with respect to neurosciences and the management of mental illness. As the public begins to conceptualize many major mental illnesses as "brain diseases" instead of as the results of parenting problems or weak character, stigma is reduced. As new discoveries take place, new and promising perspectives also evolve, thus leading to progress in the way that society perceives psychiatric disorders at a worldwide level.

Mental illness ranks first in causing disabilities among many industrialized nations, including Western European countries, Canada, and the United States. In this respect, mental illnesses currently cause more disability than cancer and heart disease combined. Schizophrenia, bipolar disorders, and depression now account for 25 percent of all medical disabilities across major industrialized nations. This situation has major implications, not only from the point of view of pain and human suffering but from an economic viewpoint as well. For instance, in 1999, the economic cost due to loss of productivity as a result of mental illnesses in the United States was $63 billion. In the United States, 5 to 7 percent of adults currently 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.

This situation is currently producing major public policy dilemmas in many industrialized countries. In the United States, for instance, one in every two persons in need of psychiatric treatment does not receive it, especially in inner-city and rural areas. This happens for several reasons; quality of care may be inadequate, diagnoses may sometimes be inaccurate, medication dosages may be insufficient, or the length of treatment may be too short. This circumstance is even worse with respect to ethnic and racial minority group members in the U.S. population. Stigma is definitely still a barrier to psychiatric care as well as to quality of care. Unquestionably, societal stigma and shame concerning mental illnesses lead to ostracism and discrimination vis-à-vis mental patients. Patients sometimes internalize this situation and thus develop low self-esteem and hopelessness; suicide may even result.

Despite these serious public policy dilemmas, the past decade has also seen major psychosocial research advances to complement the biological research, leading to new approaches in rehabilitation of the mentally ill, particularly the chronic mentally ill, and to major advances in the conceptualization and understanding of current mental health disability management. These new principles in psychiatric rehabilitation have shed new light on methods of intervention and have led to new perspectives with respect to early intervention and treatment of mental health disabilities.

A rehabilitation approach has recently been developed in which the patient becomes the center focus of the rehabilitation process. In this context, all key domains of the person's life—that is, the physical, emotional, intellectual, social, and spiritual needs of the person—are addressed from a rehabilitation point of view. In a well-integrated manner, all these personal dimensions are attended to from a rehabilitation viewpoint, with priority given to the rehabilitative expectations of the patient suffering from a given psychiatric illness or condition. This rehabilitative approach is geared toward involving the patient actively in the entire rehabilitation process. Active involvement also includes full patient empowerment—that is, the patient is provided with full information about the nature of the illness, its symptoms, its course, and potential sequelae.

In this context, hope becomes an inherent and essential aspect of the rehabilitation philosophy. Thus, the approach to the rehabilitation process becomes a core element with respect to the positive expectations of the patient and the outcome of his or her illness management. The whole rehabilitation process currently focuses on maximizing the patient's strengths, especially from a competence and skills point of view. Therefore, skill development, enhancement, and training are central to this new ideology.

The patient's environment extends itself to accommodate the factors that play a role in the mental health disability; thus, "limitations" substitute for "handicaps." Full focus is given to the patient's environment as a potential resource element. Possible resources include people such as the patient's family members and other persons in the environment, programs, services, and infrastructures that can play a positive role in the patient's rehabilitation process. In this regard, employers, coworkers, friends, religious institutions (e.g., churches and synagogues), landlords, and community centers all become potential resources on behalf of the patient's rehabilitative outcome.

Currently, vocational assessment of the patient is seen not as a way of coping with the mental health disability but as a way of maximizing the patient's opportunities in life; limitations in the patient's quality of life supersede acceptance of handicaps caused by the psychiatric illness or condition. Incentives for full rehabilitation opportunities aimed at helping the patient return to full- or part-time employment becomes the goal rather than the occasional expectation. The patient is offered full opportunities for maximum achievement and enhancement of his or her quality of life.

During the past decade, two new concepts have enlightened the rehabilitation process and the conceptualization of mental health disability: the concepts of *patient satisfaction* and *quality of life.* Although patient satisfaction has been addressed previously on many occasions, only recently has it come to be considered a quality indicator in the assessment of treatment outcomes. Likewise, quality of life is currently accepted as the major component in treatment outcomes. In this context, a successful and appropriate rehabilitation process has become an integral part of illness management.

The treatment of chronic psychiatric conditions depends less on the management of symptoms than it does on the intensive management of acute phases. Likewise, relapse is now perceived more as an expression of an acute phase of the illness than as a manifestation of a long-term disabling condition.

Research and educational efforts have resulted in numerous clinical advances in recent years, but further progress is still needed in this regard. Additionally, it is urgent that society face the current public policy dilemmas affecting mentally ill patients. Certainly, isolated state hospital facilities were not the appropriate answer to the need to provide humane care for the mentally ill, but neither are the streets of urban metropolises or the prison system.

—*Pedro Ruiz*

See also Mental Health: Law and Policy; Mental Illness.

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MENTAL HEALTH: LAW AND POLICY

Historically, severe mental illness has been merged with global incapacity. From at least the time of classical Greece and Rome to the European Middle Ages, families were expected to control, house, and provide for those afflicted with severe mental illness or intellectual limitation, and the freedom of these individuals was subject to whatever limitations were set by their families. By the fifteenth century, however, in Western

Europe the "insane" were increasingly confined to specialized institutions, a movement that grew substantially until the mid-twentieth century. Individuals with severe mental illness might be incarcerated in such facilities indefinitely, but they were not necessarily stripped of their titles or property. However, it was generally held that during the period of "insanity"—which might be lifelong—they could not exercise many of the rights of ordinary citizens, and (if they owned substantial property) guardians were appointed to act in their stead. (One interesting distinction was made in thirteenth-century England, where the property of those born severely mentally retarded—"congenital fools"—instead reverted to the king.)

Thus, those identified as severely mentally ill were considered unable—simply by virtue of being ill—to enter into business contracts, execute wills, or otherwise control their property. The laws of the Roman Catholic Church also dealt with issues such as the effect of "insanity" on the validity of matrimonial consent and whether an "insane" person could receive church sacraments.

Perhaps because of the lack of effective treatment and the chronic nature of many severe psychiatric disorders, questions of why and under what circumstances property and civil rights should be given up by the severely mentally ill were not seriously addressed until the mid-twentieth century. Prior to that time, there was little legal oversight of the treatment of those hospitalized for severe mental illness, and virtually all such patients were hospitalized at large, state-run institutions. Beginning in the latter half of the 1950s and early 1960s, coincident with the "deinstitutionalization" of psychiatric patients and in the context of large-scale social changes that led to marked liberalization of civil rights for many groups, those identified as severely mentally ill were nonetheless recognized as having the legal ability to exercise all the civil rights (e.g., the right to vote, the right to not be subject to treatment without informed consent, the right to refuse certain treatments) accorded other citizens in the United States and several other countries. Thus, a conceptual and legal shift occurred, from status as psychiatric patient being sufficient to establish absence of legal *competence* to a more nuanced view that focused evaluation is needed to determine if and to what degree mental illness might affect an individual's specific clinical *capacity* to exercise his or her rights. Only disability severe enough to compromise such capacity could negate a person's exercise of such rights.

GUARDIANSHIP

The roots of guardianship of the estate of an incapacitated individual can be traced to classical times, as noted above. Over time, the concept of guardianship has evolved dramatically, so that in some cases guardianship of the person (for example, the power to make health care decisions) is distinguished from guardianship of property (sometimes also called *conservatorship*). Guardianship may also be general (plenary), or it may be restricted to certain classes of decisions, with the ward retaining decision-making power for others. The issue of incompetence and hence need of a substitute decision maker can be based on legal definition *(de jure),* for example, if the individual is a minor, regardless of cognitive status; in other cases, proceedings can be based on the finding of actual *(de facto)* incompetence. A ward's status of incompetence can be reversed either through a change of legal status (e.g., reaching the age of majority) or through the ward's prevailing in a "restoration" hearing.

There is still significant variability among jurisdictions in the basis for appointment of a guardian, but a shift appears to be taking place from simply equating mental illness to need for guardianship to focused evaluation of the functions the individual can (or cannot) perform, with the determination based on the degree and kind of deficits identified.

CIVIL COMMITMENT

The shift described above has played out in a number of areas of mental health law. The justification for civil commitment has in large part moved away from a *parens patriae* model, in which the sovereign, or the state, is responsible for the well-being of citizens, much as the father is responsible for his family (note the gender bias), and thus is empowered to force treatment on those judged to be in need of it. This has been supplanted in large degree by a "police power" model, in which evidence of an individual's danger to self (by self-injury or inability to provide basic necessities of life) or to others (by violent behavior) is required for involuntary hospitalization. In other words, an earlier model based on social norms of which behaviors were acceptable and which merited confinement and coerced treatment has been superseded by a model in which individual liberty, within very broad bounds, can be abridged only when evidence exists of clear and significant risk of social disruption, such as threat to the physical safety of a citizen. Less severe behavioral problems, even when accompanied by suffering and risk of lesser degrees of harm (such as financial irresponsibility or disruption of the family situation), are insufficient to justify involuntary hospitalization. Indeed, physical freedom is considered so fundamental that in *Addington v. Texas* (1979), the U.S. Supreme Court held that "civil commitment for any purpose constitutes a significant deprivation of liberty" and, hence, due process protections must be in place to ensure that "the individual suffers from something more serious than is demonstrated by idiosyncratic behavior" before his or her freedom can be abridged. Under such circumstances, because the individual disproportionately bears the cost of an erroneous determination, the state must prove the need for civil commitment at least to a standard of "clear and convincing evidence."

Often associated with this deference to physical liberty is the concept of "least restrictive alternative." First explicated in the case of *Lake v. Cameron* (1966), this principle dictates that an individual's physical freedom should be restricted as little as possible consistent with physical safety and that practitioners consider the full range of services available (such as outpatient treatment, partial hospital programs, nursing homes) before mandating inpatient treatment, with precedence granted to the setting that interferes least with physical freedom consistent with safety.

TREATMENT RIGHTS

Personal autonomy is considered a higher social good than health. Disagreeing with medical advice is not necessarily evidence of impaired judgment, and in general, the patient is free to decline treatment even when the treatment is necessary to prevent serious harm or death. Conversely, it is generally incumbent on the treatment provider to obtain permission from the patient (or the patient's substitute decision maker). For permission to be valid, the patient must be able to render *informed consent.* This concept has three components: competence, sufficient information on which to base a reasoned choice, and freedom from coercion.

Competence can be a purely legal distinction (see above); in such a case, the consent is obtained from the patient's parent or guardian. Competence can also be questioned based on, for example, the presence of mental illness. Again, however, mere presence of a mental disorder is insufficient to undermine the individual's autonomy. Under such circumstances, the legal system may either make treatment decisions or determine who should act in the patient's stead.

Specific tests differ among jurisdictions, but in general to demonstrate incompetence one must show that the individual's reason for refusal of treatment is irrational. If that is so, for most health care decisions a substitute decision maker (often but not necessarily the patient's spouse, parent, or other family member) may be employed. In some cases, the individual may have previously executed a document spelling out what treatments he or she would wish (or refuse) in the event that he or she becomes severely ill. Although such contracts may not in the end determine treatment, they may be used as part of the fact base to determine the individual's wishes.

Involuntary treatment with psychotropic medication is often (by statute) handled differently from other interventions. In that case, the court (or other fact finder) might use information such as the patient's prior experience with the medication, the patient's perceptions of its purpose and effects currently, and the preferences regarding treatment previously expressed by the patient. If the patient's refusal of treatment is considered not to be competent, generally it must be further demonstrated that the proposed treatment's benefits outweigh its risks and that the underlying condition is sufficiently grave as to merit treatment over the patient's objections.

One seeming peculiarity in regulation of involuntary psychiatric treatment is that many jurisdictions now separate issues of involuntary *hospitalization* from issues of involuntary *treatment.* The presence of a disorder, even one sufficient to cause an individual to behave dangerously, does not inherently establish that the person's ability to make treatment choices is severely impaired, although this is in fact often the case. Commitment generally requires the presence of a mental illness plus some evidence of dangerous behavior, whereas involuntary treatment requires, in essence, the individual's lack of ability to make reasoned treatment choices—two separate concepts that may require two separate judicial determinations.

It is interesting to note that there has been judicial reluctance to identify a corresponding "right to treatment," even for those involuntarily hospitalized (*O'Connor v. Donaldson* 1975). Indeed, U.S. courts have paid great deference to professional judgment, requiring only that the patient be provided safe conditions, freedom from bodily restraint, and "training or 'habilitation'" (*Youngberg v. Romeo* 1982).

OTHER COMPETENCIES

Mental illness may potentially—but not necessarily—undermine a person's ability to exercise specific abilities, such as to validly enter into a contract, marry, write a will, or testify in court. The issue becomes whether mental illness has negated some element specific to a given function. For example, to execute a will competently, one must understand that one is making a will, understand the nature and extent of one's property, and have knowledge and understanding of one's heirs ("the objects of their bounty"). Great weight is placed on the will, and generally a rather strict ("clear and convincing") proof is required to invalidate it. A rather similar analysis generally informs the judgment of competence to contract; that is, the contractor must be sufficiently aware of the contract's elements and be able to make rational decisions based on them.

CRIMINAL LAW

Analogous to civil law, within the criminal law a number of kinds of competencies are noted specifically: competence to waive certain protections (e.g., one's rights under *Miranda v. Arizona* 1965) or appeals, to enter a plea, to confess, to testify as a witness, to represent oneself, and so forth. As with civil competencies, it is necessary to evaluate specifically the impact that mental illness might have on the legal tests, which may differ substantially from jurisdiction to jurisdiction. Most fundamental is the issue of competence to stand trial. The defendant's mental status *at the time of trial* must be such that the individual has "sufficient present ability to consult with his attorney with a reasonable degree of rational understanding and a rational as well as factual understanding of proceedings against him" (*Dusky v. United States* 1960).

In practice, therefore, competence to stand trial has several components, and a number of instruments have been devised to aid clinicians in assessing them. One major domain consists of knowledge of the relevant legal facts and procedures, such as the roles of courtroom personnel; awareness of legal protections, such as right to counsel and protection against self-incrimination; the charges and their potential penalties; and potential legal strategies, such as an insanity defense or plea bargaining.

A second component is the ability of the defendant to participate meaningfully in planning legal strategy. This includes such functions as the ability to weigh alternative defenses and potential outcomes rationally, the ability to collaborate with counsel regarding trial strategy, and the ability to challenge adverse witnesses realistically. Although the defendant's ability to provide counsel with a coherent accounting of the defendant's version of events is desirable, the courts have held that amnesia for events does not equate with lack of fitness to stand trial.

The last component of fitness or competence to stand trial is the degree to which the defendant is willing and able to mount a strong defense, unimpaired by the presence of mental illness that might, for example, make him or her plead guilty to a crime out of delusional guilt. Although a high standard of proof "beyond a reasonable doubt" is necessary for conviction of a crime, a lesser standard, "preponderance of evidence," is sufficient to establish competence to stand trial. A similar standard is generally used to determine other competencies relevant to criminal law, as noted above.

MENTAL HEALTH LAW, DISABILITY, AND DISCRIMINATION

The current relationship between mental illness and the definition of disability will not be discussed here;

suffice it to say that it is a complex relationship that may vary considerably depending on the legal context in which the issue is raised.

Arguably, to date the most sweeping legislation related to the rights of the disabled in the United States is the Americans with Disabilities Act (ADA) of 1990. Many mental illnesses may be considered as disabilities under the act, primarily excepting disorders of impulse control, current substance use disorders, and certain sexual disorders (paraphilias), as well as homosexuality (which is not a mental disorder). To qualify as a disability, the disorder must substantially limit one or more of the individual's major life activities. Of note, the act states that the disability so defined need not be current, as long as the individual has "a record of such impairment; or . . . [is] regarded as having such an impairment."

Title I of the ADA deals with issues of employment, Title II with public services, Title III with public accommodations and services by private entities, and Title IV with access to telecommunications. Under Title I, the ADA specifies that a disabled individual (as defined above) who, "with or without reasonable accommodation, can perform the essential functions of the employment position" comes under the ADA's protection.

Building on Title II, in the 1999 case *Olmstead v. L.C.,* the U.S. Supreme Court held that "states are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated." In that decision, the Court held that "unjustified placement or retention of persons in institutions . . . constitutes a form of discrimination" that the ADA prohibits and philosophically appears to have been influenced by the "least restrictive alternative" concept explicated in *Lake v. Cameron.* However, the Court deferred to the states the decision as to what community resources might be appropriate, addressing only the issue of equitable provision of existing services rather than what services ought to be available.

—*Stephen H. Dinwiddie*

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

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MENTAL HEALTH PARITY

The term *mental health parity* refers to the effort to treat mental health financing on the same basis as financing for general health services. Under the concept of mental health parity, health insurance and health plan coverage for treatment of mental illness would be equal with coverage of treatment for all other illnesses, using the same terms and conditions. Mental illness would be recognized as an issue equal in importance to physical illness.

Advocates for mental health parity, such as the National Alliance for the Mentally Ill (NAMI), believe that mental illnesses are real illnesses, that treatment works, and that there is no medical or economic justification for health plans to apply different terms and conditions to the coverage of treatment for mental illness than they do to coverage of treatment for physical illness.

President Bill Clinton signed the Mental Health Parity Act (P.L. 104-204) into law in 1996. With the leadership of Senators Pete Domenici (R-NM) and the late Paul Wellstone (D-MN), this law created a standard of parity for annual and lifetime dollar limits.

The law applies to employers that offer mental health benefits but does not mandate such coverage. Mental health advocates such as NAMI are concerned that the law allows health insurers to employ cost-shifting mechanisms, such as adjusting limits on mental illness inpatient days and outpatient visits, limiting prescription drugs, raising patient copayments and deductibles, and modifying the definition of *medical necessity.*

The U.S. General Accounting Office (GAO 2000) has found that lower limits for inpatient and outpatient mental illness treatments have continued in spite of the law, and, in some cases, insurers have actually expanded such measures to help keep costs down. The law does, however, apply to fully insured state-regulated health plans and self-insured plans that are exempt from state laws under the Employee Retirement Income Security Act (ERISA), which are regulated by the U.S. Department of Labor. Existing state parity laws are not preempted by the federal law. That is, a state law requiring more comprehensive coverage is not weakened by the federal law, nor does the federal law preclude a state from enacting stronger parity legislation. The law includes a small-business exemption for firms with 50 or fewer employees and an increased cost exemption for employers that can demonstrate a rise in costs of one percent or more due to parity implementation. The GAO also found that 86 percent of surveyed health plans are complying with the law. Noncompliance may be the result of a lack of effort on the part of state insurance commissioners, the Centers for Medicare and Medicaid Policy, and the Pension and Welfare Benefits Administration to educate employers about the new law.

Evidence shows that the effects of mental health parity laws on costs are minimal. By introducing managed care or increasing its level, insurers can significantly limit or even reduce the costs of implementing mental health parity. In plans that have not previously used managed care, introducing parity simultaneously with managed care can result in an actual reduction in costs.

Given that recent studies have shown that parity laws do not increase costs significantly, and given that extensive limits on mental health benefits can create major financial burdens for patients and their families, mental health parity represents an important way in which society can advance the concept of comprehensive health care.

—Richard Huston Sewell

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MENTAL ILLNESS

Mental illness is a contentious concept. Some argue that it is a pathophysiological condition that resides in the individual, whereas others assert that it is a set of behaviors produced by and interpreted in the individual's physical, social, and cultural environment. The public health viewpoint integrates these two positions. For public health scholars and practitioners, mental illness is characterized by a set of conditions and behaviors that result from the interactions among the individual, society, and the environment.

From a medical perspective, mental and behavioral disorders are understood as clinically significant conditions characterized by alterations in thinking, mood (emotions), or behavior associated with personal distress and/or impaired functioning. Mental and behavioral disorders are viewed not just as variations within the range of "normal," but as clearly abnormal or pathological phenomena. However, a single occurrence of abnormal behavior or a short period of changes in mood does not, of itself, signify the presence of a mental or behavioral disorder. In order to be categorized as disorders, such abnormalities must be sustained over specific periods (for example, two weeks for a depressive episode) or be recurring, and they must result in some personal distress or impaired functioning in one or more areas of life.

Mental and behavioral disorders are also characterized by specific symptoms and signs, and they usually follow a more or less predictable natural course, unless interventions are made. Not all human distress is mental disorder. Individuals may be distressed because of personal or social circumstances, for instance; unless all the essential criteria for a particular disorder are satisfied, such distress is not classified as a mental disorder.

Diverse ways of thinking and behaving across cultures can influence the ways in which mental disorders manifest, but these ways of thinking and behaving are not, of themselves, indicative of disorders. Thus, culturally determined normal variations must not be labeled mental disorders. Nor should social, religious, or political beliefs be taken as evidence of mental disorder.

Two systems of classification of mental disorders are widely used for both clinical and research purposes. The World Health Organization's (1993) International Classification of Disorders (ICD-10) categorizes both physical and mental health disorders. The American Psychiatric Association's (2004) *Diagnostic and Statistical Manual of Mental Disorders* presents a classification system used only for mental disorders. Medical professionals use these two coordinated classification systems to categorize mental disorders, based on criteria sets with defining features, for diagnosis, treatment, research, and reimbursement purposes.

DIAGNOSING DISORDERS

Practitioners identify and diagnose mental and behavioral disorders using clinical methods that are similar to those used for physical disorders. These methods include the careful and detailed collection of historical information from the individual and others, including the individual's family; a systematic clinical examination for mental status; and the administration of specialized tests and investigations, as needed. Advances made in recent decades have helped to standardize clinical assessment and improve the reliability of diagnosis. Structured interview schedules, uniform definitions of symptoms and signs, and standard diagnostic criteria have made it possible for practitioners to achieve a high degree of reliability and validity in the diagnosis of mental disorders. Structured interview schedules and diagnostic symptom/sign checklists allow mental health professionals to collect information using standard questions and precoded responses. The symptoms and signs have been defined in detail to allow for uniform application. Finally, diagnostic criteria for disorders have been standardized internationally. Mental disorders can now be diagnosed as reliably and accurately as most of the common physical disorders.

PREVALENCE OF DISORDERS

Mental and behavioral disorders are found in people of all regions, all countries, and all societies. They are present in women and men at all stages of the life course. They are present among the rich and the poor, and among people living in both urban and rural areas. Recent analyses conducted by the World Health Organization (2001) found that neuropsychiatric conditions, which included a selection of these disorders, had an aggregate point prevalence of about 10 percent for adults. The WHO estimates that about 450 million people suffer from neuropsychiatric conditions, including unipolar depressive disorders, bipolar affective disorder, schizophrenia, epilepsy, alcohol and selected drug use disorders, Alzheimer's and other dementias, post-traumatic stress disorder, obsessive-compulsive disorder, panic disorder, and primary insomnia.

Prevalence rates for the disorders examined differ depending on whether the focus is on a point in time (point prevalence), a period of time (period prevalence), or the whole life of the individual (lifetime prevalence). Prevalence figures also vary based on the concepts and definitions of the disorders included in the study. When all the disorders included in the ICD-10 are considered, relatively high prevalence rates have been reported. Surveys conducted in developed as well as developing countries have shown that more than 25 percent of individuals develop one or more mental or behavioral disorders in their lifetimes.

Most studies have found the overall prevalence of mental disorders to be higher among women than among men. Much of this difference is accounted for by the differential distribution of disorders, however. Severe mental disorders are about equally common among men and women, with the exceptions of depression, which is more common among women, and substance use disorders, which are more common among men.

CATEGORIES OF MENTAL DISORDERS

The ICD-10 lists 10 major categories of mental disorders under Section F as follows:

F00–F09: Organic, including symptomatic, mental disorders

F10–F19: Mental and behavioral disorders due to psychoactive substance use

F20–F29: Schizophrenia, schizotypal and delusional disorders

F30–F39: Mood (affective) disorders

F40–F49: Neurotic, stress-related, and somatoform disorders

F50–F59: Behavioral syndromes associated with physiological disturbances and physical factors

F60–F69: Disorders of adult personality and behavior

F70–F79: Mental retardation

F80–F89: Disorders of psychological development

F90–F99: Behavioral and emotional disorders with onset usually occurring in childhood and adolescence

The ICD-10 provides clinical descriptions and diagnostic guidelines for all of these diagnostic categories. Some of the most important clinical categories are described below (these descriptions are based on those provided in World Health Organization 1993).

F00–F09: Organic, Including Symptomatic, Mental Disorders

This category comprises a range of mental disorders grouped together on the basis of their having in common a demonstrable etiology in cerebral disease, brain injury, or other insult leading to cerebral dysfunction. The dysfunction may be primary, as in diseases, injuries, and insults that affect the brain directly and effectively, or secondary, as in systematic diseases and disorders that attack the brain only as one of the multiple organs or systems of the body that are involved.

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. The impairments of the cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

F10–F19: Mental and Behavioral Disorders Due to Psychoactive Substance Use

This category contains a wide variety of disorders that differ in severity and clinical form but are all attributable to the use of one or more psychoactive substances, which may or may not have been medically prescribed. Identification of the psychoactive substance should be based on as many sources of information as possible. These include self-report data, analysis of blood and other body fluids, characteristic physical and psychological symptoms, clinical signs and behavior, and other evidence, such as a drug being in the patient's possession or reports from informed third parties. Many drug users take more than one type of psychoactive substance. The main diagnosis should be classified, whenever possible, according to the substance or class of substance that has caused or contributed most to the presenting clinical syndrome.

F20–F29: Schizophrenia, Schizotypal and Delusional Disorders

This category brings together schizophrenia (the most important member of the group), schizotypal disorder, persistent delusional disorders, and a larger group of acute transient psychotic disorders. Schizoaffective disorders are included here in spite of their controversial nature.

F20: Schizophrenia

The schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and by affects that are inappropriate or blunted. Clear consciousness and intellectual capacity are usually maintained, although certain cognitive deficits may evolve over the course of time. The most important pathological phenomena include thought echo, thought insertion or withdrawal, thought broadcasting, delusional perception and delusions control, influence or passivity, hallucinatory voices commenting on or discussing the patient in the third person, thought disorders, and negative symptoms.

F30–F39: Mood (Affective) Disorders

This category contains disorders in which the fundamental disturbance is a change in affect or mood to depression (with or without associated anxiety) or to elation. The mood change is usually accompanied by a change in overall level of activity; most of the other symptoms are either secondary to or easily understood in the context of the change in mood and activity. Most of these disorders tend to be recurrent, and the onset of individual symptoms can often be related to stressful events or situations.

F30: Manic Episode

The underlying characteristics of this disorder are elevated mood and an increase in the quantity and speed of physical and mental activity. Elation is accompanied by increased energy, resulting in overactivity, pressure of speech, and a decreased need for sleep. Normal social inhibitions are lost, attention cannot be sustained, and there is often marked distractibility. Self-esteem is inflated and grandiose, and overly optimistic ideas are freely expressed.

F32: Depressive Episode

The individual usually suffers from depressed mood, loss of interest and enjoyment, and reduced energy leading to increased fatigability and diminished activity. Marked tiredness after only slight effort is common. Other common symptoms are reduced concentration and attention, reduced self-esteem and self-confidence, ideas of guilt and unworthiness, black and pessimistic view of the future, ideas or acts of self-harm or suicide, disturbed sleep, and diminished appetite.

A depressive episode may also be diagnosed when a chronic depression of mood lasts at least several years but is not sufficiently severe, or does not include sufficiently prolonged individual episodes, to justify a diagnosis of severe, moderate, or mild recurrent depressive disorder.

F40–F49: Neurotic, Stress-Related, and Somatoform Disorders

When nervousness, anxiety, and depression are persistently or episodically combined with irrational fears, obsessive thoughts, fatigue, and a number of different somatic disturbances for which no cause can be found, the condition is called *neurosis.* Stress-related disorders are characterized by the development of anxiety, dissociation, and other symptoms that occur within one month after exposure to an extremely traumatic stressor, such as death of a parent or spouse, loss of a job, or diagnosis of a life-threatening illness. The common element in somatoform disorders is the presence of physical symptoms that suggest a medical problem when, in fact, these symptoms are not explained by a general medical condition, the direct effects of substance use, or another mental disorder. An example is hypochondriasis (the preoccupation with the fear of having a serious disease based on the misinterpretation of one’s bodily symptoms or functions).

F42: Obsessive-Compulsive Disorder

The essential feature of obsessive-compulsive disorder is the recurrence of obsessional thoughts or compulsive acts. Obsessional thoughts are ideas, images, or impulses that enter the patient’s mind again and again in a stereotyped form. They are almost invariably distressing, and the patient often tries, unsuccessfully, to resist them. The patient does, however, recognize them as his or her own thoughts, even though they are involuntary and often repugnant. Compulsive acts or rituals are stereotyped behaviors that are repeated again and again. They are not inherently enjoyable, nor do they result in the completion of inherently useful tasks. Usually the patient recognizes this behavior as pointless or ineffectual and makes repeated attempts to resist performing the behavior.

F43: Reaction to Severe Stress, and Adjustment Disorders

This category includes disorders identifiable not only on the basis of symptoms and course but also through the existence of one or the other of two causative influences: an exceptionally stressful life event producing an acute stress reaction or a significant change leading to continued unpleasant circumstances that result in an adjustment disorder. The stressful events or the continuing unpleasant circumstances are the primary and overriding causal factor; the disorder would not have occurred without their impact.

F43.0: Acute Stress Reaction

An acute stress reaction is a transient disorder that develops in an individual without any other apparent mental disorder in response to exceptional physical and mental stress and that usually subsides within hours or days. Individual vulnerability and coping capacity play roles in the occurrence and severity of acute stress reactions. The symptoms typically show a mixed and changing picture and include an initial state of "daze" with some constriction of the field of consciousness and narrowing of attention, inability to comprehend stimuli, and disorientation. Autonomic signs or panic anxiety (tachycardia, sweating, flushing) are commonly present. The symptoms usually appear within minutes of the impact of the stressful stimulus or event and disappear within two to three days (often within hours). Partial or complete amnesia for the episode may be present.

F43.1: Posttraumatic Stress Disorder

Posttraumatic stress disorder (PTSD) arises as a delayed or protracted response to a stressful event or situation (of either brief or long duration) of an exceptionally threatening or catastrophic nature that is likely to cause pervasive distress in almost anyone. Predisposing factors, such as particular personality traits or previous history of neurotic illness, may lower the threshold for the development of PTSD or aggravate its course. Typical features include episodes of repeated reliving of trauma in intrusive memories ("flashbacks"), dreams, or nightmares occurring against a persisting background of a sense of "numbness" and emotional blunting, detachment from other people, unresponsiveness to surroundings, anhedonia, and avoidance of activities and situations reminiscent of the trauma. There is usually a state of automatic hyperarousal with hypervigilance, an enhanced startle reaction, and insomnia. The onset follows the trauma with a latency period that may range from a few weeks to months. The course fluctuates, but recovery can be expected in the majority of cases. In a small proportion of cases the condition may follow a chronic course over many years, with eventual transition to an enduring personality change.

F48.0: Neurasthenia

Considerable cultural variations occur in the presentation of neurasthenia, and two main types occur, with substantial overlap. In one type, the main feature is a complaint of increased fatigue after mental effort, often associated with some decrease in occupational performance or coping efficiency in daily tasks. The mental fatigability is typically described as an unpleasant intrusion of distracting associations or recollections, difficulty in concentrating, and generally inefficient thinking. In the other type, the emphasis is on feelings of bodily and physical weakness and exhaustion after only minimal effort, accompanied by a feeling of muscular aches and pains and inability to relax. In both types, several other unpleasant physical feelings are common, including dizziness, tension headaches, and feelings of general instability. Worry about decreasing mental and bodily well-being, irritability, anhedonia, and varying minor degrees of both depression and anxiety are all common.

F50–F59: Behavioral Syndromes Associated with Physiological Disturbances and Physical Factors

This category encompasses behavioral problems that are related to physiological factors, such as sleep and sexual disorders. Sleep disorders include insomnia, substance-induced problems with sleep, sleepwalking, breathing-related sleep disorders, and circadian rhythm disorders. Sexual problems such as pain during intercourse, aversion to sexual activity, premature ejaculation, male erectile dysfunction, and lack of sexual desire are examples of disorders that often have physiological components.

F60–F69: Disorders of Adult Personality and Behavior

This category includes a variety of conditions and behavior patterns of clinical significance that tend to be persistent and appear to be expressions of the individual's characteristic lifestyle and mode of relating to him- or herself and others. Some of these conditions and patterns of behavior emerge early in the course of development as a result of both constitutional factors and social experience, whereas others are acquired later in life. Specific personality disorders, mixed personality disorders, and enduring personality changes are deeply ingrained and enduring behavior patterns that manifest as inflexible responses to a broad range of personal and social situations. They represent extreme or significant deviations from the way in which the average individual in a given culture perceives, thinks, feels, and (particularly) relates to others. Such behavior patterns tend to be stable and often encompass multiple domains of behavior and psychological functioning. They are frequently, but not always, associated with various degrees of subjective distress and problems of social performance.

F70–F79: Mental Retardation

Mental retardation is a condition of arrested or incomplete development of the mind that is especially characterized by impairment of skills manifested during the development period, skills that contribute to the overall level of intelligence (i.e., cognitive, language, motor, and social abilities). Retardation can occur with or without mental or physical condition. Degrees of mental retardation are conventionally estimated through the use of standardized intelligence tests. These can be supplemented by scales designed to assess social adaptation in given environments. These measures provide an approximate indication of the degree of mental retardation, but the diagnosis also depends on the overall assessment of intellectual functioning by a skilled diagnostician. Intellectual abilities and social adaptation may change over time, and even an individual with very poor abilities may improve as a result of training and rehabilitation. Diagnosis should be based on the individual's current level of functioning.

F80–F89: Disorders of Psychological Development

The disorders included in this category have three things in common: (a) onset invariably during infancy or childhood, (b) impairment or delay in development of functions that are strongly related to biological maturation of the central nervous system, and (c) a steady course without remissions and relapses. In most cases, the functions affected include language, visuospatial skills, and motor coordination. Usually the delay or impairment has been present from as early as it could be detected reliably and will diminish progressively as the child grows older, although milder deficits often remain in adult life.

F90–F99: Behavioral and Emotional Disorders with Onset Usually Occurring in Childhood and Adolescence

F90: Hyperkinetic Disorders

Hyperkinetic disorders are characterized by early onset (usually in the first years of life), lack of persistence in activities that require cognitive involvement, and a tendency to move from one activity to another without completing any one, together with disorganized, ill-regulated, and excessive activity. Hyperkinetic children are often reckless, impulsive, and prone to accidents, and they frequently find themselves in disciplinary trouble because of unthinking breaches of rules rather than deliberate defiance. Their relationships with adults are often socially disinhibited, with a lack of normal caution and reserve. They are unpopular with other children and may become isolated. Impairment of cognitive functions is common in such children, and specific delays in motor and language development are disproportionately frequent. Secondary complications include dissocial behavior and low self-esteem.

F91: Conduct Disorders

Conduct disorders are characterized by repetitive and persistent patterns of dissocial, aggressive, or defiant conduct. Such behavior amounts to major violations of age-appropriate social expectations; it is more severe than ordinary childish mischief or adolescent rebelliousness and is of an enduring nature (six months or longer). Features of conduct disorder can also be symptomatic of other psychiatric conditions, in which case the underlying diagnosis should be preferred.

THE CONTEXT OF MENTAL ILLNESS

The preceding discussion has summarized the psychiatric/medical approach to and classification of mental illness. In contrast to this approach, a growing literature in the social and behavioral sciences argues as follows:

> 1. *Mental illness* is a term that refers to a broad range of conditions and behaviours. For this reason, the concept of mental illness is too amorphous to be useful except as a way of speaking about the aggregate subject matter of psychiatry.
> 2. The attribution of madness to aberrant thoughts, feelings and behaviours is not inherent to the condition but is rather contingent on the social and cultural context within which these thoughts, feelings and behaviours occur.
> 3. The attribution of madness depends not only on the setting but also on the person's personal and demographic characteristics such as race, ethnicity, poverty, age and sexual identity which accentuate or ameliorate the process of stigmatization. (Aneshensel and Phelan 1999:5–6)

Based on these arguments, scholars are paying increased attention to the study of behaviors and "normality" within specific groups and social and cultural contexts. In sum, these arguments have led Horwitz (2002) to the following definitions:

> Mental diseases are conditions where symptoms indicate underlying dysfunctions, are distinct from other disease conditions, and have certain universal features. Mental disorders include all mental diseases as well as psychological dysfunctions whose overt symptoms are shaped by cultural as well as natural processes. Finally, mental illnesses refer to whatever conditions a particular group defines as such. In contrast to the concepts of "mental disease" and "mental disorder" which have valid and invalid applications, the concept of "mental illness" refers to the actual labelling process in any group and so cannot be true or false. (p. 15)

—R. Srinivasa Murthy

See also Behavioral Disorders; Bipolar Disorder; Depression; Madness and Mental Distress; Normality; Schizoaffective Disorders; Schizophrenia; Stigma.

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MENTAL RETARDATION, HISTORY OF

From ancient superstition to modern science, from old to modern empires, the history of intellectual disability is largely one of expanded possibilities rather than total change. Stigma, exclusion, invisibility, abandonment, impoverishment, even systematic extermination of intellectually disabled children and adults persist today as they have throughout history. At the same time, acceptance, visibility, inclusion, support, and self-advocacy have also become increasingly available to at least some of those same individuals. Simultaneously, one can find in the current circumstances of intellectually disabled people the echoes of the worst atrocities and best achievements that history has to offer.

Like most forms of disability, intellectual disability has gone under many names. At various times, and in various countries, people judged to have some type of difficulty with learning and abstract thought have been called fools, natural fools, idiots, cretins, aments, simpletons, imbeciles, and morons; they have been described also as fatuous, feebleminded, mentally defective, mentally retarded, learning disabled, and developmentally disabled. The question arises as to whether there is something stable, something physiologically persistent, behind those terms and the historical contexts within which their usage arose and declined. Regardless of how one answers that question, the need for a history of intellectual disability that recognizes the complexity of interaction between the name and the thing being named is clear.

The history of intellectual disability, then, should include the evolution of both the concept itself and the narrative of those to whom the concept has been applied. To use a term that is now avoided but was once the professional term of choice in the English-speaking world, the history of "idiocy" (i.e., the use of the term) is different from the history of idiocy. Until recently, however, the historiography of intellectual disability has emphasized the conceptual development and programmatic innovations over the daily lives of those with the disability. As one historian has put it, the "social marginality" of people with intellectual disabilities has, until recently, been carried over into an "academic marginality" where historians seemed to feel that people who could not learn were also not worth learning about (Digby 1996:1). In part, this simply reflects the evidence that is available. For the premodern eras, for example, we have much more evidence about the conceptual developments than about what life was like for intellectually disabled people and their families. In general, we know more about what philosophers and politicians of a given era and culture proposed for definitions and policies than we do about the quotidian reality of those covered by the definition and affected by the policies.

PREMODERN ERAS

What sparse evidence there is supports the notion that intellectually disabled people have been recognized as part of societies from the earliest times. In many cases, that recognition was harsh and violent. Early laws in ancient Greece and Rome, for example, established procedures for the killing or abandonment of infants judged to be too deformed or intellectually disabled to be valued as human. At the same time, however, scholars also point to evidence of early nomadic tribes who continued to transport members of their clans even when they had congenital physical and intellectual disabilities (Goodey 1995; Scheerenberger 1983). There is also evidence that in the Greek and Roman societies some of those with intellectual—and other—disabilities who survived into adulthood became servants or slaves in the households of the ruling classes, where they were relatively well cared for compared with the majority of the poor and oppressed (Rose 2003). The Roman philosopher Seneca complained, for example, about the blind and fatuous servant his wife kept at home even as the woman's impairments became more severe. Indeed, anthropological evidence from non-Western cultures suggests that the treatment of intellectually disabled people in preliterate societies was probably tremendously varied. As one of the anthropologists who first focused on the evidence has put it, "Nothing can be more certain than the conclusion that how the mentally retarded are seen and responded to in the non-Western world is a complex and variable matter" (Edgerton 1970:537).

Throughout the Middle Ages in Europe, this variety persisted. At the same time, as disabled beggars wandered from town to town, free but unsupported, church-related hospitals developed that provided both sanctuary and care to intellectually disabled individuals abandoned by their families. While infanticide continued to receive religious tolerance, if not sanction, the court jester tradition also placed great value on having natural fools always present and cared for, but without any real location within the social hierarchy—constant outsiders. One historian of the period notes that the custom of keeping a natural fool was so popular in Germany that by the early sixteenth century, "one finds them in the household of almost any rich and powerful family" (Midelfort 1999:248). For the most part, both intellectual and physical disability were seen in the Middle Ages as part of the "hodgepodge of normality" that made up everyday society. "There was an acceptance, at times awkward, at times brutal, at times compassionate, a kind of indifferent, fatalistic integration, without ideology but also without confrontation" (Stiker 1999:65).

By the thirteenth and fourteenth centuries, legal distinctions began to appear between lunacy and idiocy. The idiot (or "natural fool") was someone incapable of abstract thought from birth, whereas the lunatic became deranged sometime after birth. Still, even with these new distinctions, the conceptual evolution of terms and explanations for intellectual disability are much less varied than was the actual treatment of people with that impairment. Consistently, from Plato to Locke, the effort was to label and exclude those who were visibly and congenitally different. Whether seen as a joke or punishment of the gods or a materialistic imbalance of the bodily humors, the birth of a child with noticeable disabilities gave permission—even responsibility—to dispose of that which was something other than fully human. However, early on, the focus was on visible difference. The changeling, for example, was the visibly disabled child of nondisabled parents. The terms of reference were many and confusing.

It is with the empiricism of John Locke, however, that the understanding of idiocy moved from a primarily visible difference associated with congenital anomalies to include those who looked "normal" but lacked the capacity for abstract or "natural" reason. The expansion was important and laid the conceptual groundwork for the subsequent emergence of a new social response based in diagnostic expertise and therapeutic efficacy. If idiocy was not always apparent or visibly monstrous, then identification through testing and intervention through training became vital for both the protection of society and the remediation of the individual.

THE MODERN ERA

As it did with other areas of human endeavor, the Enlightenment brought a wave of scientific interventionism and governmental reform to the social awareness of intellectual disability. The emerging field of psychology built on the newly empirical approaches to the mental as well as the physical to make optimistic claims of precise identification and gradual improvement. Classification typologies became increasingly elaborate, with growing emphasis on close clinical observation and physiological examination. The official social response gradually moved on the one hand from the custodial to the therapeutic and on the other hand from tolerant neglect to aggressive confinement.

Perhaps the most famous and influential "experiment" in the development of this new psychological training occurred in France at the very beginning of the nineteenth century. When a strange, uncivilized boy was captured in southern France (the so-called Wild Boy of Aveyron), a young doctor, Jean Marc Gaspard Itard, undertook to teach this "noble savage" using the careful training of the senses consistent with the radical empiricism of Condillac and other French philosophers. Although Itard ultimately regarded his experiment as a failure, because of the lack of sufficient progress by the boy he named Victor, others took over his methods and achievements to proclaim a new therapeutic regime that gave hope for the remediation or cure of at least some types of idiocy. Throughout the remainder of the nineteenth century, there was a rapid spread of specialized idiot asylums in both Europe and North America led by a new professional class of institutional psychologists who made claims of cure or dramatic improvement through early and intensive instruction and regimentation. People such as Samuel Howe and Edouard Séguin in the United States, Johann Guggenbühl in Switzerland, Carl Saegert in Germany, and William Ireland and John Langdon Down in England began congregate residential facilities for the education and training of intellectually disabled children and young adults.

By the last quarter of the nineteenth century, this wave of optimism had subsided but the institutions continued to expand. Even with this rise of institutions, most individuals with intellectual disabilities remained the responsibility of their families or the communities where they lived. Outside the walls of the new institutions, intellectual disability remained primarily an economic problem of poverty and dependence. With the progress of industrial urbanization and the need for a stable workforce, unemployable intellectually disabled people were also portrayed as a social problem: the source of the crime and degeneracy that was seen as a growing threat to the commonweal.

THE TWENTIETH CENTURY

For much of the twentieth century, emphasis remained on classification and control of the intellectually disabled rather than on education and support. Early in the century, the intelligence test developed by Alfred Binet for the Paris schools was rapidly put to use in the United States in schools and other institutions. Here finally was an operational application of Locke's definition. What came to be called IQ (or intelligence quotient) tests were efficient, supposedly objective instruments that could identify those children who were intellectually inferior even when their physical appearance was "normal" and their intellectual inferiority mild. So precise were these new tests that a new level of mild feeblemindedness could now be identified. The psychologist Henry H. Goddard coined the term *moron* to refer to these individuals, who were said to have a mental age between 7 and 12 years. *Feeblemindedness* became the generic term in the United States for all types and levels of intellectual disability.

The rapid adoption of the IQ test not only made the placement of students into the newly emerging special education classes efficient and "scientific," it also supplied more than enough evidence for eugenicists to bemoan the growing "burden of the feebleminded" as a plague on modern civilization in both moral and economic terms. The new field of psychometrics combined with the new obsession with the scientific study of heredity to produce the pseudoscience of eugenics, whose purpose was to limit the spread of feeblemindedness through incarceration in custodial institutions and involuntary sterilization. It was a practice that reached its logical extreme with the perversions of Nazi medicine, but it was pursued to greater or lesser degrees by almost all industrialized nations and continued well into the 1960s and 1970s in many countries.

Post–World War II Developments

Throughout the 1950s and the 1960s, the familiar strands of segregation and exclusion of intellectually disabled people continued to interweave with strands of community presence and family support. By the 1960s, several parent advocacy organizations had coalesced to form a national presence in both Europe and North America, lobbying for expanded educational programs and family support. By 1970, the institutional growth in the United States had crested at just under 200,000 individuals. Buttressed by journalistic exposés and lawsuits documenting patterns of institutional abuse and neglect, a slow trend called *deinstitutionalization* began to move intellectually disabled people from institutions to the community. Individuals with intellectual disabilities themselves began to organize self-advocacy groups protesting discrimination and exclusion. Programs to support the integration of intellectually disabled children and adults in home, school, workplace, and community became the official policy in most countries in Western Europe and North America. Still, by the end of the twentieth century, thousands of individuals were still living in large, segregated facilities. In the latest terminological change, *intellectual disability* has begun to replace *mental retardation* (in the United States) and *learning disability* (in Great Britain) as the term of choice.

—Philip M. Ferguson

See also Alfred Binet; Down Syndrome; Henry Herbert Goddard; Johan Jacob Guggenbühl; IQ; Edouard Onesimus Séguin.

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MERCY KILLING

See Euthanasia

MICHAEL IV, EMPEROR (?–1041)

Byzantine ruler

The Byzantine Emperor Michael IV (reign 1034–1041 CE) suffered increasingly severe epileptic fits during his reign, and his attendants made efforts to hide his condition from the public. During public audiences and other ceremonies, they watched closely for signs of an impending fit and immediately let down curtains to hide him when they saw such signs. When out walking or riding, he was surrounded by guards who usually managed to conceal him if he became ill. The contemporary courtier and chronicler Michael Psellus, who described Michael IV's reign impartially and in detail, noted that the emperor recovered quickly after his fits. Michael IV came to power in very dubious circumstances and without any significant preparation, yet Psellus considered that he conducted himself well as emperor. Even with his condition steadily worsening, "he still supervised the whole administration of the Empire, just as if no illness were weighing upon him at all" (Psellus 1966).

—*Kumur B. Selim*

See also Epilepsy.

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MIDDLE EAST AND THE RISE OF ISLAM

HISTORY OF ARAB/ PROPHETIC MEDICINE

After the prophet Muhammad's death in 632 CE, a great expansion of the Arab Empire took place throughout the eastern Mediterranean. Under the Umayyad caliphate, local political structures remained intact, but by the Abbasid caliphate, the capital of the Arab Empire's administration became centralized in Baghdad (762 CE).

What is known about medicine and disability before Islam and during its expansion is difficult to summarize, as medical approaches were not monolithic but varied and often contradictory. There is a general consensus, however, that healing the sick was, and continues to be, considered in all legal schools of Islam, one of the highest forms of serving Allah (God), second only in importance to performing religious rituals. Despite medicine's high place in Arab-Islamic culture, the Qur'an itself seldom speaks directly of medicine except for references to the curative properties of honey, instructions for ways to wash for prayer when ill, and statements that the sick, lame, or blind are not inherently at fault for their disability. Muslims consider the text to embody the guidance and wisdom that restores and maintains both physical and psychological health. The Qur'an does not espouse a mind-body doctrine of the body, but it does use metaphors of disability such as deafness and blindness in references to God's decision to make some individuals struggle to reach the truth. Mostly, attitudes about and treatment of disease and disability in Islam are embedded within the historical development of Muslim political expansion and rule rather than derived from the sacred text. Following from this, the force and contributions of Islamic medicine during the medieval period were felt by both Muslim and non-Muslim residents of the Arab Empire.

The early ninth century marked the Hellenization of Islam, with translations of Greek, Syriac, Sanskrit, and Pahlavi medical texts into Arabic and subsequent commentaries and expositions by Arabic and Persian physicians. By the end of the ninth century, nearly all of Galen's writings had been translated into Arabic, reflecting the significant influence of his medicine in Arab scientific circles. As such, the Arab-Islamic medical tradition is based on the Graeco-Roman one, with humoral theory at its core.

Several physicians who wrote original treatises and compendiums on medical topics are worth mentioning due to their handling of disability and its treatment.

Al-Razi (Rhazes), a well-known Persian clinician who lived from 865 to 925 CE, wrote *Al-Hawi fi l-tibb (All-Inclusive Work on Medicine),* a 24-volume encyclopedia of medicine. Among other things, this work deals with hereditary diseases, diseases affecting women, and eye diseases. Ibn Sina (Avicenna) wrote *Qanun al-Tibb (Canon of Medicine),* a 14-volume work that investigated the contagious nature of pulmonary tuberculosis, described the symptoms and complications of diabetes mellitus, and examined various psychological illnesses. The *Canon* became the most authoritative reference book in European universities until the seventeenth century. Finally, Abu al-Qasim al-Zahrawi (Albucasis) lived in Cordoba, Spain, during the tenth century. Regarded as an expert pharmacist-surgeon, he wrote a manual on surgery called *Al-Tasrif li-man `ajaza `an al-ta´lif (Recourse of He Who Cannot Compose a Medical Work of His Own)* that included sections detailing methods for amputating limbs and removing foreign bodies. These books were later translated into Latin for widespread use in Europe.

As opposed to the formalized form of Islamic medicine, *Tibb al-nabi* (prophetic medicine) consists of popularized answers to medical issues drawn from the sayings of the prophet Muhammad and his companions in the Hadith. A popular statement of Muhammad's that is stressed in this type of medicine is, "God has sent down a treatment for every ailment." Other statements refer to the restoration of health by God's will. For instance, the question was raised in this literature as to whether or not God would, on Judgment Day, conclude that a person with an amputation tried to escape His will. Although natural causes of illness are recognized, God is said to inflict illness so as to test the individual's strength and ultimately restore his or her faithful character. As such, according to some sayings in prophetic medicine, illness has a redemptive quality to it. Other sayings, however, cite health as the means to strengthen faith and as a reflection of the blessing of God.

In prophetic medicine, prayer rituals and the physical positions they entail are said to provide physical, moral, spiritual, and psychological healing by distracting the individual from pain. They also are believed to exercise the body and ease ailments of the stomach, heart, and intestines. Such integrity of the body is central to prophetic medicine's message. Differences in medical approaches, however, sometimes exist within and between the Hadith of the two major sects of Islam, the Sunni and Shia. Despite their goal of imparting a religious value to medical practices, medical discussions of the Hadith are not considered part of sacred law. This collected medical advice, excluding magic and extensive use of amulets or charms, reflects the preventive approaches and medical treatments commonly practiced by the general population.

Throughout Islamic history, health concerns, both physical and mental, have been imbued with ethical, moral, and religious value. This social outlook has underpinned the establishment and operation of Muslim medical institutions. For example, multifunctional hospitals comprising libraries, pharmacies, and several wards were most often established by rulers, administrators, or other wealthy individuals and were managed by *awqaf* (charitable, religious endowment) foundations on land set aside for such purposes. Hospitals for specific ailments were also founded in this way. According to most schools of thought in Sunni Islam, the endower could participate in the administration of the donated property. This precept tended to encourage the proliferation of private endowments.

The first of their kind, institutions for lepers and the blind were built in Damascus under the Umayyad Caliph al-Walid (reign 705–715 CE). Guides were employed to help blind patients. Often patients were given stipends when they were discharged to help them return to work. Such treatment stands in sharp contrast to the situation in Europe, where lepers were burned to death by decree.

Islamic hospitals proliferated during the Abbasid caliphate (750–1257), especially under Harun al-Rashid, who established the first hospital in Baghdad. Men and women were treated separately. Special hospitals were established for mental patients during this time, as well as homes for orphans and older women. In addition, large hospitals included quarters for mental patients, and some used music therapy as a form of treatment. Treatment of mental illness was considered vital for maintaining one's honor and preserving a sound mind. These were thought of as fundamental rights in Islamic law that the state should protect. These institutions seem to have been inspired by earlier Christian efforts that established hostels for the insane and blind in the Middle East before and during the early medieval period.

Visiting the sick at home or in the hospital is encouraged in the Hadith, and the sick are asked to pray for others in return due to their presumed pure state of being. The ethics of medical care and visitation motivated the foundation of mobile dispensaries during the Abbasid period. These dispensaries extended accessibility to medical services throughout the countryside. In addition, it was decreed that physicians must visit jails, and physicians' services were made more accessible in general through the location of clinics near mosques.

MEDICINE IN MEDIEVAL ISLAMIC HISTORY

Prevalent Ailments and Disabilities

Blindness was perhaps the most common disability in the medieval Islamic world and the one most written about in Islamic medicine. It is discussed in a variety of medieval texts, including theological, philological, historical, legal, and literary. Discussions of the visually disabled dealt not only with questions of a physical nature but also with issues of spiritual blindness. Discussions of blindness also intersected with debates in Islam as an oral versus a written culture.

A number of words in medieval Arabic describe blindness, including *a'ma, makfuf, kafif,* and *darir.* The first of these words means complete disappearance of vision, the next two refer to someone who has lost his or her sight, and the last is the most polite, meaning one whose vision has gone or whose injury has resulted in blindness. The word *akmah* refers to those who are blind from birth and alludes to darkness, but most words for blindness point to physical covering or injury, not symbolic darkness or mental confusion.

From the time of the prophet Muhammad's death until the thirteenth century, contagious diseases such as trachoma, conjunctivitis, and smallpox most often caused visible disabilities. During the expansion phase of Islam, Arabs often contracted eye diseases while traveling, on pilgrimage or as a result of the slave trade. Blindness was also caused by old age, corporal punishment, and battle injury, as well as by marital practices of co-sanguinity. Starting in the tenth century, one way to dethrone a ruler was to blind him. Yet stories abound in the Hadith about blind men becoming devout believers, commanding men in battle, or predicting significant events. For example, Abu Sufyan, the father of the first Umayyad caliph, is said to have lost one eye at the Battle of Attayif and the other at Al-Yarmuk.

Because of the high prevalence of eye diseases, dissection of the eye was permitted as an exception for the pursuit of medical knowledge. For the same reason, specialization in and writing about ophthalmology emerged before other medical specializations. Hunayn ibn Ishaq, an early translator of Greek texts, wrote essays on ophthalmology that were collected in a volume called *Kitab al-`ashr maqalat fi l-`ayn (Book of the Ten Treatises on the Eye),* which became the basis for further research and commentary on the subject for rest of the medieval period.

Under Mamluk rule of Egypt and Syria (1250–1517 CE), the text *Nakt al-humyan fi nukat al-`umyan* by al-Safadi (d. 1361) formed an authoritative study on blindness and the blind. This biographical dictionary mentions elite blind individuals including scholars, Qur'an reciters, lexicographers, and famous poets as well as beggars who feign blindness or are truly impaired. In other types of literature of this period, blind people are treated with other physically disabled and marginal groups, referred to generally as *ahl al-ahat* (those with a physical impairment). Blindness is treated in one of two ways: as a simple difference, such that individuals who are different in this way are not excluded from society, or unfavorably, with the blind categorized along with women and beggars. Questions about the status of a blind person as a suitable witness or transmitter of the traditions posed legal controversies that ultimately stemmed from these two approaches.

The greatest concern related to blindness in Islamic legal and literary texts of the late medieval period is the problem of mobility and the dependence of the blind person on a guide's vision for description, transport, and social interactions. As Fedwa Malti-Douglas (2001) notes, such discussions point to the integration of blind individuals in society and how to best facilitate it. Another concern with similar implications is the act of eating, particularly at a communal meal. A final topic of discussion is the virility of the blind man, which is often presented in a positive, desirous light.

In addition to blindness, discussions about disability in the texts focus on such issues as disabilities of an orthopedic nature, especially in their relation to war or punishment. For instance, the Qur'an sanctions amputation for theft but exempts from such punishment a person who steals due to dire need. Crippling from stoning during battle is also noted in Islamic texts.

In general, the average life span during the medieval period was no more than 35 years, and infant mortality rates were very high. Leprosy, tuberculosis, typhus, scurvy, dysentery, malaria, and paralysis have also been chronicled during medieval Islam. Epidemics of plague also occurred at various points during this period, causing extremely high mortality rates.

Medical and Social Treatment of Disability and Disease

Before and after the advent of Islam, disease and disability in the Arab-Islamic world were treated in ways not unlike those seen in other societies of the time. In fact, the Islamic medical tradition necessarily integrated contributions of other cultures with the expansion of Arab territory. Islamic culture taught that all should be treated with justice, including those with disabilities, in order for balance in society to be achieved. Just as the balance of the humors formed the basis for the medical treatment of disability and disease, this social balance formed the moral basis for the system of charitable works and mutual responsibility in Islamic societies.

Cauterization, cupping, bleeding, setting of bones, and herbal remedies were widely used to treat disability. The populace attributed deviations from general health not only to imbalance of the humors but also to malevolent, supernatural forces or spells; this was especially the case with mental illness. On the other hand, disability was sometimes viewed as conferring luck or blessedness on a person, who could also be seen as having special insight or as being protected from the evil eye. Specific folk treatments varied according to region, ethnic tradition, and the availability of particular medicinal/magical ingredients, but they largely included amulets marked with Qur'anic passages or incantations.

Aside from the controversial issue of blindness, political leaders were generally not barred from ruling due to disability. For example, the Caliph Uthman was said to have scars from smallpox. Although others debated the point, al-Safadi claimed that prophets could be blind but not deaf, as this would hinder the central, oral character of Islamic cultural transmission. Famous poets, philosophers, and other literati were also known to have various disabilities. Records show that women cared for wounded soldiers and for those who became disabled by fighting in wars.

Mental illness is acknowledged and discussed in the Qur'an and Hadith, and during the medieval period, doctors were often appointed to visit asylums to care for patients there. Suicide is forbidden by Islamic law. Although there are no direct or explicit phrases in the Qur'an or Hadith that refer to this issue, the judgment rests on the idea that Allah created life and therefore humans do not ultimately own it. Aside from mental illness, the psychological state of a sick person should, as much as possible, be one of reservation, restraint from complaint, attempts at cheerfulness, and deference to God.

DISABILITY IN THE CONTEMPORARY ISLAMIC WORLD

With the advent of the modern period, particularly after the Napoleonic invasions of Middle East territories in the late eighteenth century, the Ottoman Empire began to accept Western medical approaches as a way to modernize the regime. This integration continued during the period of colonialism and has continued in postcolonial Middle Eastern and other Islamic societies. Still, humoral medicine and Islamic medical texts have continued to influence the treatment of disease and disability even up to the present day.

People in the Islamic world, which entails a vast territory, currently seek both biomedical and traditional folk remedies to address illness and disability. Acceptance of the disabled population varies depending on the country and the conflicts therein. For the general Muslim population, having a disability exempts one from making pilgrimage to Mecca, considered one of the five pillars of Islam.

Organized groups of disabled individuals currently advocate for greater rights and support; these include the National Association for the Rights of Disabled Persons and Youth Association for the Blind, both based in Beirut. Much of the work done on behalf of the disabled community in Islamic countries is organized, administered, and funded by nongovernmental organizations in connection with these grassroots organizations.

Disabilities that commonly exist today in the Arab world and in other Islamic countries include infectious diseases such as tuberculosis and AIDS, chronic illnesses such as heart disease and diabetes, congenital disabilities, cognitive and mental disabilities, and war-related injuries, including quadriplegia, paraplegia, and various amputations related to land mine injuries. Religious debates continue among Muslim jurists on the topics of organ transplantation and genetic engineering.

—Sandy Sufian

See also Disability Culture; Religion.

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MILAN CONGRESS ON THE DEAF

See Deafness, Milan Congress of 1880 on

MINDFULNESS MEDITATION

There are two broad forms of meditation, and although one must be careful not to see them as dichotomous, most forms of contemplative practice across cultures and various traditions tend to correspond loosely to one of these two broad forms. One form emphasizes a single point of focus, excluding all other mental content. This point of focus might be an object, image, thought, prayer, or chant. This form of meditation, referred to as *Samatha* in the Buddhist tradition, emphasizes single-pointed concentration as a means of closing out all distractions and disturbances, resulting in a profound sense of tranquility and calm. The other form of meditation, referred to as *Vipassana* or "mindfulness" in the Buddhist tradition, has a very different emphasis. Mindfulness meditation involves an *inclusive* approach to one's ongoing experience and promotes insight through awareness of the present moment. This inclusive awareness occurs through one's nonjudgmental acceptance of everything that arises in the mind and body as one observes each moment as it arises and then dissipates. One accomplishes this by using the sensations of breathing as a means of staying in the present moment. The breath offers a practical means of centering oneself, as it is something that is always present; it also offers a constellation of subtle sensations and movements when experienced through careful attention.

The formal practice of mindfulness can be conducted in a number of ways, including being very still, as in the traditional sitting meditation, and in a form often called *walking meditation.* However, since not everyone can walk, and since the spirit of this method of meditation practice does not depend on walking per se, the term *walking meditation* is really a misnomer. More precisely, this form of mindfulness is *moving meditation,* in which one slowly and deliberately moves one's body (or part of the body) in space, focusing on the sensations of one's breathing and the physical sensations associated with movement. Access to such moving meditation is universal, although the nature of the movement may differ radically in form and degree among different individuals.

The body of research and theoretical literature on the relationship between meditation and health promotion has been growing rapidly in recent years. Recent interest in meditation in relation to health has focused a great deal on mindfulness meditation. This increased attention stems from the realization that an expanded conceptualization of health involves perceiving it as a multitude of experiences that are undergoing continuous change. In order to actualize such an approach to health, however, one must gain an *awareness* of the multitude of changing experiences one is a part of at any given moment. Mindfulness meditation is one means of practicing this awareness.

Methods of contemplative practice that foster self-awareness pose a universal challenge. Because the experience being fostered by any form of meditation is the *process* of attention, without a specific goal or end point, nobody, in fact, has a relative advantage. Because meditation is not based on any external criteria for "success," it constitutes a welcome paradox in that it is an intensely personal experience that is universally accessible. Individuals who make certain types of adaptations to various meditative practices will likely encounter the same discoveries and frustrations as those who make very different adaptations. Although each person accesses the contemplative process somewhat differently, all enter onto the same path.

Meditators tend to understand, through direct experience, that when it comes to practicing a greater awareness of one's mind and body, the challenges are similar from person to person regardless of individual differences. Whether one walks or uses a wheelchair, sees clearly or has a visual impairment, has free movement or chronic pain, the process is very much the same. As such, meditation is an inclusive process that each person must embark on for him- or herself, pursuing no goals, casting no judgments, and accumulating no achievements. It is this process of personal observation that lends meditation its "universal design."

—Daniel Holland

See also Complementary and Alternative Medicine.

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MIR NASIRUDDIN HARAWI

(?–1708)

Afghan Sufi

The Afghan Sufi Mir Nasiruddin Harawi, living at Burhanpur in northern India, appears among the Persian accounts of Sufism, with the usual attributes of piety, independent thinking, charitable giving, rejection of gifts to himself, and vigorous rebuttals of overtures by wealthy people. As a Sufi, Mir Nasiruddin was unusual in that he had been severely disabled since his youth, with paralysis of his legs and left arm. His right arm still functioned, and he worked as a Qur'an copyist, earning enough to keep himself alive. People revered him for his abstemious life, but Mir Nasiruddin gave them a hard time if they were among the powerful. When he denounced the governor of the province, Munawwar Khan, for greed and abuse of power, Munawwar responded correctly by asking the Sufi to guide him, but Mir Nasiruddin did not soften easily. He cited himself as an example of disobedience to Allah, which had resulted in his being crippled. This was not orthodox Islamic teaching, but his aim was to put the fear of God into the governor. He is also reported to have turned down a grant of land from the emperor Aurangzeb.

—Kumur B. Selim

See also Middle East and the Rise of Islam.

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MIRACLES

Western cultural traditions historically linked with Christianity have, from an early period, associated particular classes of disability with miraculous healing: the blind see and the lame walk more readily in the New Testament than in the Old. In addition to cures of the lame, deaf, dumb, and blind, stories of miracles encompass the relief of ailments ranging from leprosy to that ultimate disability, death.

Patterns established from the earliest centuries continued through the Middle Ages and, in some cases, continue to the present. In medieval miracles, disabilities seem to have been linked to gender and status. In a sample of nearly 3,000 cases (mainly from medieval England), 20 percent of the disabilities linked to "crippling" ailments (usually of the legs) were reported by lower-class women, but only 14 percent of men of the same social level reported crippling ailments; very few upper-class women, and only 7 percent of the men of this class, reported such disabilities. A second very common disability was reported as "blindness," which affected some 16 percent of all women and 11 percent of men from the lower classes, whereas only 3 percent of upper-class pilgrims reported this ailment. This suggests that the lame and the blind pilgrims at medieval shrines were generally of the lower classes and predominantly women. This could be accounted for by the lower classes' limited access to medical treatment (which was costly), poor environmental and living conditions (cold, damp quarters; dietary deficiencies), and perhaps a tendency for more women than men to suffer conversion reaction symptoms. On the other hand, upper-class folk distanced themselves from the lower by reporting symptoms that were often quite specific (suggesting that their position enabled them to consult with doctors) or by reporting "miracles" that had nothing to do with healing; this type was reported by only 3 percent of women and 13 percent of men of the lower classes, but was claimed by 23 percent of the upper-class males.

The most common disabilities, then, resulted in afflictions of the limbs and blindness, reputedly "cured" by a saint or at a holy shrine. It should be understood, however, that the medieval concept of a "miracle" was quite flexible: a miraculous cure could be (a) partial or incomplete, (b) delayed or gradual, or (c) temporary, with succeeding relapses. Even under these conditions, the "cure" was considered a miracle and recorded as such. As for the underlying mechanisms that may explain some of these releases from disability, many of the afflictions reported seem to have been self-limiting, chronic but subject to remission, and psychogenic.

Today's reported cures from places such as Lourdes follow, in general, the same pattern as that suggested by medieval data: The element of hopeful expectation that precedes a pilgrimage, the atmosphere of heightened emotion at the holy place itself, and the sight of examples of canes and crutches left by "cured" visitors create a psychophysiological context in which some disabilities seem to be, at least partially or temporarily, relieved. Apart from the religious context, in the world of modern medicine the curative efficacy latent in the mind of the patient has come to be appreciated; accordingly, medical professionals now tend to treat the whole being while attempting to alleviate the pain and suffering of physical disability.

—*Ronald C. Finucane*

See also Religion.

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MOBILITY AIDS

Mobility is a fundamental human need, an important component of the achievement of other goals of independence. Assistive technology—that is, technology that assists individuals with disabilities in being mobile—includes devices that aid in ambulation, wheeled bases that provide mobility for individuals who do not use their lower extremities for ambulation, and personal transportation vehicles used in the community.

Individuals with disabilities may use devices such as lower limb orthotics to enhance their stability during ambulation. Individuals may use lower limb prosthetics if they have acquired disabilities through amputation or if they were born with partial limbs.

Stability during ambulation can be enhanced through the use of common devices such as canes and walkers. Canes are available in several designs, from a single tip to a "quad"-tip base for added stability. Different styles of walkers are also available; some have four rubber feet, whereas others have two rubber feet and two wheels to enable the user to shift the device forward more easily during ambulation. Some walkers are equipped with baskets for carrying objects and fold-down seats for the convenience of users who may need to sit and rest during the course of travel.

A variety of manual wheelchair bases are available to enable individuals to move about in the community. For decades, manual wheelchair design was dominated by heavy, chrome-plated frames, but today many lightweight options exist, with designs utilizing alternate materials such as aluminum, titanium, and composites.

Powered wheelchair frames, which are also available in a variety of styles and materials, enable users to achieve independent mobility if they can operate a standard joystick or specialized controller.

For the users of either manual or powered wheelchairs, proper seating and positioning are required to ensure the maximum opportunity to use the bases independently and without complications such as pressure sores and scoliosis. Commercially available modular seating components and custom-fabricated cushions that exactly match the contours of individual users make such proper seating and positioning possible.

Personal vehicles can also be considered devices that serve as mobility aids for individuals with disabilities. Adaptive equipment such as accelerator and brake buildups, lever controls, and steering wheel posts may be installed in automobiles to enable individuals with disabilities to operate them safely. High-tech joystick controllers may also be installed to allow individuals to operate the acceleration, braking, and turning functions of motor vehicles.

Safe restraint is important for all users of personal vehicles. For individuals who use mobility bases, the type of securement used to anchor the base to the vehicle must take both safety and independence issues into account.

Assistive technology and universal design features of public transportation vehicles also help individuals with disabilities to achieve independent mobility in the community. Examples include buses with front-end kneel-down capability and airplanes with increased clear space for maneuverability.

—*Glenn Hedman*

See also Wheelchair; Wheelchair, Electric; Wheelchair, History of.

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MODALITIES

The term *modalities,* as used in physical rehabilitation, refers to techniques of application of therapeutic heat and cold, whether by direct transfer of heat from a warmer body to a cooler or by conversion of another form of energy to heat. Direct methods of heat transfer include convection, conduction, and radiation. Examples of these methods include Fluidotherapy, hot packs, and infrared bulbs, respectively. Diathermies (from the Greek *dia,* "through," and *thermi,* "heat") are examples of heating by conversion and include ultrasound, shortwave, and microwave diathermy. Ultrasound converts a high-frequency sound wave (i.e., a longitudinal compression wave) into heat. Shortwave uses radio frequency electrical currents. Microwave is an electromagnetic wave, similar to radar, that is transmitted even in a vacuum. The direct methods of heat transfer are also direct methods of cooling, but in the reverse direction; that is, the human body, or some part thereof, is the warmer body from which heat is transferred to the cooler, as with cold water or cold packs. The latter transfers heat by conduction and, to some extent, radiation. If the cold water is moving, then all three modes of transfer are involved, especially convection.

Physiological effects of heat that may be therapeutically useful include increased extensibility of structures made from collagen, such as burn scar and joint capsular contractures, relief of muscle spasm (but not spasticity), relief of pain, and possibly increased blood flow (but see the discussion of contraindications below). Physiological effects of cold that may be useful include decreased blood flow, prevention of swelling in acute trauma (if combined with rest, compression, and elevation), pain relief, and temporary relief of spasticity. For example, an ice pack applied to the muscles in the calf may remove clonus, a manifestation of spasticity, for up to 90 minutes. This, combined with prolonged static stretch, may improve gait in patients with stroke or central cord syndrome.

Vigorous heat has the following characteristics: The highest temperature is at the site of the pathology; the temperature is brought rapidly to tolerance levels and held there for relatively long periods, such as 20 minutes. Vigorous heat is reserved for chronic processes. It can be achieved in deeply located structures only with the diathermies; however, vigorous heat should not be considered synonymous with the diathermies, as superficial structures, such as burn scar, can be heated vigorously with superficial heating agents.

On the other hand, mild heat can be used even in acute processes, because the acutely inflamed tissues are not heated to tolerance levels. For example, a hot pack can be used over lumbar musculature in spasm associated with a herniated disc because the depth of penetration of the hot pack is only a few millimeters and is not close to the pathologic area. Paraffin is particularly suitable for burn scar, as it helps soften the scar as well as make it more extensible and amenable to stretching therapy.

General contraindications to heat include lack of sensation in the area to be treated, obtundation (dulled or reduced level of alertness or consciousness) of the patient, ischemia in the area to be treated, and cancer in the area to be treated (although special oncology centers may use heat as an adjunct to radiation or regional chemotherapy). General contraindications to cold are the same, except for the cancer; safety in the latter has not been established.

Specific contraindications to shortwave and microwave include the presence of pacemakers and metallic implants. Application near the eyes should be avoided, even with shielding, which does not provide adequate protection. Ultrasound can be used in the presence of metal implants, but safety in the presence of synthetic resins has not been established. Any of the diathermies should be used only with great caution, if at all, in pregnant women.

—Barbara deLateur

See also Occupational Therapy; Physical Medicine and Rehabilitation; Physical Therapy.

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MODEL OF HUMAN OCCUPATION

The model of human occupation is a theoretical framework developed in occupational therapy to guide services for disabled persons. It is the most widely used model in occupational therapy and is also used by other rehabilitation professionals. As its name implies, this model focuses on occupation, which is defined as the individual's engagement in work, play, or other daily living activities within his or her physical, temporal, and sociocultural context. The model seeks to explain how impairments affect the way persons engage in and experience their occupations. It focuses on how persons are motivated toward and choose what they do, how they organize their everyday behavior patterns and routines, and how performance is shaped by subjective experience.

According to the model of human occupation, the choices people make to engage in occupations emanate from a drive for action mediated by thoughts and feelings about personal effectiveness, what is important and meaningful, and what is enjoyable and satisfying to do. The model highlights how impairments can influence and resonate with a person's sense of personal effectiveness and what a person holds as important and enjoyable. It proposes that people organize their actions into recurrent patterns that are regulated by habits and roles. Habits are learned ways of doing things that unfold automatically. Roles are internalized attitudes and ways of behaving that serve as a framework for looking out on the world and for acting. The model underscores the ways in which impairments can disrupt or pose challenges to developing habits. It also calls attention to how societal attitudes can hinder access to roles. This model conceptualizes the capacity for doing things as involving not only objectively defined abilities and impairments, but also subjective experience. Thus, the model emphasizes the lived experience of impairments as a major factor in what a person can and cannot do.

The model of human occupation conceptualizes the physical and social environment as providing opportunities, resources, demands, and constraints that may affect each person's motivation, patterns of action, and performance. As with personal factors, the model underscores how the impact of physical and social environmental characteristics can be altered when a person experiences impairments. It also recognizes that physical and social environments can present significant obstacles, ranging from architectural barriers to social injustice.

More than 20 assessments have been developed (including substantial empirical validation) for use with the model of human occupation. The assessments emphasize capturing the disabled person's experience and point of view. Although some involve observation of the disabled person, most are designed to give the disabled person an opportunity to report directly his or her own perceptions, perspectives, desires, and priorities. Services based on this model do not focus on changing impairments per se; instead, they focus on how a person can be supported to achieve the kind of life he or she wants. The model emphasizes that services should be based on the client's desires and experiences. It emphasizes that achieving change ordinarily involves both physical and social environmental alterations as well as changes within the individual (e.g., changes in attitudes, habits, roles, and ways of performing).

To date, more than 300 works have been published relating to the model of human occupation. Approximately one-third of these report on empirical studies that have examined the theory and/or utility of the model.

—Gary Kielhofner

See also Employment; Occupational Therapy; Work Incentives.

Further Readings

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Websites

MOHO Clearinghouse, http://www.moho.uic.edu

▣ MODELS

A model is a conceptual tool. Models are useful for making sense of reality and for achieving consensus. They help us to see both the forest and the trees, and they ensure consistency of terminology and usage. In the field of disability, the debate over models and definitions has been particularly heated and long running. This entry explores why models of disability are important and then analyzes four different models, selected on the basis of their influence and significance. The final section of the entry explores how models have been applied in practice and presents recommendations about resolving the models debate.

THE IMPORTANCE OF MODELS

Disability is a complex, multidimensional, scalar concept. Whereas human beings have had impairments throughout history and prehistory, understandings and definitions of impairment and disability have varied in different societies and at different times. No universal, global definition of disability is possible, and there are many different and often incompatible approaches to the problem. Key terms—such as *impairment* and *disability*—are defined in various ways and for different reasons within individual cultural contexts, which can cause confusion. Additionally, translations between languages, cultures, and contexts contribute another layer of complexity.

Disability models are parts of a larger system of understanding and knowing the world. For example, a model is based on a set of definitions and leads to particular schemes of classification and measurement. A model is therefore a map of the relationships among concepts, a way of describing and explaining the complex phenomenon that is disability. For policy makers, a model may be part of the process of

Table 1 Definitions: Nagi's Model (1965)

Term	*Definition*
Pathology	Interruption in body processes
Impairment	Anatomical or physiological abnormalities and losses
Functional limitation	Restrictions on ability to perform normal role tasks and obligations
Disability	Pattern of behavior

distinguishing between disabled people and nondisabled people, which might be important in allocating welfare benefits or entitlement to services to individuals or in planning provision for populations. For clinicians and rehabilitation professionals, a model may be part of the process of assessing interventions, which may enable judgments as to whether a therapy or training method reduces pathology, increases functioning, and affects social roles. For social scientists, a model may clarify the causes of disadvantage, help analysis of the relationship between individuals and wider social environments and cultural contexts, and prioritize changes aimed at reducing social exclusion or disadvantage. For disabled people themselves, a model is a way of understanding the world that has implications for explaining the disability experience and hence has impacts on personal identity and political action.

To be effective, a model needs to be clear and simple. Yet clarity and simplicity make any model vulnerable to challenge. Particularly in regard to a complex and contested phenomenon such as disability, any model may be criticized for not providing a full picture. This explains why debates around models of disability are so important and sometimes so bitter. The challenge to traditional models of disability lies at the heart of the challenge of the disabled people's movement, particularly in the United Kingdom. The self-organized groups that developed among disabled people in the United Kingdom, the United States, and many other countries during the 1970s and 1980s were not just campaigning for better social provision or social inclusion, but for a radical redefinition of disability itself. In other words, the debate about models is not just an abstract academic problem of definitions and classifications; rather, it is a question of political struggle and personal identity.

NAGI'S MODEL OF DISABILITY

The dominant North American model of disability was developed by the sociologist Saad Nagi (1965) in the context of rehabilitation. Nagi's definition of impairment includes congenital abnormalities that may not be associated with pathologies and allows for variation of impairment along many different dimensions, which may influence the nature and degree of disability. Not every impairment results in a functional limitation, and functional limitation can arise from nonimpairment causes. Nagi's definition of disability, particularly as later refined (Nagi 1977, 1991), is dynamic and allows for social context. Patterns of behavior associated with disability are influenced by impairment and limitation, by the individual's own reaction to and definition of the situation, and by the reactions and definitions of others. Nagi (1991) later clarified that environmental barriers are an element in disability. Nagi's model has been used as the basis for the Americans with Disabilities Act, for almost all disability social policy in the United States, for statistics at United Nations and European Union level, and in many other contexts.

THE ICIDH

The International Classification of Impairments, Disabilities, and Handicaps, or ICIDH, was developed by Philip Wood, Elizabeth Badley, and Michael Bury for the World Health Organization in the 1970s and published in 1980. This model distinguishes among impairment (the medical problem), disability (the resulting functional limitation), and handicap (the social disadvantage resulting from impairment or disability that limits or prevents the fulfillment of the individual's social role). Impairment is a necessary, but not sufficient, cause of disability, whereas disability in turn is necessary but not sufficient for handicap. The aim of the developers of the ICIDH was to make the social context of disability clear. Previous

Table 2 Definitions: ICIDH (1980)

Term	*Definition*
Impairment	Loss or abnormality of psychological, physiological, or anatomical structure or function
Disability	Restriction or lack of ability caused by impairment
Handicap	Disadvantage for an individual in fulfilling appropriate roles

approaches had been dominated by a narrow focus on health and disease, whereas the new model used the handicap concept to emphasize social disadvantage.

It has been argued that this model, although not without its problems, has been a useful tool in assessing the social needs of disabled people. Despite the utility of the ICIDH for assessing the social needs of disabled people and situating persons with impairments in a wider social context, it has been widely contested by disability movements, particularly in the United Kingdom. The British Council of Disabled People—and subsequently other national and international movements—has rejected the ICIDH, labeling it a "medical model" or "individual model" or "personal tragedy theory." Critics have claimed that the causal relationship in the ICIDH starts with individuals and their impairments, which cause their disabilities or incapacities, which then make them vulnerable to handicaps or social disadvantages. This is seen as "blaming the victim" and as placing insufficient emphasis on the social barriers that cause problems for people with impairments. For many disabled activists, the term *handicapped* is offensive; it is associated with outdated social attitudes and organizations and is linked to the idea of begging and dependency through an association with "cap in hand." It should be noted, however, that this is a false etymology, as the term *handicap* derives from horse racing, not begging.

Although the framers of the ICIDH intended to create a social model, in practice approaches inspired by the tripartite definition tend to slip into individualist and medically focused remedies. Questions of social context and meaning are often neglected when the model is operationalized. The ICIDH has perhaps unfairly attracted and focused the generalized opprobrium directed toward traditional approaches to disability. Many disabled people have experienced negative cultural stereotypes and assumptions based on the medicalization of disability. Undoubtedly, the idea that disabled people are defined by their mental or physical deficits is a major obstacle to both self-esteem and social inclusion. But the framers of the ICIDH explicitly wanted to challenge this medicalization, and the ICIDH is not the cause of the widespread devaluing of disabled people. Opponents of the "medical model" have created a straw man that stands for medicalization, prejudice, and the devaluing of disabled people. It is difficult to find any authors who espouse such a "medical model" or deny the importance of social barriers and discrimination in the lives of disabled people.

THE SOCIAL MODEL

The social model of disability was developed by the Union of the Physically Impaired against Segregation (UPIAS), a small group of disabled people in England in the 1970s. Inspired by Marxist politics, UPIAS retained a concept of impairment (physical impairment) but stressed that disability should be defined as the relationship between people with impairments and a society that excludes them:

> 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. Disability is thus a particular form of social oppression. (UPIAS 1975:14)

Disabled Peoples' International (DPI) revised these definitions slightly in 1982 as shown in Table 3.

Michael Oliver used these definitions in *The Politics of Disablement* (1990), a book that was a founding text in disability studies. However, Oliver usually used the terms *medical tragedy theory* and *social oppression theory* in preference to *medical model* and *social model.* UPIAS and Oliver—and authors and organizations that followed them—succeeded in stressing the social structures and social barriers that oppress people with impairment. Disability is an additional burden that is imposed on people with impairment. Thus, the social model soon became reduced to a

Table 3 Definitions: Social Model, DPI Version (1982)

Term	*Definition*
Impairment	Functional limitation within an individual caused by physical, mental, or sensory impairment
Disability	Loss or limitation of opportunities to participate in the normal life of the community on an equal level due to physical and social barriers

slogan: "Disabled by society, not by our bodies." Social model approaches became associated with political campaigns for antidiscrimination legislation and barrier removal. The corollary of this approach was an increase in the tendencies to minimize the significance of impairment and to make social oppression the basis of disability as a political identity.

These tendencies are responsible for several logical flaws of the DPI version of the social model. First, the definition of impairment is circular: Impairment is defined as a functional limitation caused by impairment. Second, unlike the UPIAS definition, there is no mention of impairment in the definition of disability. This leads to the difficulty that other social groups—such as people who experience racism or sexism or poverty—could be included within the social model definition, even if they do not have impairments. In the attempt to decouple disability from impairment, impairment ceases to be a qualification for being a disabled person.

The British social model is not the only version of the social approach. For example, in the United States, a focus on social oppression and social barriers is encapsulated in the "minority group model," as theorized by Harlan Hahn (1988) and others. This suggests that people with disabilities (as defined in the Nagi model, for example) form a minority group that experiences oppression. The minority group version of the social model also places highest priority on barrier removal and other social change rather than medical or rehabilitation interventions. In the Nordic countries, a "relational model" similarly situates the experience of disabled people in a broader social context.

Most disabled-led political campaigns worldwide give highest priority to the improvement of the quality of life of disabled people through the reduction of discrimination and barriers. British activists have gone further than others in actually redefining the word *disability* to refer to oppression or barriers rather than to "impairments." Whereas activists in most other English-speaking countries favor the term *people with disabilities*—to signal that functional limitation is only one aspect of a person's overall identity—Britain has favored the term *disabled people,* to signal that people are disabled by society. Representatives of the British Council of Disabled People campaigned for the world body—Disabled Peoples' International—to follow their lead in rejecting the ICIDH definitions when it was formed in 1981.

In practice, the distinction between the "barriers" and "minority group" versions of the social model is not clear. In other documents, the U.K. disability movement referred to itself as a minority group from the outset, even though the formal definitions do not include this conception. As observed earlier, without a conception of a minority group of people with impairments who face oppression and barriers, the DPI model runs into the major difficulty that it does not specify the class of people it defines. Equally, U.S. discussions of the minority group model make it clear that people with disabilities are excluded by social barriers and an oppressive social relationship, although this model is weaker than the U.K./DPI version in not defining disability as barriers and oppression.

However, the implicit combination of "barriers" and "minority group" approaches within most social models does conceal tensions. In policy terms, should political action be directed at removing structures and barriers to promote equality of opportunity, or should it be directed at benefits and protections for a disadvantaged class of individuals? In terms of identity politics, the choice is between an attempt to minimize the differences between disabled and nondisabled people and the drive to celebrate disability identity, cultural distinctiveness, and disability pride.

Conversely, the social model has been criticized for neglecting the role of impairment and personal experience, and for being difficult to apply to groups of disabled people other than the people with physical impairments by whom it was devised. Often, these criticisms have come from within the disability movement

Table 4 Terms: ICIDH and Social Model, Thomas Version

ICIDH	*Social Model (Thomas Version)*
Impairment	Impairment
Disability	Impairment effects
Handicap	Disability

or disability studies, as activists or researchers have tried to operationalize the social model or think through its implications.

Some have claimed that there is no intrinsic contradiction between the ICIDH and the social model of disability, only a difference in terminology: Where the ICIDH talks about *handicap,* the social model uses the term *disability.* In attempting to deal with the common critique that the social model ignores impairment, Carol Thomas introduced an additional level of "impairment effects" into the social model binary in her book *Female Forms* (1999). She defines these as restrictions of ability that are caused by impairment, not by social relations. Although Thomas might resist this implication, the consequence might be to generate a familiar tripartite structure, as shown in Table 4. However, "handicap" (ICIDH) is the experience of disability in a social context, whereas "disability" (Thomas) places the causal emphasis on the society or environment that excludes or oppresses the individual who has an impairment by failing to meet that person's needs by actively discriminating unfairly against him or her.

THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH

A recent revision of the World Health Organization approach has attempted to bridge the impasse between "medical model" and "social models" by sidestepping the definition of the word *disability.* The International Classification of Functioning, Disability, and Health (World Health Organization 2001), sometimes called the ICIDH-2 but better known as the ICF, uses *disability* to refer to the entire process rather than to any element in the chain. It is described as a "biopsychosocial model" in an attempt to offer a way forward from the increasingly sterile debate over models and definitions. The ICF sees disability as the outcome of interactions between the features of the individual and the physical, social, and attitudinal world.

As well as avoiding the "disability" controversy, this approach has the dual advantage of stressing the social context in which individuals are enabled or excluded while not ruling out the roles of bodies and medicine. No comprehensive analysis of the ICF has been conducted to date from a disability studies perspective. However, initial reaction from several authors has been skeptical, given the model's origins within the discredited ICIDH schema. Professionals, researchers, and policy makers have welcomed the ICF. More than 150 papers have been written on or about the ICF, none of which has used it as a medical classification. This suggests that the ICF avoids the problems of the ICIDH and can be operationalized as a classification of participation and environmental interaction. DPI is a full supporter of the ICF and has officially adopted it for the UN Disability Convention.

MODELS IN PRACTICE

It has been demonstrated that the debate about models is as much about politics and identity as it is about definitions. The original ICIDH model was developed by experts to help researchers and policy makers. The UPIAS model was developed by disabled people themselves as a tool for social change. For activists, the medical/social model divide stands for the rejection of traditional approaches to disability that revolve around curing or preventing impairments. The "medical model" is equated with medicalization and the prejudice that suggests having an impairment makes an individual inferior, incapable, and dependent. The social model mandates and places high priority on barrier removal and social inclusion rather than medicine or rehabilitation. Instead of special provision based on impairment, the social model suggests that barriers should be removed so that disabled people can access mainstream services. Rather than counting the numbers of people with impairment, the social model suggests that the focus should be on discrimination and prejudice.

The social model has implications for personal identity as well as for policy and practice. It has

Table 5 Disability as the Outcome of Interactions: Terms in the ICF Model (2001)

Body function and structure
Activity
Participation
Environmental factors

proved hugely effective in enabling people with impairments to move from a position in which they believe they themselves are the problem to a position in which they identify society as the problem. Psychologically, individuals move from a poor self-image based on self-pity to a strong political identity based on anger against a disabling world. For many, this is also a move from being an isolated individual to being a member of a vocal minority group, based on solidarity, resistance, and pride. The self-esteem benefits that the social model has for individual adherents help explain why the social model is an article of faith for many in the U.K. disability movement and why debates about revising or replacing the social model have been so heated and acrimonious.

UPIAS activists never denied that impairment is important. They did not argue against medical care, only against the discriminatory ways in which it is delivered. Yet the consolidation of the social model through identity politics has led some activists to express opposition to any impairment-based approach. For example, there has been rejection of medical research, therapies, and attempts to prevent impairment; opposition to surveys of the numbers of people with impairment; and rejection of mono-impairment organizations as well as services provided to people on the basis of impairment distinctions. Because the social model has become a litmus test for progressive approaches to disability, particularly in Britain, interventions based on the ICIDH definitions have been rejected. For example, a government advertising campaign to challenge prejudice against disabled people used the slogan "See the person, not the disability." The disability movement rejected the initiative because, activists argued, the slogan should have been phrased "See the person, not the impairment." Equally, the 1995 Disability Discrimination Act (U.K.) has been challenged by many activists because it rests on a definition of disability as a medical condition.

Yet applying and implementing social model approaches is difficult in practice, and sometimes impossible. Unless impairment is part of the definition of a disabled person, no protected class can be identified in legislation. Without counting people who have impairment, it is difficult to predict the numbers of users of services and to create adequate provision. The implementation of universal design and the barrier removal mandated by antidiscrimination legislation have led to huge improvements in environmental access. However, some argue that an entirely barrier-free world is a utopian dream, for several reasons: because the natural environment cannot be made accessible, because it is impractical to make many existing buildings or systems accessible, and because different impairments necessitate different accommodations, some of which may be mutually contradictory.

The social model has huge rhetorical power as a social critique and mobilizing force. It also has great moral power: If society has constructed disability, then it has a duty to remedy the situation and remove barriers. But the model is difficult to operationalize and implement, and it is misleading as an explanation of the social world. The ICIDH may have been more coherent, but it failed to place a high enough priority on addressing the social factors that cause problems for people with impairments. Moreover, the ICIDH was never likely to inspire political allegiance or radical action by and on behalf of disabled people. In practice, the ICIDH and similar models risk collapsing disablement back into impairment-based approaches and neglecting the broader structural causes of the disadvantage faced by disabled people.

The ICF was developed over seven years with continuing input from DPI, the European Disability Forum, and a variety of other organizations of and for disabled people. The ICF has been adopted by DPI because it highlights the role of environments, accommodations, and discriminations. To date, it appears that applications of the ICF have avoided collapsing the social aspects of the experience of disability into individual, medical explanations. Yet the social model approach remains favored by disabled people's organizations in the United Kingdom and is influential worldwide.

Disability is a complex, multidimensional, scalar concept. As Irving Zola (1989) and many other authors have pointed out, impairment is part of the human condition. Over a lifetime, all individuals experience limitations, vulnerabilities, and permanent or transitory illnesses or impairments. Impairment per se cannot therefore be the defining criterion for a disabled person, although the presence of impairment—or belief that it is present—is necessary for a person to be defined as disabled. The category "disabled people" exists only because social definitions and thresholds have been adopted. Different definitions and thresholds will result in the category's being larger or smaller, excluding or including people with different impairments and experiences. Disability categories play wider roles in social policy, as Deborah Stone has demonstrated in her book *The Disabled State* (1984).

It should be accepted that models and definitions are relative and contingent. Disablement is always a combination of the individual and the structural, the biological and the social. Different questions—medical, psychological, social—have to be investigated at different levels of a disability model. Disabled people experience a combination of bodily restrictions and social barriers, and the two factors cannot easily be extricated from each other. Where the social model would make a polar distinction between "impairment" and "disability," in practice impairment is always already social, and impairment is always implicated in disability.

Therefore, models should not become the touchstone of progress. It may be impossible to choose one model for every situation. A model is not an end in itself, but a means to an end. Models do not matter, in themselves, but are often taken as proxies for wider political or academic affiliations and strategies. Many commentators believe that the debate over models has now become an obstacle to the development of disability studies and achievement of the equality and inclusion of disabled people. Good initiatives have been created on the basis of "medical models" and failures have resulted from "social models," as well as vice versa. Rather than using the concepts "medical model" and "social model" as ways of judging "reactionary" and "progressive," activists and scholars need to pay attention to the details of the research, policies, or provisions that are being attempted. Two fundamental questions underlie all such interventions:

1. *Will this intervention improve the quality of life of disabled people?* Rather than focusing on ideological judgments about models, critical evaluation should explore the outcomes of interventions in terms of the quality of life of disabled people. Quality of life can be improved through the reduction of pain and suffering, the improvement of physical functioning, the provision of aids and adaptations, the removal of social and environmental barriers, and the reduction of discrimination and oppression.
2. *Is this intervention targeting the most appropriate level of disablement?* This question draws attention to the complexity and multidimensionality of disablement. Difficulties arise when medical or individual solutions are offered for problems that are social and structural—and vice versa. Disablement involves medical, psychological, and social aspects, and it cannot be reduced to any one of these dimensions.

Efficiency and appropriateness are major criteria for assessing particular proposals.

—Tom Shakespeare, Jerome E. Bickenbach, David Pfeiffer, and Nicholas Watson

See also International Classification of Functioning, Disability, and Health (ICF/ICIDH); Social Model: Sweden.

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MODERNITY

Modernity expresses the self-definition of a generation about its own technological innovation, population makeup, and "progressive" social organization schemes. To participate in modernity is to conceive of one's society as engaging in organizational and knowledge advances that make one's immediate predecessors appear antiquated or, at least, surpassed. The eminent Victorians thus appeared old-fashioned to a new generation of "moderns" at the beginning of the twentieth century, and the motto of poets of the time was to "make it new." The ubiquitous emphasis on "newness" within modernity signaled an *epistemological break* with the certainties of premodern societies.

Modernity for U.S. and British citizenry of the first half of the twentieth century meant new formats for new thoughts—innovative ways of writing and thinking, the infusion of women's views into university life and male-dominated labor markets, short skirts and short hair, rapid urbanization, a jazz era, and silent film narratives, among other products and technologies. As William Carlos Williams, a preeminent "modern" physician-poet, put it in his poem "To Elsie" (1923): "The pure products of America go crazy." Williams thus conjoins mass production with the now destabilized institutions of family and social life that occur in the wake of the first "modern" war, World War I. The dedicatee of the poem, Elsie, was a "broken-brain" nanny who came to work for the Williams family from an institutional orphanage as an adult ward of the state of New Jersey. The poem thus invests modernity in her figure and makes her into an emblem for speed and productivity in modern America gone awry. Elsie—at least in Williams's celebrated poem—indicates the degree to which the modern age became obsessed with human "defects." Disabled people were continually represented as somehow mis-fit or displaced in the midst of a press to standardize public and private spaces. Their bodies and minds were thought to fall too far short of an idealized, albeit elusive, body—one that would be measured, weighed, surveyed, and assessed for "baseline" capacities.

Thus, the "modern era" (generally identified here as synonymous with the age of industrialization) segmented bodies into their constituent parts. This process of segmenting bodies sought to make labor power more efficient while also rendering any single body replaceable. Assembly lines for autos, such as those instituted by Henry Ford and celebrated as egalitarian mergers of human and machine by the muralist Diego Rivera, implied better practices and technologies for all. But they also further entrenched citizens within a deepening nexus of debt and consumption—conscription to labor power. Ford declared that each worker should earn the purchasing power to drive an automobile even as he would spend his workweek toiling on an assembly line to make cars for others.

Under modernity, technologies develop that yield advantages of speed or efficiency over older terms of labor and consumption that rapidly disappear on a historical horizon. These technologies result in revised workplace organization, often displacing workers with established expertise, at the same time they introduce modifications to the organization of everyday life. From movable type to steam engines, from the telegraph to the advent of photography, technological innovations alter modes of inhabiting environments and daily living for entire population groups. Such innovations also precipitate the mass exclusion of whole communities under various rubrics of inferiority—namely, immigrants, people of color, lower-class people, and disabled people. Often marginalization occurs on the basis of a mutual referencing strategy that is bound up with disability definition. In other words, individuals situated in categories of incapacitation or insufficiency to the demands of a modern world rarely find themselves referenced by only one stigmatizing category. Instead, their bodies become identified as hosting multiple insufficiencies that are often believed to be "biological" in nature.

Behind the development and introduction of technologies are the investments of an increasingly global capital that targets markets and labor pools. The marginalizing strategies of modernity ultimately sought to produce what Marx called "surplus labor pools": labor rendered "superfluous," "expendable," or "excessive" to the needs of capitalist markets. In reality, modernity oversaw strategies of worker disqualification where entire populations found themselves sidelined from the demands of labor. All "inferior" peoples of the modern period presumably shared a natural incapacity to function competitively in the labor market, and, consequently, they were relegated to segregated communities, reservations, almshouses, and workhouses, and—particularly in the case of disability—confinement in colonies, "training centers," and institutions.

To operate within modernity also means to participate in the belief that one finds bold contrast between modern conceptions of the cosmos and the worldview of premoderns or "ancients." "God is dead," declared Friedrich Nietzsche (1844–1900), a famous German philosopher of modernity, not hesitating to add that this was because his contemporaries had killed God off with their own disbelief. In the field of philosophy, premodern beliefs yield to modern dismay about how social systems, from organizations of class privilege to theories of heredity, determine a great deal of life experience for any one individual. Nietzsche himself proposed that modernity is typified by crises in systems of morality, so that once belief is crushed there can be no restoration. Of course, he discussed the fact that many of these crises in self-perception occur due to advancements in knowledge and an uncritical embrace of new technologies.

For example, Copernican proofs that the earth revolves around the sun heralded revolutions in reasoning about the universe and the not-so-central place of humans within it. Charles Darwin's (1809–1882) theories of natural selection, demonstrating as they do that a changing human species evolves among multiple shifting life forms, precipitated the arrival of a fully "modern" sensibility. The founder of modern psychoanalysis, Sigmund Freud (1856–1939), who studied states of psychological aberrance in order to expand definitions of human existence, also typifies, in his work, the displacements wrought during modernity. His proposition that an unconscious conditions human behavior and actions likewise unsettled general Enlightenment faith in human rationality. In the film *Modern Times* (1936) Charlie Chaplin spoofs the users of high-speed contraptions; herein, products "gone crazy" not only foil the ambitions of their users, they also seem to have plans for the users that mechanize all involved.

As this entry has emphasized, technologies themselves participate in this decentering of human confidence in perception and planning. Modernity as a historical coordinate, a mere marker in a chronology of named epochs, depends on the distinction between new modes of existence as well as new perceptions of a self that attends to transport, architecture, mass events, and media that quite simply replace former ways of inhabiting space and experiencing time. Thus, some scholars will even go so far as to locate modernity with the advent of the printing press and the mass circulation of print information that brings about expanded literacy in a middle class during the fifteenth century.

The most prevalently cited examples include microscopic technologies that replace the human eye as an arbiter of evaluation and laboratory heredity texts that can prove parentage with or without testimony. Often bodies themselves experience a new inferiority as they come to be outdistanced by superior visual, aural, and detective devices of modernity. All bodies might come to be perceived as increasingly inadequate without supplementation, even as methods and mechanisms of enhancement, from telephones to typewriters, increase. The camera eye, for example, can seem to capture discrete elements of an activity and therefore offer a vantage point superior to any human eye. Eadweard Muybridge (1830–1904), an early technician of camera and motion, combined scientific experimentation with photography in a series of chronophotographic demonstrations. He famously showed that a horse becomes fully airborne during a cantor. The cinematic eye can therefore improve on the human gaze, wholly delimiting its privileged gaze on reality, just as Freud's modern concept of a human "unconscious" literally undermines the stated intentions of individuals. From a disability studies perspective, it should be noted that Muybridge also did chronophotographic studies of "nonnormative" human gaits, inaugurating an entire field of analysis, known as gait training analysis, that is linked to imaging devices. Likewise, early silent films turned on the "secret" knowledge offered by a camera that showed a beggar getting up and walking away with a charitable offering after having feigned paralysis or blindness. In each instance, the powers accorded to visual recording devices sought to break down, survey, and expose the exact source of dysfunction. This form of modern mechanization shifted conceptions of the body from an "organic" to an increasingly "artificial" entity. In the process, prior ideas about the body as a sacrosanct temple gave way to a more fluid and, ultimately, disposable material being.

This lowering threshold of respect wrought by modernity can be analyzed across numerous fields of inquiry. For instance, many scholars, particularly in the wake of Michel Foucault, connect modernity to medical practices that reference human anatomy as a result of the direct observation of dissected human corpses. The practice of anatomical dissection, with its violation of sacred beliefs about bodily boundaries, neatly encapsulates a change in sensibility toward behaviors that violate sacred prohibitions with the goal of knowledge about bodily mechanics. In his lectures on the topic "abnormal," Michel Foucault locates a rupture between agrarian communities and the arrival of a modern state in its imposition of psychiatric and confinement solutions for bodies deemed pathological. In this scholarship, confinement practices, as opposed to quarantine colonies (such as those for leprosy, tuberculosis, epilepsy, and "insanity"), initiate modernity as a matter of brutal concealments, torture, and controlling technologies that take place under professional purview. Foucault traces a shift toward modern practices when an ordinary "village idiot" becomes susceptible to medical interventions, experimentation, state management, and regulation—in other words, when mere madness becomes mental illness, a modern category to be officiated, contested, recorded, and detected. If corpses can be "cut up," then all bodies become potential targets for a host of modern interventions.

Certainly this clarifies the point that little consensus exists as to when modernity begins. However, histories on and about Western Europe do concur that a modern era arrives at the end of colonial invasion and expansion across the globe, with modernity coming at the end of a chronology that proceeds from the ancient world, the Middle Ages, the Renaissance, the Enlightenment, the Age of Exploration, and the period of colonial expansion. A British writer who straddled colonial expansion and World War I, Ford Madox Ford (1873–1939), wrote a four-volume epic in order to declare that with World War I there would be "no more parades," meaning that the idea of fighting for any heroic cause had been rendered obsolete—the antiquated product of a bygone era. For Ford, wars are fought on behalf of economic interests with little effective resistance to the military conscriptions of modern nation-states. Little meaningful celebration accompanied a "victory" for the living participants who survived such violent enterprises. In short, modernity means that heroism is dead.

In modernity, governance by distant colonizing powers yields to governance by locals, and the boundaries of nation-states are perceived to reflect oversight by resident officials as opposed to colonial military powers. Occurring in tandem with the arrival of modern warfare methods, those capable of enacting genocide on a massive scale, modernity has been thought to indicate awareness of the missionary conceit that colonial settlement plans and military ventures overseas constitute sources of "improvement" for nonmodern geographies. Thus, not only were bodies deemed insufficient, but entire nations could be imagined as "damaged goods." Irish poet William Butler Yeats's dictum that "the center cannot hold" in his poem "The Second Coming" presages the degree to which modern societies seem to experience themselves as fracturing along with the bodies housed within them. As the nineteenth century came to a close, numerous cries could be heard that even the most advanced nations were succumbing to the forces of degeneration. Nations continually assessed their "wealth" in terms of percentages of nondefective bodies inside their borders. As the 1927 U.S. health propaganda film *Are You Fit to Marry?* put it: "As goes its babies so goes the nation." In order to actively improve the "national stock," moderns sought to sequester as many deviants as possible. A dream of homogeneous futures guided much action during the modern period, and social marginals found themselves increasingly under siege by a variety of improvement schemes contrived by "progressives" and other professed social do-gooders.

In 1893, Edvard Munch painted *The Scream,* a figure that is often taken as a quintessential expression of modernity. Munch himself wrote that he had experienced intense fear during a moment of isolation while on an evening walk: "My friends walked on—I stood there, trembling with fear. And I sensed a great, infinite scream pass through nature" (quoted in BBC News 2004). In the painting, wavy lines and a red sky capture the sensation of terror he describes, and Munch's effort to capture his own feelings of besiegement by emotions struck a cord of sentiment for many denizens of the time. Joseph Conrad's 1902 novella *Heart of Darkness,* which is also taken as an emblematic text of modernity, matches the psychic journeying of a European protagonist with the atrocities he recounts having encountered on a colonial venture on the Congo while he drifts in present time in a boat on the Thames. He remembers native bodies tossed aside as mere labor power now exhausted, but he also emblematizes Africa as a site of disease. This would have been so for the European journeyers, such as those who often accompanied David Livingston, who lacked immunity as adults to a common West African childhood illness such as "yellow fever." "The horror, the horror," reputed to be the dying words of the character Kurtz, may refer to the protagonist himself, his venture, or the blissful ignorance of the ultrafeminine "intended," who, as the evident manifestation of civilized society, must be protected from men's savagery at all costs.

Until quite recently, with the dissolution of the Soviet Union, modernity had been taken, more or less, as the matter of an international consensus on nation-state borders. With a growing global practice of commodity capitalism, with capital's requisite ventures to open up consumer markets, modernity now is mostly associated with ever-increasing speed, both in the transport of financial exchanges and in cross-border communications. It is important to note the fact that modernity as crisis, where "the center cannot hold," operates differently across classes and privileged parties. In that sense, modern dislocations may be heralded as opening up new possibilities for those on the periphery—those previously excluded from the spoils of empire and the opportunities of education and leisure time. Hence, women in London and Chicago, African Americans in Harlem, and many others find potential for professional development and expression in the wake of the empire's crises in epistemologies and central governance. Likewise, and particularly for groups, institutions, and colonies of disabled persons, interior pockets of self-governance or incarceration may not yield as readily as schools, churches, or principalities, for example, to oversight from nation-state governance. Thus, they are already "colonies" as opposed to under the purview of central governance.

In sum, nearly all scholars of modernity agree that scientific methods serve neatly to mark a break between modern and ancient in that research designs precisely enable a new means for testing reality—from telescopes to electron microscopes, case notes, surveys, weights, and scales, along with systems for data analysis from means deviation equations to infrared scans. Yet unlike Enlightenment thinking about scientific experimentation, often now termed a mere "faith" in Enlightenment principles, citizens in modernity are wise to the ways that scientific development results in many means for mass destruction and population control alongside material improvements in the standards of daily living. In this respect, theorists of modernity seek out means for resistance, but not necessarily revolution, no longer believing that an equitable society can be gained through military struggle or transcendent social visions. Some have mourned this surrender of revolutionary universal programs as the final capitulation to capitalist logic. The failures of communism to provide fully desirable modes of inhabiting the world inform this pessimism and indicate, themselves, the difficulty in sustaining a belief in any effective counterforce to the new global inequities wrought by venture capitalism.

Inasmuch as modernity displaces a recent past, it is often associated with forward-looking progressive social policies that include modes of social engineering. For disability, then, modernity often indicates ideologies of eugenics and the promise to eradicate certain kinds of human "suffering" and "misery" through prevention and segregation campaigns. With this emphasis underwriting the schemes of modernity with respect to "deviant" bodies, one witnesses an explicit emphasis on bodily rather than social "renewal." Rather than work to make plastic environments more flexible—and thus habitable—modernity sets its sites primarily on the enhancement of individual physicalities and minds to fit inflexible locations. If those bodies fail in such efforts, then they are effectively extracted from participation. The body winds up as the barometer for all interventions—a surface to be molded by the forces of history come home to roost. Modernity can be viewed as a rather sinister program in this respect, one that is led by innovations in manufacturing and economic venues while neglecting the needs of populations that must navigate those very locations as well as many others.

At present, modernity no longer means "modern" as exemplified by the period subsequent to modern warfare, typified by two world wars, and succeeded by postmodernism. Today, theorists of modernity look for the effects of postnationalism in the face of uneven development. The underside of a belief in the goodness of modernity is perpetual interpretation of agrarian regions as underdeveloped. Modernity thus comes to define savage inequities on a global scale; infrastructure development such as roads, plumbing, mass transportation, and labor practices; and cultural biases in the provision of public education. Today, modernity most likely means the rapid-pace movement of global capital, industries run for the profit of invisible shareholders, satellite transmission of images, and immediate transglobal communication. Part of this fluid transcultural passage of capital also entails traffic in disability technologies and policies usually designed for Western contexts. Such an export economy of disability results in absurd situations: Wheelchairs designed for paved streets literally run aground and shatter when faced with the demands of other terrains, and disability service delivery systems designed for consumption practices in one capitalist context fail of inertia in other, less acquisitive, cultural venues.

This glimpse of the underbelly of modernity has come to the fore in influential scholarship and thinking of our own time. For instance, political theorist Zygmunt Bauman (1989) sees modernity through a much darker lens when he observes that Nazi genocidal procedures toward disabled, ethnic, and sexually stigmatized populations became an "inevitable" consequence of the modern regulation of bodies and measures taken for the sake of "population" control. Bauman inflects modernity as riddled with assembly lines and population demographics. Within such regulatory labor systems, some bodies find themselves excluded almost by definition. Within modernity, the rising prominence of labor capacity as synonymous with the privileges of citizenship came to eclipse older definitions of embodied difference (such as monstrosity or marvel). In their place, disability became increasingly tantamount to "incapacity to work." In other words, modernity oversaw a transition of the power of extreme alterity by promoting a domesticating mission that tended to denote disability as a mere loss of productivity. Disability theorists then must consider the ways in which modernity actually produces disability as a matter of displaced persons.

In many ways, disability groups are directly consolidated out of shared predicaments of modernity: those persons who have been displaced from mass transit, trampled in crowd control settings, and indentured for their subsistence to welfare schemes promoting absolute dependency. One thinks of the bodies that cannot make it across moving walkways at railway stations or of buses with steep stairs at their doors, with no alternative navigation pathway in sight. Under modern management practices, categories for "special assistance" get generated in order to accommodate for "normative" patterns and expectations necessitated by policies and practices that prove exclusionary but nonetheless may be insisted upon as mandatory. Voice technology ordering at drive-through restaurants, for example, excludes those who might order by sign language, gesturing, or pointing. Those who can't push open heavy doors must wait until someone comes along who can do so. Disability politics concerns itself with modern environments, from websites to cruise ships to personal facilities, that in demanding body conformities build exclusions into their offering and, therefore, quite undemocratically create groups of nonusers.

—Sharon L. Snyder

See also Citizenship and Civil Rights; Disability Culture; Inclusion and Exclusion.

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MOLECULAR, CELLULAR, AND TISSUE ENGINEERING

Molecular, cellular, and tissue engineering is an emerging discipline that addresses the principles and development of engineering therapies for restoring the structure and function of disordered molecules, cells, and tissues. Pathological disorders occur in biological systems at the molecular, cellular, and tissue levels in response to genetic alterations and environmental stimulations induced by chemical, microbiological, and physical factors. Engineering therapies are established based on the mechanisms of pathological disorders and principles of biomedical engineering (see Langer and Vacanti 1993; Liu 1999).

Molecular disorders occur due to mutation of genes or alterations in gene activity. Gene mutation often abolishes protein expression or generates malfunctioned proteins, whereas alterations in gene activity induce an increase or decrease in protein production. These changes influence cellular activities, such as cell proliferation, differentiation, apoptosis, migration, and adhesion, inducing or enhancing pathological disorders. For gene mutation-induced disorders, such as sickle-cell anemia, mutant genes can be identified, analyzed, and manipulated through the use of genetic technologies. A therapeutic strategy for such disorders is to replace the mutant gene with a natural or engineered gene, which can be expressed to correct mutation-induced disorders. An example of such a strategy is the introduction of an engineered beta A-globin gene into hematopoietic stem cells to treat sickle-cell anemia, which is caused by the formation of abnormal hemoglobin due to a single-point mutation in the beta A-globin gene (see Pawliuk et al. 2001). For disorders due to alterations in gene activity, such as atherosclerosis, genes involved in pathogenic processes can be identified and analyzed through molecular approaches. An effective engineering approach for such disorders is to introduce into target cells with genes encoding proteins that suppress pathogenic processes induced by altered gene activities. An example is the introduction of growth inhibitor genes into atheromatous cells to suppress cell proliferation and thus to reduce the progression of atherosclerosis, a disorder enhanced by the up-regulation of growth factor genes (see Dzau, Braun-Dullaeus, and Sedding 2002).

Cell and tissue injuries or disorders occur due to physical impacts, chemical toxication, ischemia, cancerous metastasis, and/or microbiological infection, resulting in disability of involved organs. A therapeutic strategy is to identify and collect functional cells from the hosts or donors, regenerate cells in vitro, construct cell-based tissues by incorporating cells into scaffolds of biological matrix or synthetic polymers, and replace disabled cells and tissues with regenerated cells or tissue constructs. Such an engineering approach can facilitate the regeneration of injured tissues and prevent permanent organ disability. Because stem cells, including embryonic and adult stem cells, are capable of self-renewing, differentiating, and repopulating, these are preferred cells for cellular and tissue engineering. An example is the repair of bone defects with bone stem cells from the marrow stroma (see Quarto et al. 2001).

For the past decade, experimental investigations have provided sufficient information for the establishment of molecular, cellular, and tissue engineering therapies. Clinical trials have been conducted to test the feasibility and effectiveness of these therapies. It is expected that molecular, cellular, and tissue engineering will contribute significantly to the treatment of human disorders and disabilities.

—Shu Q. Liu

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MONSTERS

For most of Western history, the monster exemplified one extreme form of what is now known as disability, the departure from expected physical type. Monsters included a variety of people and animals with dramatic and obvious congenital anomalies, such as conjoined twins and intersexuals, beings with too many or too few members, and the unusually short or unusually tall. Although even in its heyday, the medieval and early modern period, the category of the monstrous overlapped only imperfectly with disability, it nonetheless shaped modern attitudes toward people whose bodies lie outside the norm.

Medieval European writers derived the word *monster* from the Latin verb *monere,* which means "to warn." In Christian Europe, as in the ancient world, monsters were originally understood as signs of divine displeasure, by which God informed human communities of His anger at their misdeeds and warned them of misfortunes to come if they did not mend their ways. At the same time, however, the term could signal another characteristic of monsters: the fascination they engendered. "Monsters are called monsters," one seventeenth-century writer noted, "because everyone wants to show them to each other"—a play on the Latin verb *monstrare,* which means "to show" (see Daston and Park 1998:200). Thus, at the root of the premodern understanding of monsters lay two powerful ideas: spectacle and threat.

The idea of threat was at first the most powerful. For the Greeks and Romans, as for medieval Europeans, monstrous births were one type of portent or prodigy, a category that included celestial apparitions, comets, earthquakes, and unusual meteorological phenomena. As signs of divine wrath, they evoked terror and dread. In 1317, for example, when conjoined twin boys were born in the countryside outside of Florence, the city fathers refused to look on them out of fear, and a bas-relief depiction of the boys was placed over the gate of one of the local foundling hospitals to spur the population to live in conformity with God's will. Many such children died in infancy—the Florentine twins lived only 20 days—and some were even killed at birth out of fear that they might harbor demons; having delivered their threatening message, they had fulfilled their purpose.

Even in the Middle Ages, however, we find other, less fearful reactions to people of anomalous appearance. The English chronicler Matthew Paris recorded the arrival in 1249 of an extraordinary young man in the Isle of Wight: "He was not a dwarf, for his limbs were of just proportions; he was hardly three feet tall but had ceased to grow. The queen ordered him to be taken around with him as a trick of nature to arouse the astonishment of onlookers" (quoted in Daston and Park 1998:190). Some 250 years later, around 1500, there is evidence of commercial display; parents or guardians of monstrous children took them from town to town, showing them for money, and some cities began to issue licenses or permits for spectacles of this sort.

Over the course of the sixteenth and seventeenth centuries, this practice became increasingly common. Adult men and women displayed themselves in inns, taverns, and fairs, advertising their unusual appearances and abilities in broadsides and flyers, and became the guests of princes and nobles. Petrus Gonsalvus, a native of the Canary Islands whose face was covered with long, silky hair, was raised at the court of Henri II of France and, together with his wife and equally hairy children, was memorialized in contemporary portraits that emphasized his noble bearing and exquisite attire.

This culture of display bespoke a different attitude toward monsters than the horror engendered by the fear of divine wrath. Philosophers and popular writers referred to people with unusual anatomies in terms of admiration and appreciation, describing them as signs of God's marvelous creativity and unceasing power for innovation; those who were lucky enough to view or meet many such individuals—medical men, collectors of broadsides, frequenters of fairs and taverns—prided themselves on their connoisseurship and their ability to make fine distinctions between the merely unusual and the absolutely unique. Like works of art, these special products of divine craftsmanship were collected, both alive and dead, by rulers and wealthy elites.

By the second half of the seventeenth century, scholars and medical men also were engaging in the intensive study and description of monsters as part of an effort to untangle the natural order of the world. This effort was not new. Medieval and Renaissance physicians and natural philosophers had also offered natural explanations for the birth of people of unusual appearance. The French surgeon Ambroise Paré invoked, among other things, the presence of too much or too little matter in the uterus, the effects of maternal imagination, and the workings of chance. But late-seventeenth- and eighteenth-century naturalists—the protagonists of the intellectual movement often known as the Scientific Revolution—increasingly understood nature in a new way: as governed not by general habits or regularities, violable in both principle and practice, but as governed by inalterable laws. This new investment in natural uniformity began to deprive monsters of their scientific interest and their appeal. They were seen increasingly as embarrassing mistakes that marred the natural order and uniform beauty of the world. In a world where the physical norm—a concept pioneered by the Belgian statistician Adolphe Quételet (1796–1874)—came quickly to be identified with the ideal, people with unusual anatomies were reconceived as ugly, abnormal, even pathological.

By the nineteenth century, the fear of monsters as portents of divine wrath had gradually lost its hold, and the reaction to monsters as abnormal, even repellent, coexisted with curiosity and fascination. The freak shows that flourished from the mid-nineteenth century to the mid-twentieth century, of which the most famous example in the United States was that operated by P. T. Barnum, were similar to the displays of armless men, giants, and hairy ladies at the fairs of seventeenth- and eighteenth-century Europe with respect to the crowds they attracted and the diversity of reactions they inspired. The same might be said of some more recent daytime television talk shows. For white, middle-class nineteenth-century Americans, people with unusual anatomies—many of them of exotic birth, like the "Siamese" conjoined twins Chang and Eng and the hairy Mexican Indian Julia Pastrana, advertised as the "ugliest woman in the world"—evoked fascination with the truly different and satisfaction with their own conformity to modern, "civilized" norms.

Perhaps the most dramatic change in attitudes toward people whose appearance challenged such norms, however, came in the years after 1900, as these people became increasingly subject to medical scrutiny. Although medical men had long presented themselves as experts on human anatomy, including anatomical irregularities, they had never claimed to be able to correct such irregularities—that was beyond their technical skill. Because monstrous people were not treatable, however different they might appear from others, they were not, by definition, ill. With new developments in surgery, however—anesthesia, antisepsis, new imaging technologies—doctors not only began to medicalize such conditions, describing them in terms of medical pathology, they attempted to intervene surgically to "fix" them. Intersexuals (long referred to as "hermaphrodites") had their genitals normalized, and conjoined twins were separated in infancy. More recently, surgical and hormonal interventions have been deployed to normalize height as well.

In some cases, such interventions have met with dramatic success, increasing mobility and social acceptance. In others, the record is far more ambiguous, as in the case of conjoined twins "sacrificed" in separation operations. There is no question, however, that the medicalization of unusual anatomies has done little to lessen their stigma. Not only have people with such anatomies been reconfigured as victims and as patients—whether or not they are subject to cure—but the unquestioned power of effective reconstructive and cosmetic surgical techniques has reduced the range of appearances deemed socially acceptable, paradoxically enlarging the ranks of people who see themselves, or are seen, as "monstrous," despite their having anatomies that would have evoked little reaction—or even positive reaction—in earlier periods. Thus, intersexuals are no longer seen as marvelous emblems of divine fertility; rather, they are viewed as physical deviants to be fixed at birth.

In sum, neither the fear nor the fascination engendered by people with socially challenging appearances has disappeared over the course of time. Rather, the fear and fascination have taken changing forms as the meanings associated with unusual anatomies have themselves changed. No longer seen as signs of divine wrath, symbols of an admirable natural diversity, or emblems of an imperfect and exotic Other, monsters are now interpreted in terms of pathology, dependent on the doctor's extraordinary power to both harm and heal.

—Katharine Park

See also Freak Show; Normality.

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MONTESSORI, MARIA (1870–1952)

Italian physician and educator

Maria Montessori was born in 1870 in Chiaravalla, Italy, and died in 1952 in the Netherlands. She is known as the founder of a pedagogical method specifically intended for children between the ages of 3 and 12 years. Montessori studied engineering science, mathematics, physics, and medicine and became one of the first female physicians in Italy in 1896. She was also an active supporter of the international bourgeois feminist movement. During her tenure at the psychiatric clinic of the University of Rome, Montessori developed an interest in disabled children. In 1899, she and Giuseppe Montesano founded the Scuola Magistrale Ortofrenica, which was both an educational institute for disabled children and a training institute for instructors. In 1898, Montessori gave birth to their son Mario, who lived in a foster family until the age of 15.

Montessori was a lecturer of disability pedagogy from 1900 to 1918 at the Regio Instituto Superiore Femminile di Magistero in Rome. In 1907, she founded the Casa dei Bambini in the working-class neighborhood of San Lorenzo in Rome. Her pedagogical convictions and stimuli for the development of her own didactic material were inspired by Jean Itard (1774–1838) and Edouard Séguin (1812–1880). Above all, she relied on the concept of sensory-based instruction as a means for developing intellectual competence. With help of the so-called prepared environment, the child should, allowing for the greatest possible independence, foster his or her own development (the child's own inner "building plan"). The didactic material, which should be available once per group, serves as a "polarization of attentiveness." Further methodological principles include the age-mixed grouping of children and instructors' stepping back as much as possible to facilitate children's self-education.

Montessori traveled extensively and presented her work—with the support of her son—in order to disseminate her ideas. In addition, the worldwide Foundation for Instruction and Apprenticeship sponsored the publication of her pedagogy. In 1928, the Regia Scuola Magistrale di Metodo Montessori was established in Rome; in 1929, the International Montessori Association emerged in Copenhagen (this organization was later headquartered in Amsterdam). Maria Montessori was nominated for the Nobel Peace Prize three times.

—Vera Moser

See also Jean Marc Gaspard Itard; Edouard Onesimus Séguin.

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▣ MOON, WILLIAM (1818–1894)

British evangelist and blind activist

William Moon, an Englishman who was partially sighted in childhood and blind in his teens, spent his life in Christian evangelism and enabling blind people to read. In 1847, he developed an embossed script based on Roman capitals that blind adults could learn to read in a few days and began a monthly magazine using the script. Moon's script facilitated the integrated education of blind children in many schools across Britain. One of his strategies was to teach sighted children to use the embossed material and then send them out to find blind people whom they would teach to read or blind children whom they could bring to school. From the 1850s onward, the script was transferred to India, China, Egypt, Australia, and West Africa by missionaries who included blind children in the schools they established and taught blind adults at home. Many of Moon's home teachers were blind men who walked great distances to serve other blind people. By 1880, Moon's annual report claimed to have reading material in 194 languages. Moon's script was the first reading system for the blind to be widely adopted across the world, but was costly to print. It was overtaken in the late nineteenth century by Braille, which was cheaper and could be produced by blind individuals for themselves. Moon's system is still used in Britain by people whose fingertips lack the sensitivity to use Braille.

—Kumur B. Selim

See also Agnes Gutzlaff; C. Colden Hoffman; Jane Leupolt.

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▣ MOSCOW THEATER OF MIME AND GESTURE

Founded in 1962, the Moscow Theater of Mime and Gesture (Moskovskii teatr mimiki I zhesta) was the first professional deaf theater in the world. The theater has been in continuous operation for more than 40 years and has staged more than 100 classic and modern plays by Russian playwrights and playwrights of other nationalities. It has won many Russian and international theater contests and has toured in many countries.

—Anna Komarova and
Victor Palenny

See also National Theatre of the Deaf (United States).

MOVEMENT OF DISABLED PEOPLE, GERMANY

See Advocacy Movements: Germany

MULTIPLE SCLEROSIS

Multiple sclerosis (MS) is the most common demyelinating disease of the central nervous system, named for focal scars in the brain, spinal cord, and optic nerve. Myelin insulates the impulse-transmitting extensions (axons) from nerve cells and promotes fast transmission of electrical impulses. Demyelination results in slowing of impulse conduction. Clinical manifestations include sensory, motor, visual, gait, balance, bladder, speech, swallowing, sexual, mood, and cognitive disturbances, as well as spasticity, weakness, and fatigue. Ultimately, demyelination can result in axon loss, causing permanent damage. Diagnosis of MS is based on clinical presentation, nerve transmission, spinal fluid, and imaging studies.

Jean Martin Charcot provided the first clinical-histological description of MS in 1868. Since then, theories regarding the etiology of MS have included abnormal sweat suppression, toxins, poor circulation, allergy, and viruses. The prevailing theory today is that MS is an autoimmune disease—that is, the body attacks its own nervous system—that may occur preferentially in genetically susceptible people. Immune function in MS is studied in animals with experimental autoimmune encephalomyelitis.

MS most commonly affects women of childbearing age and of northern European descent. The best medical prognosis is in young women who first present with sensory symptoms and whose disease is relapsing-remitting (i.e., periods of exacerbation alternate with periods of improvement) rather than chronically progressive. Pregnancy does not affect long-term outcomes. MS does not alter lifespan. Psychological stress is suspected to exacerbate symptom severity.

Pharmacotherapy for MS includes medications to manage spasticity, pain, bladder dysfunction, sexual dysfunction, and fatigue, as well as corticosteroids to reduce exacerbation severity. In the 1990s, chemicals that modulate the immune system (immunomodulators), thought to alter the course of MS, were developed. Immunomodulators are used widely today, despite possible debilitating side effects. On the horizon are neuroprotective agents, stem cell transplants, and gene therapies.

The course of MS is highly variable. MS can result in a range of disability, from nearly none to the inability to write, speak, and walk. Physical therapy, occupational therapy, adaptive devices for ambulation and function in the home and workplace, and psychological and social supports are critical components of overall care.

As young adults adjust to new careers and families, those with MS must also adjust to loss of body function and the social stigma and losses of self-esteem, job opportunities, family time, and independence that come with it. Unpredictability of disease course makes acceptance and coping particularly difficult, both for the individual with MS and for the primary caregiver. Community support networks can help individuals with MS and their families adapt to disruptions in social, family, and work life, and can help to maximize both functional status and quality of life. In recent years, the Internet has increased the accessibility of individualized information on MS, clinical trials, and support networks.

Currently, there is no cure for MS. Its etiology—and whether more than one etiology could result in the clinical picture characterized as “MS”—has not been definitively determined. In the future, increased understanding of interactions among genes, immunity, central nervous system damage, clinical manifestations of disease, and psychosocial well-being will allow medical practitioners to provide maximally effective individualized treatment programs.

—Dorothy Weiss

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MURPHY, ROBERT FRANCIS

(1924–1990)

American anthropologist and disability scholar

Robert Murphy was one of the most influential scholars in the field of disability studies. His work proved critical to the disciplinary beginnings of disability studies as a field that challenged the medicalization of human differences as pathology. In 1976, at the age of 52, Murphy was diagnosed with an inoperable spinal tumor and later became increasingly paralyzed. At the time, he was already an established anthropologist at Columbia University and had spent many years (along with his wife, Yolanda, who was also an anthropologist) in the Amazon among the indigenous peoples. His most significant contribution to disability scholarship is the autobiographical work titled *The Body Silent,* in which Murphy takes up his experience with disability outside of more traditional narrative modes such as the first-person overcoming story. In doing so, he transforms disability into a journey of cultural discovery. As Murphy himself characterizes his efforts, "Since it is the duty of all anthropologists to report on their travels . . . this is my accounting." *The Body Silent* presents Murphy's accounting with the zeal of a field anthropologist investigating an unknown landscape or culture. Murphy thus successfully shifts the understanding of disability from a tragic encounter to one of profound intellectual value. His work moves disability out beyond an individual experience and into a profound analysis of societal and historical investments in bodies that exist outside of aesthetic and functional norms. Ultimately, Murphy's work transforms the disabled body from a socially bequeathed silence into a vehicle of social exposé.

—David T. Mitchell

See also Anthropology; Autobiography.

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MUSCULAR DYSTROPHY

The neuromuscular diseases (NMDs) are disorders of muscle or of the peripheral nervous system that cause generalized muscle weakness or paralysis but either mildly affect or completely spare the brain. The weakness most commonly results in inability to achieve or loss of independent ambulation, scoliosis (childhood onset), respiratory complications (which are generally preventable), and occasionally heart failure.

Before the French physician N. Andry's attribution of NMDs to muscle pathology in 1743, it was believed that they were caused by bony lesions. In 1853, the French physicians Duchenne and his colleague Jean Cruveilhier distinguished between generalized weakness due to muscle pathology and "paralysis" denoting muscle dysfunction on the basis of neurological disease. Duchenne described these disorders as resulting from febrile illnesses that affect the spinal cord (later called *poliomyelitis*), from syphilis, and from heavy metal toxins, and both paralyses and muscle diseases (from "impaired circulation or nutrition") could lead to fatty transformation of muscle. The most common and most rapidly progressive NMD has become known as *Duchenne muscular dystrophy.* However, it was not until 1868 that Duchenne distinguished muscular dystrophy, primarily a muscle disorder, from other NMDs. This was 16 years after the English physician Meryon's (1852) classical description of this condition and

32 years after its initial description in Italy (Conte and Gioja 1836).

Meryon (1852) described how a patient died at 16 years of age from acute respiratory failure during a febrile episode with "profuse secretion of mucus from the trachea and larynx" (quoted in Archibald and Vignos 1959). All NMDs cause death by respiratory complications due to weakness of inspiratory, expiratory, and throat (bulbar-innervated) muscles. Inspiratory muscle weakness can result in coma and death from carbon dioxide narcosis. Expiratory (essentially abdominal and chest) muscle weakness results in pneumonia and respiratory failure due to airway secretion encumberment from an ineffective cough. Bulbar muscle dysfunction results in death from massive aspiration of airway secretions; however, this is seen only in advanced bulbar amyotrophic lateral sclerosis (Lou Gehrig's disease) and virtually never in muscular dystrophy or other NMDs. In the case of myopathic disorders, heart muscle weakness (cardiomyopathy) can also result in death.

The inability to find very effective medical treatments or cures for any of these conditions and the failure to appreciate how respiratory muscles can be aided has resulted in therapeutic nihilism (see Dubowitz 1977). However, effective means of preventing or limiting musculotendinous contractures, prolonging ambulation, preventing scoliosis, and increasing limb function are now available; the use of specially designed robotics and computers can prevent morbidity and death and help to maintain a good quality of life for individuals with NMDs (see Bach 2004). The use of inspiratory and expiratory muscle aids can consistently and indefinitely prevent death from respiratory causes (see Bach 2002b), and effective regimens of cardiac medications have been developed that can prolong effective cardiac function for patients with myopathies (see Ishikawa and Bach 2004).

Respiratory muscle aids are devices and techniques that involve the manual or mechanical application of forces to the body or intermittent pressure changes to the airway to assist inspiratory or expiratory muscle function. The devices that act on the body include body ventilators that create atmospheric pressure changes around the thorax and abdomen and exsufflation devices that apply force directly to the body to mechanically displace respiratory muscles. Negative pressure applied to the airway during expiration or coughing assists the expiratory muscles as forced exsufflation just as positive pressure applied to the airway during inhalation (noninvasive ventilation through mouthpieces or nasal interfaces) assists the inspiratory muscles (see Bach 2002b). Despite the extraordinary efficacy of respiratory muscle aids in preventing hospitalizations, resort to tracheotomy, and death (see Gomez-Merino and Bach 2002; Bach et al. 2002; Bach 2002a), respiratory complications continue to cause death for the majority of patients with NMDs (Bach 2002b). This is because of a general lack of awareness of the availability of these aids and the medical community's low level of interest in helping patients with rare conditions that cause severe disabilities.

—John R. Bach

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MUSIC

Ethnomusicologists have long understood that music can be the focus of highly autonomous cultural units whose rules and rituals—including their constructions of (dis)ability—may vary considerably from those of their host communities. What constitutes disability or impairment may differ greatly between a musical "world" and its extramusical environs. For example, in Japan and Ukraine of bygone eras, blindness was far from disabling for professional minstrels. In contrast, deafness, while regarded as a cultural identity rather than a disability by the Deaf, renders participation in music ("musicking") difficult. Nonnormate hand function typically regarded as minimally significant—left-handedness, small hands, single-finger mobility impairment (such as that experienced by composer Robert Schumann)—may be disabling for musicians. Addiction, epistemologically complex as regards disability, becomes exponentially more challenging taxonomically in music, where substance abuse may be regarded as a rite of passage, identification badge, or hearing (that is, musicking) aid.

Mobility impairments mandate either accommodations to facilitate normate musicking or at least nonnormate strategizing. While challenges to musicking with a disability are, ultimately, socially constructed, they may be formidable. Many remain unaddressed.

CLASSICAL MUSIC

Perhaps Western classical music's greatest advocate for disability accommodation was pianist Paul Wittgenstein. After losing his right arm in World War I, Wittgenstein commissioned five one-hand piano works; the concertos by Ravel and Prokofiev became standard repertoire, mostly for two-handed pianists. That compositions originally intended to accommodate Wittgenstein's disability have entered the twentieth-century canon—few modern concertos have—exemplifies universal design principles.

Ambulatory impairment barely impedes classical musicking, significantly affecting only instruments with pedals—keyboards and harp. Mobility-impaired conductors James DePriest and Jeffrey Tate use high stools on the podium. Renowned violinist Itzhak Perlman walks with crutches and performs seated; a colleague carries his instrument onstage. Recent improvements in concert stage/backstage accessibility are said to owe much to Perlman's prominence.

The most famous disabled classical musician was composer Ludwig van Beethoven (1770–1827). Gradual, ultimately profound hearing loss forced the composer to abandon instrumental performance and conducting. Contemporaneous biographical accounts take notice of his use of the adaptive technologies of his day, ear trumpets and conversation books. Many of the latter have been preserved, providing an exceptional biographical reference. Beethoven's compositional prowess was surely undiminished by his deafness. Whether some of his stylistic preferences were shaped by his hearing loss is a matter of speculation.

Contemporary Scottish percussionist Evelyn Glennie also has significant hearing loss. She eschews disability/Deaf identity. Her public statements could be interpreted as anti–Deaf culture; her official website (http://www.evelyn.co.uk) is inaccessible. She is a supporter of the Alexander Graham Bell Foundation, widely perceived as opposed to Deaf culture and a major advocate of orality and cochlear implants.

The late Canadian pianist Glenn Gould (1930–1981) was noted for his musical and personal eccentricities and abandonment of concertizing in favor of an exclusively recording career. His hypochondria and psychological dependence on prescription medications, which Gould obtained in great and often contraindicated variety and in large quantities by going to several physicians who were unaware of what others had prescribed, has been reliably documented. It is widely and exceptionally convincingly speculated that Gould had Asperger's syndrome, a high-functioning condition on the autistic spectrum and a diagnosis virtually unknown at the time of the pianist's death. Whatever Gould's cognitive differences and whatever the affect on his health and quality of life, it is precisely the iconoclasm of his music making—doubtless related to his unique cognitive makeup—that remains highly cherished.

POPULAR MUSIC AND JAZZ

Probably the most disabling aspect of Americanist global popular culture is the insistence that artists be exceptionally physically attractive by normate standards, particularly in youth popular music, where prominent figures with visible disabilities are virtually unknown, with such minor exceptions as late-disabled, established figures like Curtis Mayfield and Teddy Pendergrass, whose careers certainly declined postdisability. (Hidden conditions such as Karen Carpenter's anorexia and the substance addictions of Jimi Hendrix, Janis Joplin, Jim Morrison, Kurt Cobain, and others are common.)

More (under)class conscious musicians have been somewhat more accepting of artists with apparent disabilities. (Alt-)country has produced prominent singers whose impairments, although obvious, do not impede their performance: Vic Chesnutt (paraplegia) and Mel Tillis (speech disfluency).

Important jazz musicians have also been noticeably, although not musically, disabled. They include Benny Goodman band trumpeter Wingy Manone (amputee), pianist Michel Petrucciani (small stature, brittle boned), and blues singer-guitarist Brownie McGhee (mobility impaired). Others, including Charles Mingus (ALS) and Ella Fitzgerald (double amputee, owing to diabetes), were late disabled and continued to work.

Several jazz artists' physical impairments are incorporated seamlessly into their uniquely virtuosic styles. Pianist Horace Parlan, well-known for his work with Charles Mingus and also as a sideman for jazz legends Dexter Gordon, Archie Shepp, and Rahsaan Roland Kirk, had polio that left his right side affected, in particular his right hand, the fourth and fifth fingers of which cannot play at all. Parlan was fortunate that at age eight, piano teacher Mary Alston encouraged him to develop a uniquely personal technique rather than dismissing his musical aspirations. It is interesting to compare the careers of classical pianist Wittgenstein and jazz pianist Parlan. Wittgenstein's disability compelled him to commission a whole new one-handed literature, which, however, provided him only a minuscule repertoire. Parlan, working in an idiom whose essence is flexibility and improvisation, knew no such limits. He is able to play with his unique technique the entire jazz repertoire alongside legendary players.

Even more remarkable than Parlan was Roma guitarist Django Reinhardt. Badly burned at the age of 18, Reinhardt lost most of the use of the fourth and fifth fingers of his left hand. (The left hand uses fingers 2–5 to fret the strings, often simultaneously, when chords are played.) Even less able than Parlan to play with the conventional technique of his instrument, Reinhardt is known for having invented the single-string jazz guitar solo and revered as one of the greatest jazz guitarists of all time.

Singer Jimmy Scott, Billie Holiday's favorite, has Kallmann's syndrome, a hereditary hormonal condition that inhibits growth and prevents the male voice from deepening at puberty. Known for his work with Lionel Hampton, his newly revived career is currently at its peak, with international tours, recordings, and a recent biography.

MUTUAL ASSISTANCE AMONG MUSICIANS WITH DISABILITIES

The notable achievements of individual musicians with disabilities do not justify the lack of technological and other accommodations that would enable more universal musical participation. Organizations of disabled musicians in Canada and the United States provide important models.

Founded in 1988, the Vancouver Adapted Music Society (VAMS) is devoted to facilitating, through the development and commissioning of highly sophisticated technologies, musicking by people with "significant disabilities," mostly mobility impairments. Much of the new technology emphasizes composition and sound synthesis, although real-time performance aids have also been developed. VAMS views music making as inherently valuable rather than therapeutic or rehabilitative. Program participants tend to be avocational, rather than professional, musicians. In 1993, the organization's showcase band, Spinal Chord, recorded an all-original CD titled *Why Be Normal?*

Founded in 1986, the Long Island–based Coalition of Disabled Musicians (CDM) is concerned primarily with professional music making: Several members have acquired workplace disabilities that mandated career changes. CDM advocates and disseminates information about adaptive technologies, typically simpler if no less effective than those developed at VAMS, as well as nontechnological accommodations such as "tag-team performance"—that is, the use of several musicians in alternation as a strategy for dealing with fatigue issues. Like VAMS, CDM has a featured band, Range of Motion.

Organizations like VAMS and CDM have tremendous value for the advancement of music making by people with disabilities. In particular, the development of technologies for composition and sound synthesis and the emphasis of real-time performance address the needs of potential musicians with mobility impairments.

—*Alex J. Lubet*

See also Music and Blindness.

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MUSIC AND BLINDNESS

Blindness usually presents no obstacle to music making; indeed, the blind are often regarded as exceptionally musical. Nations have even reserved classes of musical employment for the blind, and blind musicians have often formed unions.

Blind musicians flourish where musical praxis is predominantly oral. Western classical music's reliance on notation creates difficulties for blind musicians, and conductors present another problem. Still, notable blind classical musicians include composer-organists Francesco Landini, Louis Vierne, and Jean Langlais, and composer-pianist Joaquin Rodrigo. Louis Braille, inventor of tactile writing and music notation for the blind, was an accomplished organist.

FRANCE

Pierre-François-Victor Foucault (1797–1871) was a blind professional hornist in postrevolutionary Paris and husband of blind author Thérèse-Adèle Husson (1803–1831). Foucault and Husson were partially supported by Quinze-Vingts hospice for the blind, sponsored by French royalty since the thirteenth century. An 1825 census shows that 34 of 225 hospice members were professional musicians, including 9 women, most of Quinze-Vingts's working blind. While music was considered a suitable occupation for the blind, Foucault's colleagues defied hospice authority by serving as the house orchestra for the questionably reputed Café des Aveugles (Blind People's Café), a manifestation of the tendency for the blind of Paris "to form a support network beyond the reach of an institution" (Weygand and Kudlick 2001:140), a transgression likely disapproved by hospice administrators. Braille entered Quinze-Vingts within a year of Foucault and Husson's departure.

UKRAINE

Since at least the fifteenth century, Ukraine hosted a folk bardic tradition, with singers accompanying themselves on *kobza* (a lute that later evolved into the bandura) or *lira* (hurdy-gurdy). Blindness was obligatory for minstrels, and minstrelsy was reserved as a profession for the blind; artistry was a secondary consideration. Evidently, blind female minstrels sang a cappella and sang a repertoire different from that sung by men. Musical instruction was nearly universal for the blind, perhaps for all otherwise unable to work. Minstrels were associated with the Orthodox Church, but their social position was ambiguous; they were respected as workers and compensated as beggars.

Minstrels' "remarkably democratic and egalitarian" guilds trained, protected, and policed the profession

(Kononenko 1998:xii). Apprenticeships included musical training as well as training in life/social skills and a secret language. Most guild members owned homes and raised families. Unlike most peasants, they traveled extensively. Minstrels hired sighted child guides, often with disabilities, who typically later became instrument builders, a skill acquired from their blind masters.

In 1939, Joseph Stalin convened a minstrel conference in the Ukraine. Fearing nationalism in minstrels' lyrics, he had all in attendance shot, nearly ending the tradition.

JAPAN

Japan's *biwa hōshi*—blind "lute-priests"—bear remarkable parallels to the minstrels of Ukraine. Even more than in Ukraine, in Japan the art and patronage of mendicant bards were religion based, with Indian and Chinese Buddhist antecedents perhaps as early as the sixth century BCE. The repertoire of the *biwa hōshi* syncretized Buddhism, Shinto, earlier local folk religion, historical narrative, and popular culture.

The principal function of the *biwa hōshi* evolved from spirituality to entertainment. Japanese attitudes toward blindness were complex and ambivalent, combining ancient beliefs that the blind have powers of divination and "extraordinary ability in communicating with invisible, yet very powerful, natural forces" (Matisoff 1978:30) and the Buddhist association of disability with negative karma. Disability was considered an opportunity to accumulate merit for future incarnations, fueling numerous morality tales in art and folk genres. Legendary *biwa hōshi* Semimaru has been described as "an archetype of the performing arts in Japan . . . a virtual 'patron saint'" (Matisoff 1978:6), inspiring stage works for Noh, Bunraku (puppet theater), Kabuki, and Butōh. Semimaru's status rose from local Shinto deity to bodhisattva, Buddha incarnate. The power that the *biwa hōshi* had over important popular narratives advanced his social position.

In the fourteenth century, *biwa hōshi* Akashi Kakuichi founded Tōdōza (the Proper Path Guild), which was eventually recognized by the government as a regulatory agency for blind lutenists. Tōdōza classified members "according to a system of four graded titles, divided into sixteen ranks" (Matisoff 1978:43). Beyond direct government control, the guild assumed the authority of "a country of the blind" (Matisoff 1978:43). Tōdōza was abolished in 1871, early in the modernist, pro-Western Meiji era.

The unionization of blind musicians in Ukraine and Japan implied broad societal consensus that certain categories of musical employment were apt and thus reserved for the blind, owing as much (or more) to extraordinary ability as to disability.

UNITED STATES

American democracy and market economics render impossible the existence of exclusivist guilds of blind musicians such as those established in Japan and Ukraine. The principal achievements of blind American musicians have been in forms of music with African American roots (although some notable blind exponents of these genres are neither American nor African descended). This is likely owing to the prevailing orality of African musical cultures and African American aesthetic preference for deeply personalized interpretation, often including improvisation. One ramification of the high value placed on individuality is that artists shape their interpretations around whatever idiosyncratic musical techniques emanate from their bodies, including vocal range, tone color, level of virtuosity, and the shaping force of a physical disability. African American music has produced distinguished musicians with a variety of impairments, including blindness.

Blindness has been particularly associated with the blues, especially older, acoustic varieties, the institution of the blind bluesman (blind blues musicians are apparently exclusively male) having nearly vanished in electric blues bands. Best known include Blind Lemon Jefferson, Blind Blake, Blind Willie McTell, Blind (or Reverend) Gary Davis, and Sonny Terry—the only one of this group whose sobriquet does not include "Blind." Although many acoustic bluesmen of this era were not blind, playing the blues appears to have been recognized as a suitable calling for blind musicians. Some, like Blind Lemon Jefferson, achieved considerable financial security and social status from their music making.

Although jazz makes greater use of notation than does blues, its prevailing orality/improvisation has made it an expressive medium for numerous blind musicians (not all African American), some of whom are acknowledged masters. They include pianists Art Tatum, Marcus Roberts, and George Shearing; pianist-vocalists Ray Charles and Diane Schuur; and saxophonists Rahsaan Roland Kirk, Lenny Tristano, and Eric Kloss. Among Motown's most illustrious performers and composers is Kennedy Center honoree Stevie Wonder. One of the best-known gospel groups in the United States is the Blind Boys of Alabama. Somewhat more removed from African American roots are folk musician Doc Watson and Latino vocalist-guitarist José Feliciano. Harder to characterize stylistically and largely forgotten musically but vital to disability history is composer-pianist "Blind Tom" Bethune (1849–1908), whose life is chronicled in three volumes by Geneva Southall (1979, 1983, 2002).

ELSEWHERE

Since the 1930s, the Royal New Zealand Foundation of the Blind has operated a program of music education and performances that has its origins in the pre-mainstreaming residential school system. A tradition of blind mendicant street ensembles, reminiscent of Japan and Ukraine, resides in Cuzco, Peru. The award-winning, extensively toured Light and Hope Orchestra of Cairo, made up entirely of women, is the world's only blind symphony orchestra. The South African Blind Musicians Association, which receives federal funding, performed at that nation's South African Music Week in 2002. The "blind-musicians" Listserv (blind-musicians-subscribe@yahoogroups.com) has worldwide subscribership.

Organizations of blind musicians have existed for centuries on nearly every continent. Blind leadership appears to be the rule in such organizations.

—Alex J. Lubet

See also Music.

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MUTATION THEORY

Mutation theory joined two seemingly opposed traditions of evolutionary thought at the beginning of the twentieth century. First, its practitioners accepted the primary contention of saltationist theory, which argues that new species are not formed, as Darwinism holds, through the gradual accumulation of variation over vast epochs, but instead are produced during sudden and unexpected shifts in the constitution of elemental species (a process referred to as *sports*). Second, unlike saltationists, who argue that some organismic variations are inherently undesirable, the first mutationists tended to hold the stricter Darwinian line that all differentiation is for the good of the organism/species. This argument was premised on the belief that more variation provides better opportunities for adaptation to a variable environment. This second emphasis has often escaped the reasoning of evolutionary theorists, many of whom have appeared to be perplexed that mutationists have claimed a Darwinian lineage (see Gould 2003:443). This important dovetailing of seemingly antithetical traditions made mutation theory one of the vanguard movements in twentieth-century evolutionary and, ultimately, genetic theory.

The first self-acknowledged theorist of mutation was the Dutch botanist Hugo de Vries. In his breakthrough two-volume work *The Mutation Theory (Die Mutation Theorie),* de Vries (1909) stubbornly insisted that he was first and foremost a Darwinian in spite of the fact that mutation functions as an expression of what the eugenicist Sir Francis Galton called *sports.* De Vries held that new species arrive suddenly and without prior precedent through the process of mutation, which he defined as "the change of one species into another [due to the formation of] a new center of analogous variations" (pp. 66–67). Rather than simply argue that species are discontinuous from each other—as in the case of neo-Lamarckism—mutation theory originated the idea that variations themselves are discontinuous, as in the cases of "dwarfism," "giantism," and "albinism." In the *O. Lamarckiana* species of plant that de Vries studied, these new species came into existence fully formed and viable while lacking all defining characteristics of the parent generation. Thus, de Vries's analysis focused on the creative force of discontinuity as a prime explanation for the origins of new species. This argument attempted to address a key lack in Darwinian analysis with respect to the incompleteness of the fossil record. Rather than insist that knowledge of the fossil record is insufficient to identify transitional stages in the gradual accumulation of incremental variations over time, de Vries's mutation theory insisted that no such gaps in the genealogical trees of organisms existed. Thus, what appeared to be absences in the fossil record could be marshaled as evidence in favor of a Mendelian and saltationist-based theory of evolution.

Mutationist theories developed after de Vries's work, such as Richard Goldschmidt's (1933) "hopeful monsters" and Gould and Eldredge's (1977) "punctuated equilibrium" theories, not only remained faithful to the saltationist basis for new species formation but also championed de Vries's devotion to the pure Darwinian belief that all variation proves beneficial, including above and below the organismic level. In doing so, mutationist theories have recognized alternative, viable organismic formations (often labeled "disabilities" at the human level) as examples of the creative force of new species coming into existence through mutation. This interpretation flies in the face of eugenicist—and geneticist—assertions that some mutations are monstrosities or organismic abominations. Those who have taken up this stance in favor of productive readings of mutation have been readily critiqued by a discourse that remains faithful to its investment in designating some organismic expressions "unnatural."

Rather than try to settle this dispute of more than 100 years' duration here, we need to ask this question: Why are efforts to embrace rather than malign the existence of recurrent forms of mutation so routinely banished from the theoretical canon of evolutionary and genetic traditions?

—David T. Mitchell

See also Charles Darwin; Evolutionary Theory.

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MUWAFFAK AD-DIN MUZAFFAR (1149–1226)

Egyptian philologist and poet

Muwaffak ad-Din Muzaffar was a blind Egyptian philologist and poet. Ibn Khallikan remarked that Muzaffar's treatise on prosody "testifies, by its excellence, the acute intelligence of the author." He quoted a little of Muzaffar's verse, in which the poet commented, rather wearily, on how strange sighted people found it that he could be in love: "You are in love, and yet you are blind! You love a dark-eyed nymph with rosy lips, yet you never saw the charms of her person; you cannot then say that they captivated your imagination." In a later era, the puzzled questioners might have listened to the radio and had the experience of falling in love with someone's voice; thus Muzaffar's reply, "I love through the medium of my ears," which Ibn Khallikan expanded with similar thoughts from earlier blind poets. The skills of memorizing and expounding Arabic literature, and expressing well-worn ideas about female beauty in neatly turned verse, continued in the thirteenth century to provide an opportunity for a few capable blind men to take part, without much disability, in the literary and courtly life of their times.

—*Kumur B. Selim*

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MYASTHENIA GRAVIS

Myasthenia gravis (MG) is a syndrome of fluctuating skeletal muscle weakness that worsens with use and improves with rest. Eye, facial, oropharyngeal, truncal, and limb muscles may be involved in varying combinations and degrees of severity. MG occurs throughout the world at any age from birth to the tenth decade. Today's overall annual incidence is 20 new MG cases per million individuals, with a remarkable increase with age. Current point prevalence rates of MG are in the range of 100–200 per million population.

The etiology of MG is varied, divided initially between those rare congenital myasthenic syndromes that are genetic and the bulk of MG that is acquired and caused by the body's own immune system attacking itself (autoimmune). The autoimmune conditions are divided into those that possess measurable levels of an antibody to a substance that allows communication between nerves and muscles (acetylcholine receptor, or AChR) and a smaller group that does not. The latter includes those MG patients who have antibodies to a chemical critical to normal muscle function (MuSK).

General treatment measures include rest, high-potassium diet, and avoidance of infections and drugs that exacerbate MG. Except for some of the congenital myasthenic syndromes, drugs that help overcome the diminished communication between nerves and muscles (anticholinesterases) are usually effective for temporary treatment of MG symptoms. Short-term immunological treatments for autoimmune MG emergencies such as breathing difficulties (crisis) include filtering the blood, plasmapheresis, and/or intravenous immunoglobulin. For long-term immunological treatment, therapies differ for early-onset MG, late-onset MG, and MG associated with tumor of the thymus gland, thymoma. Thymectomy is often effective for early-onset MG (before age 50). Drugs that suppress the immune system, including corticosteroids, are useful for late-onset MG and for MG associated with thymoma (following thymectomy). Most MG patients can be treated effectively, but more specific therapies are still needed.

—*John C. Keesey*

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MYOFASCIAL PAIN

DEFINITION AND SYMPTOMS

Myofascial pain is a chronic regional musculoskeletal pain syndrome characterized by the presence of trigger points, which are discrete areas of focal tenderness within a muscle that reproduce the patient's pain and have a characteristic referral pattern when palpated.

The characteristic symptoms of myofascial pain may begin after a discrete trauma or injury or may be of insidious onset. Patients note localized or regional deep aching sensations, which can vary in intensity from mild to severe. The myofascial trigger points of each muscle have their own characteristic pain patterns. Often associated subjective symptoms are present, such as abnormal sweating, vasomotor/temperature changes, paresthesias ("pins and needles" sensation), edema (swelling), joint stiffness, impaired muscle coordination, decreased work tolerance, fatigue, and weakness.

CAUSE

Although many theories have been developed, no absolute answer has been reached concerning the cause of myofascial pain syndrome. The recent medical literature demonstrates that excess release of acetylcholine (the chemical responsible for communication between the nerve and muscle at the neuromuscular junction) may result in chronic muscle shortening, relative ischemia (diminution of local blood flow), and reduction of energy supply to the muscle.

In addition, in this chronic pain syndrome, neurochemical changes occur at higher-level pain-processing centers in the spinal cord and brain, rendering the nervous system more sensitive to pain. This results in a hypersensitivity to both painful and normally nonpainful stimuli.

PHYSICAL EXAMINATION AND TREATMENT

A comprehensive medical, neurological, and musculoskeletal physical examination is performed to identify underlying structural causes of regional pain, such as sciatica, bursitis, or tendonitis. Thereafter, careful palpation of the painful region is necessary to search for trigger points. Trigger points feel like ropy bands of muscle and are painful when pressure is applied. Pain is often referred distally (away from the area). Pain recognition by the patient is important to confirm that the trigger points are indeed the cause of relevant pain.

The treatment of myofascial pain may be either pharmacological (involving the use of medications) or nonpharmacological. *Pharmacological* treatments may include anti-inflammatory medications (for example, ibuprofen) to help treat any associated bursitis, tendonitis, or other inflammatory condition. Several different types of muscle relaxants are useful as well. Low doses of antidepressants have demonstrated utility in reducing pain even in the absence of clinical depression. In severe cases, botulinum toxin may be injected in the painful musculature. *Nonpharmacological* options include massage, ice, heat, acupuncture, and relaxation training. Trigger point injections are reserved for recalcitrant cases.

Rehabilitation and Exercise

Physical therapy is indicated both to provide local treatment and, most important, to ensure that the patient is educated in appropriate exercise, including stretching, graded strengthening, and aerobic exercise to decrease pain and improve function. An occupational therapist can be helpful in educating the patient on proper body mechanics and improving workplace ergonomics. Reinforcement of appropriate posture, stretching, and relaxation training can be helpful components of rehabilitation.

FUNCTIONAL OUTCOME AND DISABILITY

To date, few outcome studies have examined myofascial pain and its treatment. One research study found improvements in life satisfaction and coping skills as well as decreased sick-leave time after rehabilitation. Growing evidence suggests a link between arm pain and physical risk factors in the workplace. Therefore, possible ergonomic solutions may be forthcoming. No studies have yet been conducted regarding myofascial pain and disability.

—Joanne Borg-Stein

See also Pain.

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MYOPATHY

Myopathy is a general term referring to a disease of the muscle. Myopathies can be subdivided into hereditary and acquired variants. The hereditary myopathies include the various forms of muscular dystrophy, congenital myopathies, metabolic myopathies, and some mitochondrial myopathies. The acquired myopathies include a group of diseases known as the inflammatory myopathies, toxic myopathies caused by drugs or other chemicals, and myopathies due to endocrine dysfunction. All myopathies cause skeletal muscle weakness, which can cause disability.

The hereditary myopathies come from genetic defects affecting the expression of a protein, enzyme, or other structure within muscle. With the explosion of molecular genetics, many of these genetic defects and gene products have been identified. The three most common hereditary myopathies are all forms of muscular dystrophy: Duchenne dystrophy, myotonic dystrophy, and facioscapulohumeral (FSH) dystrophy. Both myotonic and FSH dystrophy are inherited in an autosomal dominant fashion, meaning that an affected parent has a 50 percent chance of passing the disease on to a child. The congenital myopathies are further classified by abnormalities seen on muscle biopsy. In the past, they were also distinguished from the dystrophies by nonprogressive weakness; however, it is now recognized that weakness does progress in some of these disorders.

The metabolic myopathies are caused by abnormalities in glycogen or fat metabolism in muscle, producing weakness, early fatigability, and muscle cramping. Mitochondrial myopathies are caused by abnormalities in the mitochondria, the energy source for cells. Unfortunately, there is no effective pharmacological treatment to reverse weakness caused by the inherited myopathies. However, the use of rehabilitation strategies limits the disability and handicap produced by these diseases.

The acquired myopathies are often treatable with medications. The inflammatory myopathies (dermatomyositis, polymyositis, and inclusion body myositis) are the most common acquired myopathies, with an incidence of 1–2 per 100,000. Dermatomyositis and polymyositis are autoimmune diseases, which can be treated with drugs that modulate the immune system (e.g., steroids). Inclusion body myositis does not respond well to pharmacological treatment. The endocrine myopathies can be treated through correction of the underlying hormonal imbalance, such as hypothyroidism or hyperparathyroidism. The toxic myopathies can be reversed through elimination of the responsible drug or the offending toxin (e.g., alcohol).

The disability associated with myopathies is caused by muscle weakness. Depending on the particular disease, the limb, trunk, breathing, chewing and swallowing, and ocular muscles can all be involved. Some of the myopathies have an abrupt onset with rapid development of weakness (e.g., dermatomyositis), whereas others present with gradual weakness (e.g., some cases of FSH and myotonic dystrophy). Onset can occur in childhood or adulthood. Disability and impairment due to limb muscle weakness can be minimized through the provision of appropriate assistive devices, braces, and alternate modes of mobility (scooter, wheelchair). Respiratory muscle weakness is often managed through the use of noninvasive ventilation and through assistance with coughing. Speech therapists can teach patients compensatory strategies to minimize swallowing and speech difficulties caused by bulbar muscle weakness. In some myopathies, cardiac muscle is involved as well as skeletal muscle, producing another source of disability, which may be managed through medications and/or pacemaker placement.

In the near future, advances in molecular genetics that have identified the causes of many of the inherited myopathies may translate into effective treatments that will reduce the disability caused by these diseases. Likewise, ongoing research on the pharmacological treatment of the inflammatory myopathies may reduce disability from these diseases.

—Lisa S. Krivickas

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N

NARCISSISTIC PERSONALITY DISORDER

Although prevalent in human society since the beginning of recorded history, narcissistic personality disorder has attained prominence as a distinct disability only in the past quarter century through the work of psychoanalysts. The disorder is characterized by most of the following: extreme sensitivity to slights, a grandiose sense of self-importance, a great need for admiration accompanied by a personal lack of empathy, a sense of being so special or unique that only high-status people or institutions are worthy of association, a sense of entitlement (unreasonable expectations of especially favorable treatment), and arrogance.

Rather than seeing them as people who were overly indulged growing up, contemporary psychoanalysts view such persons as having been partly arrested in their emotional development at a stage of early childhood. Seeking the parents' validation and a sense of personal specialness is within normal developmental bounds at age two or three. When such emotional supplies are not adequately provided to them in childhood, the inappropriate seeking of them well into adulthood is the hallmark of people with this disability. Treatment rests on the psychotherapist's tolerance of their self-centered behavior without gratifying it and promoting insight into the patient's exaggerated vulnerability to empathic lapses by the therapist and others in their world.

—*Jerome A. Winer*

See also Psychiatric Disorders; Psychiatry.

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NATIONAL ACTION PLANS IN NORWAY

See Norway: National Action Plans

NATIONAL CENTER FOR MEDICAL REHABILITATION RESEARCH (UNITED STATES)

The National Center for Medical Rehabilitation Research (NCMRR) has primary responsibility for medical rehabilitation research that is supported by the U.S. government's National Institutes of Health (NIH). The center's professed mission is to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of persons with disabilities. Research is emphasized that addresses the health-related problems of people with disabilities and that has implications for enhancing their daily functioning. The center pursues its mission principally by providing multiyear grants-in-aide to investigators located in universities, medical schools, and other institutions throughout the United States.

The *Research Plan for the National Center for Medical Rehabilitation Research* (National Institute of Child Health and Human Development 1993) describes a conceptual framework for identifying research that the NCMRR supports. Seven priority areas are the following:

Improving functional mobility

Promoting behavioral adaptation to functional losses

Assessing the efficacy and outcomes of medical rehabilitation therapies and practices

Developing improved assistive technology

Understanding whole-body system responses to physical impairments and functional changes

Developing more precise methods of measuring impairments, disabilities, and societal and functional limitations

Training research scientists in the field of rehabilitation

The NCMRR's annual expenditure in 2002 for research and research training was $57,659,000. The bulk of those funds supported research grants that originated with unsolicited, investigator-initiated applications for funding that then were submitted to peer review. A small percentage of applications were funded in response to solicitations that were announced by the NCMRR on topics of special importance to the center.

Established by legislation passed by the U.S. Congress in 1990, NCMRR is a component of the National Institute of Child Health and Human Development (NICHD), a part of the NIH. That legislation established two other entities, the National Advisory Board on Medical Rehabilitation Research, and the Medical Rehabilitation Coordinating Committee. The Advisory Board consists of 12 scientists and clinicians in medical rehabilitation, 6 people with disabilities who have been recipients of medical rehabilitation services, and 17 ad hoc members from government agencies that fund research or service programs of relevance to medical rehabilitation. Its principal functions are to recommend research initiatives that it believes the center should undertake and to advise the directors of the NIH, NICHD, and NCMRR on matters and policies relating to the center's programs. The Coordinating Committee is charged with making recommendations to the directors of the NICHD and NCMRR regarding the center's research plan and its activities that are carried out in conjunction with other organizational entities within the NIH and throughout the federal government.

The NCMRR's efforts are organized in terms of three programs. The Biological Sciences Program promotes basic research to provide the scientific underpinnings of clinical rehabilitation. Research supported by this program strives to understand the mechanisms of recovery from, and adaptation to, injury and disease. The Clinical Practice Program applies scientific findings to improve clinical practices in rehabilitation. Work supported in this area includes development of new therapeutic interventions, clinical trials of new interventions, and clinical studies to improve and validate existing rehabilitation practices. The behavioral science portion of the Behavioral Science and Rehabilitation Engineering Program supports research that is relevant to the development or redevelopment of individuals' emotional, cognitive, and behavioral functioning. The rehabilitation engineering component encourages applications of engineering and bioengineering principles to promoting the habilitation or rehabilitation of people with physical disabilities. Examples include research on various forms of assistive technology, including prostheses and devices for wheeled mobility.

—Marcus J. Fuhrer

See also National Institute on Disability and Rehabilitation Research (NIDRR) (United States); Rehabilitation Engineering; Research.

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NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH (NIDRR) (UNITED STATES)

The U.S. National Institute on Disability and Rehabilitation Research (formerly the National Institute on Handicapped Research and hereafter referred to as NIDRR) was established in 1978. The U.S. Congress adopted the Rehabilitation Comprehensive Services and Developmental Disabilities Amendments of 1978 (Public Law 95–602), which removed the engineering and training programs previously administered by the Rehabilitation Services Administration (RSA) in the U.S. Department of Health, Education, and Welfare and placed them in NIDRR located in the newly reorganized Department of Education under the Office of Special Education and Rehabilitative Services. The institute's name was changed to NIDRR by the 1986 amendments to the Rehabilitation Act. The mission of NIDRR is to contribute to the independence of persons of all ages who have disabilities by seeking improved systems, products, and practices in the rehabilitation process.

NIDRR is an old program. The official role of the U.S. government in vocational rehabilitation, prosthesis research, and other disability-related research dates back to the 1930s and 1940s. Much of the groundwork for the current system of rehabilitation research was laid in the 1940s by the National Academy of Sciences and the armed services response to the postwar needs of veterans. A large share of the initial research was conducted by the Department of Defense and the Veterans Administration (VA) on prosthetic devices. The Interagency Committee on Rehabilitation Engineering, a working group composed of representatives of the National Science Foundation, National Bureau of Standards, National Aeronautics and Space Administration (NASA), VA and other agencies, and the Senate Committee on Labor and Human Resources, was responsible for NIDRR's initial long-range plan. The Interagency Committee for Disability Research, which is coordinated by NIDRR, is responsible for reviewing proposed research projects and for identifying areas that overlap with ongoing projects.

NIDRR's initial research plan focused on functional areas of research needs including mobility, communication, function, education, employment, recreation, and activities of daily living. Using a competitive grant process, NIDRR program mechanisms included the following: rehabilitation research and training centers (RRTCs), rehabilitation engineering research centers (RERCs), spinal cord injury rehabilitation centers, centers for deaf-blind youths, and coordination with international rehabilitation research centers.

After the passage of the Americans with Disabilities Act in 1990, NIDRR increased its emphasis on research related to independent living and community integration. The most recent long-range plan for 1999–2003 was issued in 2000. The disability paradigm, which provides the value framework for the plan, maintains that disability is a product of an interaction between the individual and the environment. The plan listed the following research agenda areas: (a) employment outcomes, (b) health and function, (c) technology for access and function, (d) independent living and community integration, and (e) associated disability research areas such as statistics. The plan also listed priorities for related activities in knowledge dissemination and utilization and capacity building for rehabilitation research. RRTCs and RERCs continued to receive the largest percentage of NIDRR's resources with 22.8 percent and 10.78 percent, respectively, of the $70 million appropriated to NIDRR in fiscal year 1996.

In an enumeration of research and administrative accomplishments from 1993 to 2001, NIDRR identified both administrative reforms and research outcomes. Administrative reforms include reinvigorating the Interagency Committee on Disability Research, overhauling its peer and program review processes and implementing a Center of Excellence model that balances scientific rigor with consumer relevance. Research accomplishments include the following: (a) establishing the first RERC on telerehabilitation, (b) continued decrease of decubitus ulcers and other secondary complications of spinal cord injury, (c) expanding the Traumatic Brain Injury System and initiating a system in Burn Rehabilitation, (d) research support for the accessibility features in the Windows operating system, and (e) initiating voting research.

NIDRR has been involved in a number of science and technology policy issue areas and initiatives during this period including the President's Executive Memorandum on Technology Transfer, the President's Information Technology Advisory Committee and Section 508 and electronic accessibility in the workplace, and signing cooperative agreements with federal laboratories. NIDRR unleashed new international initiatives that included the Web Accessibility Initiative within the World Wide Web Consortium (W3C), and the establishment of an RERC on land mines.

—Katherine D. Seelman

See also National Center for Medical Rehabilitation Research (United States); Rehabilitation Act of 1973 (United States); Rehabilitation Engineering; Research; Telerehabilitation.

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NATIONAL THEATRE OF THE DEAF (UNITED STATES)

The National Theatre of the Deaf (NTD) is the world's first professional deaf theater company and the oldest continually producing touring theater company in the United States. NTD's influence is widespread and renowned: The company has trained most of the deaf theater artists working today, and a number of its alumni have started their own deaf theater companies across the United States and abroad. NTD has also educated generations of hearing audiences about American Sign Language and Deaf culture and provided intercultural experiences that bring both deaf and hearing audiences together. Despite the company's successes, some deaf audience members have criticized the company for gearing productions to primarily hearing audiences.

NTD was conceived and eventually founded by a hearing medical professional and several high-profile, hearing theater artists. Dr. Edna S. Levine, an expert in deafness and psychology as well as an ardent attendee of Deaf amateur performance events, originally conceived the idea for NTD in the late 1950s and early 1960s. She garnered the support of actor Anne Bancroft, who had consulted Levine for research about deafness for her role as Anne Sullivan, the visually impaired teacher of deaf and blind Helen Keller, in Broadway's version of *The Miracle Worke*r. Broadway directors Gene Lasko and Arthur Penn and Tony Award–winning Broadway set designer David Hays also lent their support. Early efforts foundered when the federal government turned down two different grant applications. Hays and Levine continued to pursue funding with the assistance of faculty at Gallaudet University; hearing administrator Mary Switzer of the Department of Health, Education, and Welfare; and deaf and hearing administrators of the Vocational Rehabilitation Administration.

This persistence and networking paid off in 1965 when NTD earned its first federal grant for the 1966–1967 season. Along with federal grants, NTD is supported by corporate donors and ticket revenue. The company's first home was the Eugene O'Neill Memorial Theatre in Waterford, Connecticut, moving to Chester, Connecticut, in 1983, and moving to its current home in Hartford, Connecticut, in 2000. Throughout its history, NTD has collaborated frequently with Gallaudet University faculty and students.

NTD's repertoire includes adaptations of canonical dramatic literature (both Western and non-Western), children's literature, poetry, letters, novels, and fables. The work has appeared on stage, film, and television. The company strives for cultural diversity, a goal furthered by exchanging company members with international deaf theater companies and the regular inclusion of international artists in their professional training programs. In addition, NTD has collaborated with hearing theater luminaries such as Peter Brook, Arvin Brown, Colleen Dewhurst, Bill Irwin, Marcel Marceau, Chita Rivera, Jason Robards, and Peter Sellers.

In addition to its theatrical productions, NTD has included a professional actor-training program (Deaf's Actors Academy, its earliest incarnation founded in 1967), a touring theater for young audiences (Little Theatre of the Deaf, founded in 1968), workshops for deaf playwrights (primarily active from 1977 to 1982), and educational outreach programs. NTD has performed in all 50 of the United States and on five continents.

To appeal simultaneously to both deaf and hearing audiences, NTD has developed a unique theatrical style, a seamless hybrid of corporeal and spoken languages in which audiences "see and hear every word." Because of his background and training as a set and lighting designer, David Hays recognized that the sculptural qualities of sign language theater had the potential to revolutionize theater aesthetics as a whole. In contrast to traditional Western theater's focus on spoken text and realistic acting styles, NTD's performance style emphasizes the spatial and dance-like qualities of human communication. The resulting style blends the spoken word, American Sign Language, sign-mime, invented theatrical sign language, music, and stylized individual and ensemble movement. A hallmark of NTD's style is the creation of visual scenic elements using only the actors' bodies, a few suggestive props, music, and unusual sound effects. NTD employs both deaf and hearing performers. Deaf performers most often portray main characters with hearing actors located on the stage's periphery voicing the main characters' lines, a technique called *shadowing*. Sometimes hearing actors play minor characters as well.

The NTD's performance style and repertoire have not succeeded without controversy. During its early years, while the company was in the process of inventing its theatrical vocabulary, deaf audiences complained that the American Sign Language used in the productions was unintelligible to them. They complained that the signing was performed too quickly and invented signs were cryptic. Furthermore, deaf audiences felt that the material was more often than not geared toward hearing audiences and that Deaf cultural issues went unexplored. Deaf audiences also tended to be suspicious of a company whose leadership was almost entirely hearing. To address these concerns, NTD began developing original work for deaf audiences about Deaf culture. As deaf theater artists became trained and experienced, they moved into leadership positions within the organization and took on more directing and design assignments. Complaints from the deaf community about the productions' unintelligibility have quieted as well. Audiences may have simply become accustomed to NTD's theatrical vocabulary as it has become more conventionalized and used by numerous companies. While the majority of NTD's audiences remain hearing (about 90 percent), over the years the company has dedicated portions of its season to work by, for, and about the Deaf community.

—Carrie Sandahl

See also Aesthetics; Dance; Deaf Culture; Drama and Performance.

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NAZISM

Disabled people have faced both neglect and oppression within different cultures and political systems, throughout history. Yet the period of Nazi control in Germany (1933–1945) is notorious for genocidal policies toward disabled people. In the postwar period, the magnitude and cruelty of the "Final Solution" or Holocaust of the Jewish people has overshadowed the parallel exterminations of disabled people, homosexuals, Gypsies, Communists, Jehovah's Witnesses, and other minorities. Reclaiming the story of the Nazi eugenic and euthanasia program has been an important part of the disability studies project and the political development of the disability movement. Where neo-Nazi groups have been resurgent in America and Europe in the late twentieth century, disabled people have been targeted for abuse, attack, and sometimes murder, showing the continued need for awareness of Nazi ideology.

THE NAZI VIEW OF DISABILITY

Social Darwinism—the application of Herbert Spencer's idea of "the survival of the fittest" (it was English philosopher Spencer who first used the phrase)—was widely accepted and promoted in the Germany of the 1920s. Adolf Hitler's political manifesto, *Mein Kampf*, adopted a strongly social Darwinist approach: "The strongest asserts its will; it is the law of nature" (quoted in Gallagher 1995, p. 21). One of his perennial concerns was with the biological basis of the German race. This took the form of perorations against Slavic or Jewish intermarriage with Germans, and the threat of "mongrelization." It also led Hitler to express prejudice against the weak, sick, and disabled. Thus, he expressed admiration for the Spartan city-state of classical times: "The exposure of the sick, weak, deformed children, in short their destruction, was more decent and in truth a thousand times more humane than the wretched insanity of our day which seeks to preserve the most pathological subjects" (quoted in Gallagher 1995, p. 21).

In his speeches and policies, Adolf Hitler negated both the Christian and humanist traditions, by explicitly promoting militarism and putting the good of the nation above the rights of individuals. For example, he claimed: "Nature is cruel; therefore we are also entitled to be cruel. When I send the flower of German youth into the steel hail of the next war without feeling the slightest regret over the precious German blood that is being spilled, should I not also have the right to eliminate millions of an inferior race that multiplies like vermin?" (quoted in Fest 1974, pp. 679–680).

Mein Kampf is full of prejudice against disabled people and expresses the view that disabled people should be prevented from reproducing. However, these views were not unique to Nazi ideologues: Beliefs about race and fitness had been popular since the late nineteenth century in German science and medicine. Old ideas were reinforced and emboldened by the development of the Nazi movement. During the 1930s, and especially after the takeover of power in 1933, propaganda against disabled people became more common. For example, the film *I Accuse* featured a husband who killed his wife, who was suffering from multiple sclerosis. This idea of mercy killing was to become a major element in the Nazi approach to disability. Other terms used in propaganda posters and films to describe disabled people included "useless eaters," "ballast existence," and "life unworthy of life."

NAZI ACTIONS AGAINST DISABLED PEOPLE

After 1933, eugenic laws were passed in Germany, which prohibited marriage for certain individuals and mandated sterilization for some. These laws were comparable to equivalent legislation in the United States and the Nordic countries. After the advent of war, a covert euthanasia program (T4) was authorized by Hitler, which led to the murder of 70,000 disabled people in six killing centers, largely by gassing them. The main targets for murder were individuals who lived in institutions, particularly people with learning difficulties or mental health problems. After complaints and concerns were raised among the public, the official euthanasia program was halted. However, it was replaced by other measures to murder disabled people and also people with tuberculosis and other diseases, particularly as the German army took over territory to the East—"wild euthanasia" as it was called. The technicians of the T4 program moved on to staff the new extermination centers, which murdered Jews and other minorities. Meanwhile, a children's euthanasia program murdered thousands of disabled children in hospitals, via starvation or lethal injection: this program continued until 1945.

The motivation for euthanasia was largely economic: In the context of war, it was an attempt to save money and resources by eliminating dependent people. The aim of racial purification was often subsidiary to the financial motive; for instance, disabled people outside institutions were less likely to be killed.

As well as official and unofficial euthanasia, disabled people were subjected to medical experimentation, particularly in the concentration camps such as Auschwitz. During the Nazi era, such research was conducted with little or no regard for the rights of the subjects, or concern for the origins of the medical specimens that were used. Corpses or body parts were sent to scientists from residential institutions, killing centers, and concentration camps. For example, Julius Hallervorden, working at the Kaiser Willhelm Institute for Brain Research in Berlin—now the Max Planck Institute—received more than 600 brains from institutions. He was very prominent in the field of neurology and gave his name to Hallervorden-Spatz disease. While the means and values of Nazi science may have been reprehensible, not all the findings can be dismissed as bad science. For example, alongside the eugenic and euthanasia programs, public health physicians were making major discoveries about the causes of cancer, linking tobacco to lung cancer for the first time.

This raises important questions about the extent to which all these developments should be attributed to the Nazis themselves. Hugh Gallagher (1995) argues that "although this program was authorised by Hitler and carried out under the auspices of the National Socialist government of the Third Reich, it would be a mistake to call it a Nazi programme. It was not. The program was conceived by physicians and operated by them. They did the killing. While many of these physicians were Nazis, many more were not. The program's sponsors and senior participants were the leading medical professors and psychiatrists of Germany, men of international reputation" (p. xv).

Nor was eugenics solely a Nazi ideology. In the United States, the Nordic countries, and across the world, involuntary eugenic sterilization was widely used during the twentieth century. However, in adopting official and unofficial euthanasia programs, the Nazi regime went further than any other.

It should be noted that the eugenic and euthanasia programs, although authorized by Hitler and carried out under the National Socialist government of the Third Reich, were largely conceived and carried out by senior medical professionals, not Nazi storm troopers or party ideologues. However, medical professionals were undoubtedly the professional group with the highest percentage of members of the Nazi party (approximately 50 percent). Many Nazi doctors escaped postwar prosecution, and some continued to take a leading role in German and international medical science after 1945.

THE NAZI ANALOGY

Referring to the eugenic and euthanasia programs carried out against disabled people during the Nazi era has rhetorical force in contemporary political arguments. For example, it is not uncommon for disability activists to label modern genetic research or screening services as "Nazi." Individuals who take positions that appear threatening or hostile to disabled people—such as the bioethicist Peter Singer—have been tarred with the "Nazi" epithet.

Equally, advocates of particular screening policies have used the Nazi example as a way of distinguishing between their own ideas and the discredited notions of eugenics that predominated prior to 1945. Distinctions between "bad science" and "evil eugenics" versus "good science" and "reproductive choice" are used to exonerate governments, medical professionals, and families from having immoral motivations or actions. Yet, on closer examination, freedom of choice is not always a reality, and the attitudes of doctors may sometimes sound implicitly or explicitly eugenic.

The descriptor "Nazi" has huge power, and it should be deployed with care and accuracy, not simply as a way of dismissing others with different views. Equally, when arguments about saving money by preventing the birth of disabled people—or about putting the interests of society above those of the individual—are being used by scientists and policy makers, then it is important to remember the past contexts in which these arguments were deployed. Understanding how the abuses of the Nazi era came about—and guarding against similar measures in modern medicine or social policy—remains vital in the twenty-first century, in democracies as well as in less liberal regimes.

—Tom Shakespeare

See also Bioethics; Eugenics; Eugenics: Germany; T4 Program.

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NCMRR

See National Center for Medical Rehabilitation Research (United States).

NESBITT, MURROGH DE BURGH (1889–1959)

South African independent living pioneer

Murrogh de Burgh Nesbitt lost his legs at 13, falling from a train on which he hitched a ride at Jagersfontein. The next 30 years of activity and adventure, overcoming physical obstacles and attitudinal barriers in others' minds, appeared in his much-reprinted autobiography, *The Road to Avalon* (1944), where Nesbitt also sketched his dream of a rural center for self-help rehabilitation, run by disabled people. The dream was realized in 1946, after publication of his first book. A further book (1958), including many descriptions and first-person accounts of people overcoming disabilities, described how the center "Avalon" was built and developed by Nesbitt, his wife Fraan, and a few companions, near Tulbagh in the Winterhoek Mountains, with fundraising and control vested in a committee of like-minded people at Johannesburg. However, by 1951, with Avalon in full swing, the original committee had largely been replaced, and the Nesbitts were ousted from Avalon. They moved to farming in the Orange Free State, living among the Basuto people. Murrogh Nesbitt was years ahead of his time in implementing ideas of self-help, mutual therapy, and the importance of disabled people as leaders and role models.

—*Kumur B. Selim*

See also Disability in Contemporary Africa.

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See Experience of Disability: The Netherlands

NEURAL ENGINEERING

Neural engineering refers to a new discipline that has emerged by combining engineering technologies and mathematical/computational methods with neuroscience techniques. The objective is to enhance our understanding of the functions of the human nervous system. Neural engineering also holds promise to improve human performance, especially after injury or disease. As befits such a broad definition, the field is multidisciplinary, in that it draws from neurological sciences (especially neurobiology and neurology) but also from a diverse range of engineering disciplines, including computer sciences, robotics, material sciences, neural networks, signal processing, and systems modeling and simulation.

While the potential applications of neural engineering are very broad, the discipline offers particular opportunities for improving motor and sensory function after major human central nervous system illnesses such as stroke, traumatic brain injury, or spinal cord injury. In these illnesses, the new technologies can be applied to help reroute neural signals around damaged areas of brain or spinal cord, or to substitute one type of neural signal for another type that is lost after the injury.

A particularly innovative example relating to the descending control of muscle actions in spinal cord injury relies on the application of multi-electrode recording techniques to enable long-term, simultaneous recordings from clusters of neurons in the motor cortex during the performance of skilled voluntary movement tasks. These cortical signals can be used to drive assistive devices, to program electrical stimulation of muscles (functional electrical stimulation or FES), or to interact directly with computers as communication systems.

Leading investigators in this area are Andrew Schwartz (2004) from the University of Pittsburgh, John Donoghue (2002) from Brown University in Rhode Island, and M. A. Nicolelis (Patil et al. 2004) at Duke in North Carolina. Each group has developed impressive animal models that involve recordings from various cortical areas during normal voluntary behaviors. These neural signals are usually filtered and processed to allow them to be used to instruct computers, to control simple robotic devices, or to activate electrical stimulators to control limb muscles. Exemplar approaches includes studies in which primates can be trained to use cortical neuron discharge to control simple planar robots, or they can be used to activate neural stimulators to excite muscles and move joints.

Alternative approaches allow signals from skin or other sensory areas to be routed around damaged areas and to be delivered to the cerebral cortex by other means. For example, sensory signals from the eye or from skin can be detected by a range of electronic sensors then delivered to the cortex in the form of electrical stimulus trains.

Other potentially helpful applications of neural engineering include the development of novel recording systems to allow long-term recording from small groups of nerve fibers in peripheral muscle or skin nerves and the development of implantable stimulators for use in promoting recovery of walking in individuals with spinal cord injury or for the restoration of motor function after cortical damage sustained as a result of stroke. Neural cuffs placed around nerves innervating the foot sole can be used to sense foot contact during walking or to detect other phases of locomotion, allowing accurate programming of muscle nerve stimulation.

Clinical applications of neural engineering are increasing rapidly in number, and there will certainly be many new practical applications emerging over the next few years.

—William Zev Rymer

See also Bioemechanics; Spinal Cord Injury; Stroke; Traumatic Brain Injury.

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NEURASTHENIA

Neurasthenia literally means nerve weakness. Although the New York neurologist and electrotherapist Georg Miller Beard may not have coined the term, contemporaries certainly considered him to be the father of neurasthenia. Beard's publications on neurasthenia appeared from 1869 until 1883, the year that he died. His most influential books were *A Practical Treatise on Nervous Exhaustion (Neurasthenia): Its Symptoms, Nature, Sequences, Treatment* (1880), and *American Nervousness: Its Causes and Consequences* (1881). A German translation of *A Practical Treatise* already appeared in 1881; a French translation followed in 1895. In the meantime, the neurasthenia concept had become widely known on both sides of the Atlantic, including Russia and Italy but also in, for example, the Dutch East Indies. From the early twentieth century onward, the diagnosis would also be introduced in countries such as Japan and China.

The label of neurasthenia was applied to a whole range of physical and mental symptoms, varying from anxiety, despair, phobias, and insomnia to inattention, extreme fatigue, palpitations, migraine, indigestion, and impotence, among others. Neurasthenic symptoms were attributed to a lack of nerve force, stemming from excess demands on the brain, the digestive organs, and the reproductive system. These demands, in turn, were thought to result from the fast pace of modern, urban life. Beard had presented neurasthenia as a truly American disease that was more or less the acceptable by-product of American civilization, but in the European context, next to modernity, heredity and degeneration also figured as explanatory concepts.

The therapeutic repertoire included treatment with electricity; visits to spas, seaside resorts, or the mountains; psychotherapy in combination with a stay in a sanatorium of (mental) hospital; or the rest cure of the American physician Silas Weir Mitchell, consisting of seclusion, bed rest, electrical treatment, a nutritious diet, and massage.

Neurasthenia acquired many different faces, geographically, socially, and through time. Not only was neurasthenia appropriated in many different ways, its popularity as a diagnosis also varied significantly, as did the popularity of its various therapies. Beginning as an affliction of the elite and the educated classes, neurasthenia was later "democratized" to a certain extent, by including ordinary people. Male neurasthenic patients tended to constitute the majority. In America and Europe, neurasthenia's heyday continued into the first decade of the twentieth century. From the early twentieth century onward, neurasthenia shifted from a somatic into a psychic diagnosis. After World War I, the diagnosis of neurasthenia gradually became outdated, although it by no means disappeared, as witnessed by its inclusion in the 10th revision of *International Statistical Classification of Diseases and Related Health Problems* (*ICD-10*) and the fourth edition of *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*). Conditions similar to the ones that used to be called neurasthenia now tend to be labeled as chronic fatigue syndrome. In eastern Asia, neurasthenia is still a preferred diagnosis, presumably because of its somatic rather than mental connotation.

—*Marijke Gijswijt-Hofstra*

See also Anxiety Disorders.

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NEUROLOGICAL IMPAIRMENTS AND NERVOUS DISORDERS

Neurology is the study of human neuromuscular system, including the brain, spinal cord and roots, peripheral nerves, junctions between nerves and muscles, and the muscles themselves, in health and disease. Neurological impairment arises from an alteration of function in any of these structures and can result from a wide variety of etiologies, from inherited genetic conditions to obstructed blood flow to a particular part of the nervous system. Common neurological symptoms and related disabilities include problems with memory, attention, concentration, speech or language (aphasias); sleep disturbance; visual changes; dizziness or vertigo; fatigue; weakness; involuntary movements or muscle rigidity; pain; loss of sensation or abnormal sensations; and problems with coordination or gait.

Neurology has a long history, and knowledge of the structure and function of the nervous system, along with conceptions of neurological impairments and their related disabilities, can be roughly divided into three phases: the preclassical, classical, and scientific phases. During the preclassical period, from antiquity until the early nineteenth century, medical scientists described several neurological syndromes, including epilepsy (the "sacred disease" or "falling sickness"), migraine and cluster headaches, hemorrhagic stroke (apoplexy), paralysis, and a variety of psychiatric disorders. Anatomical knowledge during this period was largely limited to the gross anatomy of the brain, spinal cord, and peripheral nerves. Concepts of the nervous system's function were correspondingly guided by structural appearance, so that peripheral nerves were believed to be conduits for the flow of animal spirits or nervous fluid; or by extrapolation from simple observation or experimentation, such as the notion of reflex action. With a relatively short human lifespan, limited knowledge of the structure and function of the nervous system, and the absence of effective medications or interventions, neurological disability during the preclassical era frequently involved chronic pain, paralysis, social stigma, and institutionalization.

The classical period of neurology, from the early nineteenth century to the mid-twentieth century, witnessed a dramatic growth in knowledge about the structure and function of the nervous system, and detailed clinical descriptions for dozens of neurological disorders along with their underlying pathology. During this period, neuroanatomy advanced beyond the surface structure to the microscopic descriptions of the nervous system, including individual nerve cells (neurons) and their connections, and provided a foundation for the understanding of normal function and pathophysiology. Physiological concepts were still closely tied to general concepts of nerve impulses and reflex action, but were integrated with psychological notions of inhibition, association, and representation. Many neurological disorders were first described during this period, including the aphasias or disorders of language (Paul Broca, Carl Wernicke, Ludwig Lichtheim), several brainstem stroke syndromes, general paresis and tabes dorsalis (syphilis of the brain and spinal cord), movement disorders such as Parkinson's and Wilson's diseases, multiple sclerosis (Jean Martin Charcot), hemi-transection of the spinal cord (Charles Éduoard Brown-Séquard), and muscular dystrophy (G. B. A. Duchenne).

Although several anesthetics, aspirin, and potent anticonvulsants (phenobarbital and phenytoin) were also developed during the classical period of clinical neurology, disability was still largely related to the progressive or fixed paralyses, chronic pain, and institutionalization, with the addition of traumatic brain lesions resulting from war injuries and generalized syndromes related to combat and advancing technology ("railway spine," neurasthenia, shell shock).

The scientific phase of clinical neurology, dating from the early twentieth century until the present, has produced an explosion of detailed knowledge about the structure and function of the nervous system. Several innovations made this rapid evolution possible, including the development of information theory, storage, and analysis; techniques for molecular and genetic analysis; structural imaging of the nervous system from magnetic resonance imaging (MRI) of the entire brain to electron microscopy of individual neurons and their connections; and techniques for studying brain function such as electroencephalography (EEG), positron-emission tomography (PET), and functional MRI. Knowledge of the different organizational levels of the nervous system (genetic, molecular, membrane, cellular, and functional systems) is now integrated to provide a detailed account of many neurological disorders.

These techniques have also produced new concepts such as neurodegenerative disorders, autoimmune syndromes, disease-modifying drugs, and critical time periods for therapeutic intervention. Indeed, recent decades have seen the development of highly effective symptomatic treatments for many neurological disorders, as well as agents that alter the natural history of neurological diseases. Neurological disability has been likewise transformed by our ability to diagnose neurological disorders at earlier stages, detect and manage risk factors for stroke, alleviate the paroxysmal pain of migraine as well as the chronic pain of peripheral neuropathy, delay the progression of conditions such as Parkinson's and Alzheimer's diseases, and provide technologically advanced treatment or life support for patients with life-threatening neurological conditions.

Examples of common neurological disorders, their associated impairments, and treatments in Western medicine follow:

Movement disorders. Parkinson's disease, the most common movement disorder, involves three cardinal features, namely, tremor, rigidity, and bradykinesia, but it is frequently associated with fatigue, cognitive changes, and sleep disturbance. Medical therapy with carbidopa/levodopa and other dopamine agonists (medications that stimulate dopamine receptors) have significantly reduced these symptoms and their associated disability. Surgical treatment with deep-brain stimulators is available for severe cases.

Headache. Migraine is one of the most common headache syndromes and is frequently associated with severe pain, visual changes, dizziness, nausea, and vomiting, requiring several hours of rest for symptomatic relief. Development of a novel class of neurochemicals (serotonin agonists, or triptans) and the use of antiseizure medications to prevent migraines has significantly reduced the frequency, intensity, and duration of attacks.

Epilepsy. Recurrent seizures involve unpredictable lapses of awareness and are frequently associated with either subtle automatic movements or violent jerking movements of the entire body. They pose significant risks of bodily injury or death. In addition, personal and social activities including driving, employment, and interpersonal relationships are restricted in many cultures. Over a dozen new antiepileptic agents developed over the past 20 years have resulted in significantly fewer medication side effects and some improvement in seizure control. Epilepsy surgery for refractory cases has excellent prognosis in select patients.

Stroke. Temporary or permanent interruption of blood flow to an area of the brain typically can produce a variety of neurological symptoms including aphasia, weakness, visual problems, difficult swallowing, or paralysis, in addition to long-term neurological and medical complications. Recovery of neurological function is highly variable and depends on several factors. Acute intervention with thrombolytic agents ("clot busters") or revascularization strategies can produce a significant improvement in neurological outcome, but these techniques are underused and limited to a very brief time window after the onset of symptoms.

Demyelinating diseases. Multiple sclerosis is a progressive, disabling autoimmune syndrome that typically affects young women and involves inflammatory lesions in the brain or spinal cord. Typical symptoms include cognitive difficulties and poor memory, loss of eyesight, weakness, incoordination, a decline in gait, incontinence, and prominent fatigue. New chemicals that modulate the immune system reduce the number of acute attacks, but their impact on long-term disability (i.e., average years before a patient is a wheelchair user) is not yet clear. Other medications can alleviate symptoms of profound fatigue and incontinence, improving the disability associated with these symptoms.

Dementia. The most common form, Alzheimer's-type dementia, is increasing in both incidence and prevalence and typically involves loss of memory and higher intellectual abilities. Symptoms include a progressive loss of memory, difficulty with basic activities of daily living, loss of autonomy, and institutionalization in severe cases. Anticholinesterase agents mildly slow the progression of disease.

Radiculopathies. Symptoms of weakness, muscle atrophy, and numbness in the arms of legs commonly result from compression of a spinal cord root compressed by the bones of the vertebral column, osteoarthritis, or displaced vertebral discs (herniated or "slipped" disc). Physical therapy, anti-inflammatory agents, or surgical decompression or stabilization provide effective symptomatic relief.

Neuropathies. Injury to the peripheral nerves is most commonly produced by chronic disease (diabetes mellitus), toxins (alcohol), infection (leprosy, hepatitis), or repetitive mild trauma (carpal tunnel syndrome). Neuropathies can produce a loss of sensation in distal extremities, abnormal burning or lancinating pain, weakness, and a decline in gait. Minor trauma due to numbness in the feet can lead to major complications such as infection of the bone (osteomyelitis) or destruction of a joint (Charcot joint). Medical treatment of any underlying conditions producing nerve damage and the use of various medications for symptomatic relief can minimize related disability.

Motor neuron disease. Amyotrophic lateral sclerosis (ALS) is a relentlessly progressive disease typically affecting males in the fifth and sixth decades of life that involves symptoms of weakness and spasticity. Disability is typically associated with loss of use of the arms and legs, requiring the use of a wheelchair, as well as progressive weakness of the muscles of speech, swallowing, and breathing. Physical therapy is helpful in managing symptoms of muscle cramping and spasticity but does not have an impact on the overall disability or course of disease.

This brief list of neurological conditions highlights the variability of neurological symptoms and their extraordinary impact on human function, life, and culture. A historical view of neurological conditions and impairments also illustrates the evolving interaction between medical knowledge, technology, practice, and therapeutics across history.

—David Millett

See also Aphasia; Dementia; Diabetes; Epilepsies, Temporal Lobe; Epilepsy; Gait Analysis; Multiple Sclerosis; Neuropathy; Neuropsychiatry; Parkinson's Disease; Repetitive Strain Injuries; Stroke; Vestibular Disorders.

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NEUROPATHY

Neuropathy is a loss of the function of nerves. Symptoms depend on which nerves are damaged. The main motor symptom is weakness, whereas common sensory symptoms are numbness, paresthesias (abnormal sensations such as pricking, tickling, burning, or tingling), and pain. Neuropathy is a common neurological disorder resulting from damage to the peripheral nerves and thus is more often called peripheral neuropathy. Peripheral nerves include the nerves branching off the spine, nerves innervating the head and neck area, and the autonomic nerves regulating functions such as blood pressure and motility of the intestines.

Historically, in the eighteenth and nineteenth centuries, neuropathy was not recognized as a separate disease, but rather diagnosed as progressive paralysis together with many other diseases. In the nineteenth century, many different forms of neuropathy were described as ascending or descending according to the direction in which the disease progressed, because the common thought was that nearly all disorders of the nerves were based on inflammation. A second diagnosis often used was progressive muscular atrophy (degeneration). Due to the work of great nineteenth-century French neurologists such as Jean Martin Charcot and G. B. A. Duchenne, many new diseases were split from this general category of progressive muscular atrophy: various diseases of the muscles, the spinal cord, the brain, and the many diseases of the peripheral nerves, the neuropathies.

Neuropathies can be classified into mononeuropathies when one restricted area is damaged, polyneuropathies if there is damage of the nerves in more areas, and symmetric neuropathies with bilateral manifestations. Another classification is according to which type of nerve is involved. Sensory neuropathies account for damage to nerves carrying sensory information and motor neuropathies for those innervating the muscles.

Common causes of neuropathy are diabetes and alcoholism. Other causes include mechanical pressure such as repetitive strain injuries, direct damage, toxic substances, certain medications, inflammation, autoimmune disorders, and endocrine and hereditary diseases. Recent diagnostic DNA tests have greatly increased our understanding of the complexities of hereditary neuropathies.

Although there is a wide range of causes, the type of damage to the nerves is limited. The nerve is composed of a cell body and a fibrous extension (axon), which conducts electrical nerve impulses. Isolation cells (myelin sheath), which facilitate electrical conduction, surround most of the axons. In toxic or metabolic injuries (e.g., diabetes) the axons and the myelin degenerate, resulting in a numb feeling in the area, the so-called sock or glove hypesthesia. Degeneration of myelin can be due to hereditary, inflammatory, or autoimmune factors and usually shows patchy damage to the myelin sheath.

Treatment of neuropathies involves eliminating or regulating the causes. Surgery can help when a nerve is entrapped; optimizing drug treatment is required in the case of diabetes. Some drugs are prescribed to relieve symptoms such as burning sensation, pain, and painful contractions of muscles. Physical therapy and splints can also relieve the burden of muscle contractions. Some complementary therapies ([electro]acupuncture) can be useful in alleviating symptoms such as pain.

Most hereditary and autoimmune neuropathies are incurable and often show a gradual deterioration leading to a lifelong use of a wheelchair or chronic pain. The impairment of sensory neuropathies, such as those of diabetes or leprosy, can lead to secondary injuries, infection, gangrene, and limb amputation. Providing the means to increase quality of life and improve self-image and providing emotional support are critical for dealing with the disabilities of neuropathy.

—David J. Kopsky and
Jan M. Keppel Hesselink

See also Burns; Diabetes; Neurological Impairments and Nervous Disorders; Pain; Repetitive Strain Injuries.

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NEUROPSYCHIATRY

Neuropsychiatry is a nonboarded subspecialty of the medical discipline of psychiatry that focuses on the treatment of persons whose psychiatric symptoms appear to be most related to *documented* brain disease or brain injury. The term *neuropsychiatry* refers to psychiatrists who have had one or more years of postresidency training in a neuropsychiatry fellowship program or who have had some neurological experience. The qualification, *documented* brain disease, restricts the field of neuropsychiatry and limits the overlap with other related subfields of psychiatry, such as biological psychiatry, in that biological psychiatry attempts to define the biological abnormalities that correlate with mental illness in the otherwise normal brains of psychiatric patients. Because of this difference, patients treated by neuropsychiatrists not only have documented neurological disease but are often under the care of a neurologist as well.

The overlap with the subspecialty of neurology called behavioral neurology is therefore the strongest for neuropsychiatry. However, the differences between these two fields are more significant than their overlap. Behavioral neurologists diagnose and treat the cognitive and behavioral disturbances that correlate with the patient's documented brain lesions. Neuropsychiatrists view these same brain lesions in the context of the patient's total psychosocial context and also within the context of the remaining healthy part of the patient's brain function, that is, the patient's emotional reaction to his or her brain impairments. In this regard, neuropsychiatry overlaps to some extent with the medical field of physiatry, or rehabilitation medicine, and the psychological subspecialties of neuropsychology and neurorehabilitation.

Neuropsychology is more concerned with the precise measurable characterization of both cognitive and emotional symptoms of brain impairment using standardized testing materials and structured interviews to give as complete as possible a cross-sectional view of the patient's function. Neurorehabilitation concerns itself with the application of new technologies to promote recovery of brain function or limit the progression of brain disease. Because the neuropsychiatrist has the larger psychosocial picture of the patient in mind and follows the patient longitudinally with relatively frequent follow-up visits, the final integration of the multifaceted care of the brain-impaired patient often falls into the hands of the neuropsychiatrist, which triggers an overlap with the legal and ethical aspects of medicine as a whole.

Therefore, the questions of medical as well as financial competency often arise in the course of the neuropsychiatrist's longitudinal care of the patient as well as forensic issues related to legal state of mind during impulse dyscontrol in patients with disinhibition due to the progression of their brain disease. This is particularly true in the treatment of older patients who suffer from progressive dementias, and this triggers another overlap with the psychiatric subspecialty of geropsychiatry. Unlike neuropsychiatry, geropsychiatry is a fully established board-accredited subspecialty of psychiatry that specializes in the psychiatric care of older patients who may or may not have documented brain disease but do have psychiatric symptoms.

In the process of treating psychiatric symptoms of brain-impaired patients, both positive symptoms of delusions and hallucinations and negative symptoms of apathy and neglect, as well as mood symptoms such as hypomania and depression and dysexecutive symptoms such as poor judgment and impulse dyscontrol, neuropsychiatrists attempt to make use of the most recent work in integrative (clinical and basic) neuroscience. This includes neuropsychopharmacology, neuroimaging techniques such as single-photon-emission-computed tomography or brain SPECT, magnetic resonance imaging or MRI with its specialized techniques of functional imaging, magnetic resonance angiography, and diffusion tensor imaging, as well as positron-emission tomography or brain PET imaging, with radioligand binding, electroencephalography including EEG (electroencephalographic), MEG (magnetoencephalographic), QEEG (quantitative EEG), and EPs (evoked potentials), clinical neurogenetics, neural network theory, and medical informatics databases. In using these sources of clinical information, the neuropsychiatrist must rely on the expertise of the established practitioners, such as the neuroradiologist and the electrophysiologist, but because the neuropsychiatrist knows the larger history and psychosocial context of the patient and has generally spent more time with the patient in the clinic, it becomes his or her responsibility to make optimal use of this information in guiding the overall treatment plan.

The following are some examples of clinical problems that might be managed by a neuropsychiatrist: (1) a Parkinson's patient with delusions and hallucinations on high doses of dopamine-enhancing medications, (2) a Huntington's patient exhibiting violent behavior and personality changes, (3) a developmentally disabled patient exhibiting self-injurious behavior, (4) a dementia patient who is causing behavioral and social disruptions, (5) a postoperative neurosurgical patient with delirium and speech impairment, (6) a seizure patient with psychosis and/or depression, (7) a patient with recurrent seizures, (8) a patient with chronic fatigue syndrome and decreased cognitive function, (9) a patient with a traumatic brain syndrome with an unstable mood and cognitive impairments, (10) a poststroke patient with apathy, (11) a patient with both schizophrenia and dementia, (12) a patient with Tourette's syndrome and severe obsessive-compulsive disorder, and (13) physical violence in a patient with known brain disease.

A major contribution of neuropsychiatry has been the management of the violent patient with known brain disease. Neuropsychiatrists have been active in treating patients who exhibit patterns of violence related to different types of brain lesions. These include (1) violence related to hypomanic or manic behavior after right parietal stroke, (2) impulsive aggression in the setting of congenital brain abnormality or diencephalic injury, (3) reflexive aggression to transient environmental stimuli in patients with dementia, (4) violence emanating from a dysexecutive syndrome due to prefrontal cortical disease, (5) violence related to deepened affect or delusive ideation in patients with temporolimbic epilepsy, and (6) violence in childhood abuse victims who have experienced traumatic brain injury. Carefully crafted combinations of beta-blockers, anticonvulsants, antipsychotics, serotonin re-uptake inhibitor antidepressants or SSRIs, and psychostimulants have been used to enhance cortical control of limbic circuits for these patients. Decreasing the frequency and intensity of violent behavior in these patients is essential to effective nursing care and rehabilitation as well as outpatient management.

Neuropsychiatrists have helped to significantly reduce morbidity in stroke patients. Stroke is the third leading cause of mortality and morbidity in North America. More than 20 percent of stroke victims become severely depressed, greatly complicating their rehabilitation. Neuroimaging studies suggest that infarction of the left anterior cortex as well as left rostral prefrontal cortex and left rostral caudate area carry the greatest risk for poststroke depression. Vascular dementia is also receiving the attention of neuropsychiatry with extensive use of psychoactive agents especially anticholinesterase inhibitors to enhance cognitive function. Early treatment of stroke and vascular dementia patients with antidepressants and psychostimulants can substantially increase their success at rehabilitation. Also, since the psychiatric symptoms in vascular dementia can often be more disabling than the cognitive deficiencies, the neuropsychiatrist can play a substantial role in improving the patient's overall function. Neuropsychiatrists are also taking an active role in the treatment of other dementias particularly Lewy body dementia, which often presents with delusions and mood instability, and frontotemporal dementia, which frequently presents with anxiety, obsessions, and delusions. The patient's quality-of-life issues with these dementias often depend on the effective control of their psychiatric symptoms.

—Thomas Jobe

See also Delirium; Dementia; Epilepsy; Neurological Impairments and Nervous Disorders; Parkinson's Disease; Psychiatric Disorders; Psychiatry; Schizophrenia; Stroke; Traumatic Brain Injury; Violence.

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▣ NEUROPSYCHOLOGY

Neuropsychology is the study of brain-behavior relationships. Clinical neuropsychology is an applied science dealing with the behavioral manifestation of brain dysfunction. Neuropsychological evaluation therefore entails assessing the various psychological/behavioral functions governed by the brain. Evaluations are useful in differential diagnosis among similarly appearing neurological disorders or between psychiatric and neurological conditions. Neuropsychological assessments often serve as the nucleus of rehabilitation and educational intervention plans and are instrumental in the evaluation of their effectiveness.

As with all psychological evaluations, neuropsychological assessment involves a process of answering clinical questions and responding to unique clinical situations that vary somewhat from patient to patient and across practice settings. The clinical application of neuropsychological principles can be used to determine the etiology and behavioral consequences of disabling conditions, as well as provide medical, rehabilitation, and psychiatric treatment recommendations. Treatment intervention is also an important and developing area within the specialty of neuropsychology.

Lezak (1995) delineated four knowledge areas important for neuropsychological practice: (1) clinical psychotherapeutic and assessment skills, (2) psychometrics, (3) neuroanatomy and functional neuroanatomy, and (4) neuropathologies and their behavioral effects. A fifth important knowledge area is a theoretical understanding of how the previous four content areas interrelate and interact. Such a conceptual framework helps the neuropsychologist integrate the historical information, medical material, current cognitive abilities, and general psychological functioning; provide an accurate description of a person's cognitive strengths and weaknesses; arrive at correct diagnoses (etiological conditions and anatomic location); outline the implications of the results for that person's functional living potential; formulate prognostications; and make clinically useful recommendations or design appropriate treatment interventions.

NEUROPSYCHOLOGICAL ASSESSMENT

There are three general reasons for conducting a neuropsychological evaluation: differential diagnosis, patient care, and research. The first step in the assessment process is defining the questions that need to be answered to meet particular clinical needs. Next, the neuropsychologist must determine what information is required and how best to obtain it. Neuropsychological testing might be only one of several methods used. In fact, a psychological test is simply a sample of behavior obtained under controlled or standardized conditions. Other methods of obtaining information about a person's past and present behavioral capabilities include the case history, clinical interview, mental status examination, direct behavioral observations, and reports of other people who are involved with the patient (e.g., spouse, children, friends, employer, and other professionals such as nursing staff or rehabilitation therapists). If testing is to be conducted, then test selection must be competently addressed. Structuring the testing session, administration procedures, scoring, and clerical issues also are important factors in the overall competent completion of the data collection phase of the evaluation process. Following data collection are the interpretation and application phases of the evaluation process.

A wide variety of cognitive and intellectual abilities are typically assessed during a neuropsychological evaluation. These include attention and concentration; learning and memory; sensory-perceptual abilities; speech and language abilities (sometimes including academic skills such as reading, spelling, and math); visuospatial and visuoconstruction skills; overall intelligence; executive functions (such as abstraction, reasoning, problem solving, behavioral self-monitoring, response discrimination, selection, inhibition, and mental-processing efficiency and flexibility); and psychomotor speed, strength, and coordination. Included are measures of sensory-perceptual input, the two principal central processing systems (verbal-language and nonverbal-visuospatial), executive organization and planning, and response output (motor abilities). Underlying them all are attention, concentration, arousal, and motivation. Although this list of cognitive functions might be organized or labeled differently by different neuropsychological schools of thought, these behaviors would generally be evaluated in most comprehensive neuropsychological evaluations. Frequently, aspects of psychological functioning (i.e., psychopathology, behavioral adjustment, and interpersonal issues) also are included in a neuropsychological evaluation.

Neuropsychological evaluation differs from other neurodiagnostic procedures such as computed tomography (CT) or magnetic resonance imaging (MRI) scans that examine the anatomical structure of the brain. With a neuropsychological evaluation, cognitive capabilities, from which inferences about the brain and its function can be derived, are examined. In this regard, it is similar to neurodiagnostic tests that assess other functional capabilities of the brain. For example, the electroencephalogram (EEG) and event-related potentials (ERPs) measure the electrical activity of the brain, and positron-emission tomography (PET) scans or single-photon-emission-computed tomography (SPECT) scans assess anatomical patterns of cerebral blood flow or metabolic activity. Among these, the neuropsychological evaluation is the only neurodiagnostic procedure that can evaluate how a person cognitively and behaviorally functions in real life. Neuroimaging studies may review a location of dysfunction, but two people with damage in the same brain region may have different behavioral manifestations of that damage. Neuropsychological examinations can identify and quantify those differences.

Neuropsychologists must be aware of the anatomic considerations and behavioral sequelae associated with various etiological conditions in the evaluation and interpretation of data. For example, some cognitive functions depend on well-defined anatomic structures (e.g., lower-level sensory-motor skills and even higher-level perception such as recognition of familiar faces dependent on functions of the sensory-motor strip and bilateral basal occipital-temporal regions, respectively). Other abilities (e.g., new learning, abstract reasoning, and speed of information processing) are diffusely organized or rely on complex interacting cortical and subcortical networks. The effects of brain injury can result not only in deficits in various cognitive abilities but also in the emergence of new behaviors or symptoms such as perseverations, unilateral neglect, or confabulations. Furthermore, congenital conditions (e.g., hydrocephalus, renal disease, William's syndrome) can result in similar deficits that result in learning disability and attentional disorders manifested in infancy and childhood.

NEUROPSYCHOLOGICAL INTERVENTIONS

In addition to neuropsychological evaluations, many neuropsychologists also provide intervention services. The neuropsychologist is informed by general psychological principles and knowledge of adjustment issues and mental health disorders, as well as by the influence of brain-behavior relationships on psychological and behavioral functioning. Treated patient populations include the spectrum of medical, neurological, and psychiatric disorders. Interventions often focus on adjustment, coping, and adaptation issues but may also involve attempts to remediate the adverse cognitive or psychological effects of various neurological disorders. Treatments include adjustment counseling, cognitive-behavioral therapy to deal with the emotional and psychological consequences of various neurological or medical conditions, cognitive rehabilitation therapies designed to enhance recovery or adaptation to cognitive limitation from various disorders, or family/marital therapy.

DIFFERENT PRACTICE SETTINGS

As the field of neuropsychology has grown, practice settings have diversified. Neuropsychological evaluations historically have been used to help determine lesion location in neurology and neurosurgical settings. That function has decreased in importance with the advent of such neuroradiological procedures as CT and MRI scans. However, evaluations remain a frequently requested procedure to help identify the pattern and severity of deficits associated with various brain lesions or neurological conditions. Neuropsychological evaluations are often an important factor in helping medical staff, patients, and families make decisions about treatment issues and placement after hospitalization. They are also important in educational planning and treatment planning for children with developmental and other disabilities. The assessment contributes to the diagnosis of subtle disabilities and clarifies the nature of any cognitive problems underlying learning disabilities.

In rehabilitation settings, neuropsychologists are most typically asked to detail and quantify a given patient's cognitive deficits, as well as explain how these deficits may affect the patient's daily life. Neuropsychologists help identify deficits that would be amenable to treatment and identify behavioral capacities that remain relatively intact and potentially useful in a compensatory fashion for other impaired cognitive functions. Finally, the neuropsychologist is asked to make treatment recommendations. These recommendations are typically for immediate treatment purposes (e.g., while the patient is in the rehabilitation treatment facility) as well as more long-term issues (e.g., are the deficits likely to improve, can the patient drive safely, can the patient return to work or school). In educational settings, neuropsychological evaluations can be important in identifying different learning disabilities, serve as an important ingredient in designing treatment and/or educational plans and in setting realistic goals, and help evaluate the effectiveness of various treatment interventions.

Neuropsychological evaluations continue to play an important role in the differential diagnosis between neurological and psychiatric conditions that may appear clinically similar (e.g., dementia vs. a pseudodementia secondary to depression or anxiety) but that have different prognostic implications and require divergent treatments. Finally, neuropsychological evaluations are appearing with increasing frequency in forensic settings where they are used to help document the presence or absence of behavioral impairments secondary to injuries (personal injury or medical malpractice cases) or in helping to evaluate issues of diminished capacity or disability and competency.

—Rodney D. Vanderploeg and
Heather Belanger

See also Dementia; Psychiatric Disorders; Psychology; Traumatic Brain Injury.

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NEUROSIS

Sigmund Freud's early work with neurotic patients was in a population that was totally disabled and dependent on others for care. Conversion hysteria was reportedly rampant in Europe at the end of the nineteenth century, and Freud's work as a neurologist exposed him to a large number of cases of total disability where no clear-cut organic etiology was evident. Neurotic patients with phobias, conversion symptoms, hysteria, obsessions, repetition compulsions, and inhibitions then and now range in functional level from highly successful to very disabled. The most severe cases are totally dependent on others for care and are still seen in long-term care facilities. Neurotic patients overlap with patients with personality disorders, and symptoms usually have a greater effect on the individual than on his or her friends and family. Some cases of conversion hysteria are still seen and may be more common in certain cultural settings. These patients, as a hundred years ago, are dependent on others, often family, for basic care and are disabled without clear evidence of depression or psychosis.

The extent of disability due to neurotic illness is difficult to quantify as the concept of neurosis has been replaced by a more descriptive diagnostic system. In the past, anxiety neurosis or panic attacks would have been seen as clearly disabling neurotic illness. For example, students who are unable to succeed due to neurotic issues often may end up underemployed rather than fully disabled. Adaptation to other illnesses is also an area where degrees of neuroticism may increase disability. Pseudo-seizures are a condition in which the patient usually unconsciously feigns a very realistic seizure episode witnessed by others. They continue to be a cause of diagnostic confusion and often are found in patients who suffer from genuine organic-based seizures. Disability post-myocardial infarction is also increased in patients with depression and preexisting neurotic illness. Currently, much of organized psychiatric research has focused on treatment and disability prevention in psychotic states and mood and anxiety disorders, and fewer resources have been devoted to the issue of neurotic illness. However, cognitive-behavioral approaches to anxiety, phobia, and dysthymia have led to good symptom improvement and time will tell if the associated disability will diminish with treatment. Also the improvement in anxiety phobia and dysthymia seen with the newer antidepressant medications suggests that neurotic illness may also share an organic substrate with the mental illnesses. Psychoanalysis continues to be used to treat a variety of neurotic illnesses especially when less intense and demanding treatment strategies have failed.

—*Dennis Beedle*

See also Anxiety Disorders; Behavior Therapy; Hysteria.

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See Experience of Disability: New Zealand

NIDRR

See National Institute on Disability and Rehabilitation Research (United States)

NIETZSCHE, FRIEDRICH

(1844–1900)

German philosopher

Friedrich Nietzsche, the *enfant terrible* of Western philosophy and culture, is usually hailed as the greatest forerunner of twentieth-century intellectual innovations, from psychoanalysis to postmodernism to cultural critiques of various stripes. Reared in pre-Bismarckian Germany, he quickly became its most vociferous critic and exile. His public debut began with an *éclat* over *The Birth of Tragedy out of the Spirit of Music* (1872) that cost him his reputation as the rising young star of classical philology at Basel. Thereafter, he drifted off into increasingly unruly and shrill philosophical and cultural writings, but never found much of an audience until shortly after his death. Once the darling of the Right, he remains the darling of the Left and an inspiration to all counterculturalists.

His writings are treacherous things, open to misreading and misappropriation. As in other matters (such as questions of race, gender equality, power, and violence), so too here Nietzsche can easily be taken to task for his merciless indictments of human disability. After all, doesn't he declare the better part of humanity shriveled and impaired, both psychologically and physically, and for that reason unworthy of life and hence worthy of extermination? And wasn't he from the first happy to view ugliness and deformity as sure signs of degeneracy—as, for instance, in his lifelong crusade against Socrates, that "monstrosity *per defectum*"? In that case, one would have to attribute to Nietzsche not only a distasteful prejudice but something like a pathological obsession. Max Nordau's ([1892] 1993) inclusion of Nietzsche in his gallery of European degenerates seems all too justified.

Nevertheless, several factors tell against these conclusions. First, Nietzsche's true meaning is notoriously hard to locate amid the polyphony—or cacophony—of his writings. Second, much of the time disability, like disease and weakness, seems to be a metaphor for culture, not a reference to the empirical body or to nature. "Nothing is beautiful" or "ugly" intrinsically, "there is no health as such [*an sich*]," and even the infirm demonstrate a will to life and to power that has to be affirmed and admired, yet everyone alive is diseased. How stable is Nietzsche's apparent indictment of disability and disease? If his prescriptions were taken seriously, the entire human race would have to be eradicated. A likelier conclusion is that Nietzsche is embarrassing, not perpetuating, a widespread cultural idiom, by bending it back upon itself. To be sure, this does nothing to erase the prejudice from his texts, although it does a lot to emphasize its untenability.

—James I. Porter

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NIRJE, BENGT (1924–)

Swedish activist

Bengt Nirje is internationally known for his work in promoting self-determination among people with intellectual disabilities. Born in Sweden and educated in comparative literature, law, and philosophy, Nirje's first work with people with disabilities was with the Swedish Red Cross and later with the United Nations where he was a welfare coordinator. As director of the Swedish Parents' Association for Mentally Retarded Children (1961–1971), he formed social clubs for persons with intellectual disabilities. These social clubs gave people with intellectual disabilities opportunities to exercise control over their leisure activities, including the right to take risks and make mistakes.

Nirje was deeply concerned with the lack of power and participation in normal community life experienced by people with intellectual disabilities. His work to formalize the principle of normalization led to the first English publication on the principle in 1969. This paper was highly influential throughout the Western world, particularly with respect to residential care and treatment of people with intellectual disabilities. Nirje's legal advocacy has resulted in the enactment of progressive legislation and policies reflecting the concept of normalization throughout Europe and North America. Nirje is one of the founders of the self-advocacy movement.

—Katherine E. McDonald

See also Niels Erik Bank-Mikkelsen; Normalization.

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NONTI NATAKAM (TAMIL CRIPPLE DRAMA)

The *nonti natakam* (cripple drama), also sometimes *ottraikkaal natakam* (one-legged drama), is a genre of Tamil drama or street theater originating in southeastern India in the seventh century or earlier, having a lame rogue as hero. The protagonist becomes obsessed with a prostitute, engages in crime to fund the habit, is caught stealing a horse, and is punished by amputation of a leg (sometimes also an arm). Next he comes under the influence of a holy man, renounces evil, and regains his limb(s) by intervention of the god Subramaniya (Murukan). This provides a serious frame while lending itself to bawdy, slapstick, and farce as the hero hops about on one leg recounting his sexual and criminal adventures. Disability is clearly portrayed as a consequence of wrong conduct, from which repentance leads to healing. There are also nonti natakam giving Muslim or Christian accounts of similar themes in southern India. These minor dramas can also be linked to broader themes of bandit heroes and kings with physical deformities in Tamil literature, as well as with East Asian and European medieval farce.

—Kumur B. Selim

See also Drama and Performance.

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NORMALITY

Defining normality has presented a puzzle to medicine and society for decades. Health and normality remain obscure concepts particularly in the medical field, which is historically reductionistic and its practitioners trained to recognize and treat pathology. Constructing concepts of normality requires philosophic inquiry as well as experience with general populations of people rather than those presenting only for treatment. As public policy has developed around concepts of disability, the implications for definitions of normality are profound.

The word *normality* derives from the Latin word *norma*, which referred to a tool used to show a square angle and by extension to mean a rule, standard, or principle. Over time, the definition of normal came to mean ordinary, usual, or "naturally occurring." Interestingly, if one applied the "naturally occurring" definition, many individuals born with "anomalies" or "birth defects" or with behaviors different from mainstream could be considered normal. But most societies did not take this definition. Instead, a departure from the typical physical or behavioral characteristics was usually seen as abnormality or deviance.

Although terms such as *normal* and *normality* serve some purpose in medicine and the study of human behaviors, they also perpetuate labeling and discrimination. The utility of the normality concept can be seen in how it benefits or contributes to the well-being of and services to the full range of human beings. Several attempts at defining normality are worth reviewing to examine examples of traits felt to be abnormal. Two different models to normality relevant to disability are the medical and social. Both have merits as well as limitations; attempts at integrating these models would be useful.

Offer and Sabshin (1980) reviewed four perspectives on normality, originally designed for purposes of examining mental health. These perspectives are rooted primarily in the medical model but allow an attempt at integration with the sociological. In their first definition, normality as health, normality is seen to exist in the absence of disease in terms of noticeable pathology and corresponds to medicine's concern with treating patients with observable signs and symptoms of illness. Such a perspective tends to be binary and reductionistic: One is either normal or has a disease. This view obscures the continuum of physiology and functionality that exists in almost every human physical and mental attribute. More important, this view does little to advance the principles of prevention or early intervention in the pathological progression of an altered physiological state.

A good example of the weakness of this approach is seen in the evolution of fetal alcohol syndrome (FAS) in the past two decades. Physicians first diagnosed that condition by a set of criteria including appearance (small head/body, certain facial characteristics), behavioral disorder such as attention deficit, heart defects, sight/hearing problems, and joint anomalies. Useful as this diagnosis is, it did not draw sufficient attention to the fact that maternal alcohol use can be hazardous to the developing fetus. In fact, low levels of maternal alcohol intake, below that seen in typical FAS, can cause milder problems for the fetus and newborn child.

Vitamin deficiency is another good example in which a disease state (e.g., scurvy from the absence of vitamin C) obscures the wide variation in vitamin C intake and blood levels, some of which are dangerously low and interfere with optimal functioning, but not to the extent of meeting the criteria for disease. Clinical medicine sometimes recognizes this problem by employing the term *subclinical* disease, again trying to use categorical distinctions rather than a continuum model, which would show the range of vitamin C levels and note the points within that range where various symptoms of pathological processes may emerge.

A second perspective is normality as utopia. Offer and Sabshin (1980) date this idea back to Sigmund Freud, who wrote, "A normal ego is like normality in general, an ideal fiction." This perspective highlights the ideal form and being, and it recognizes the diverse, interrelated mechanisms that define functionality.

A third perspective is the one most commonly used in medicine today: normality as average, based on the principle of the bell-shaped distribution around a central point where the greatest number (median) or average (mean) of findings (e.g., height, weight, IQ) occur. Various statistical measures further define *deviance* from this center point with boundaries that encompass various percentages of population (e.g., 2/3, 98 percent). By such methods, one can look at the "tails" or outliers in this normal distribution as being so many standard deviations away from normal. If one measures vitamin C intake as an example, this method captures disease state but also reflects subclinical deficiencies.

While there are many limitations to normality as average, there is also inherent value over other definitions of normality. Using this definition and applying it to medicine can define illnesses such as coronary artery disease, obesity, and blindness better than simply deciding when one has it or does not. For example, using a continuum model, we can see that adolescents start depositing plaque on their arteries and that this process continues through life. This allows intervention at any level as well as monitoring for later intervention. Similarly, an individual did not become *morbidly obese* (defined as twice one's "ideal weight") overnight. There was a progression, likely started in childhood, whereby the individual gradually gained weight to the point of severely limiting mobility and causing added health risks. Similar examples of this continuum of a trait can be found for vision, blood sugar levels, intelligence, movement, height, and many other traits that appear first in "normal" form before becoming pathological.

A variation on normality as average is to consider two bell-shaped curves, one representing the distribution of a characteristic, for example, hearing acuity of individuals with known hearing impairment, and compare them with a representative group from the general population without known or perceived hearing loss. The hearing-impaired group will have a narrower curve that will overlap with individuals in the general population on one end of the curve. This overlap consists of a group of individuals who may not be diagnosed as having hearing loss, but indeed show the common characteristic of hearing reduction with age. An interesting part of this example is that such hearing loss with age is considered part of "normal aging."

The continuum method allows for interventions and prevention as can now be seen with worldwide attention to the diets of children in Western countries and its relationship to adult obesity. However, when certain conditions or traits are congenital or currently irreparable (e.g., Down syndrome), intervention or prevention to a more "normal" state is not always possible, and using this as a benchmark might be damaging to a disabled individual.

A final perspective is normality as a transactional system that recognizes that behavior or traits cannot be examined by themselves but only in the context of other systems. It also implies that culture and context help determine what we define as normal: How and what we consider normal varies over time and space, with values shifting according to culture, gender, ethnicity, national origin, and age.

The social model of disability holds that it is society that defines, stigmatizes, and discriminates against the disabled by setting norms for and values on physical appearance and behaviors. This reasoning leads to the conclusion that it is not the physical aspects of the person, per se, that lead to damage. Rather, when a society or culture labels disabled bodies as inferior or diseased, it leads to reduced self-worth as well as devaluation and marginalization in society. The social model conceives of bodies as bearers of differing value as defined by society that acknowledges and distributes economic and social capital depending on these values. People with speech impediments, for example, are made to feel inferior, which directly affects their social interactions, often reduces their capacity to get around in the world, and clearly limits their employability. Social practices from genetic testing and subsequent abortion to devaluations of disabled people throughout childhood and adult life reflect a social definition of normality that can marginalize disabled people and reduce their sense of self-worth.

The social model is critical of the medical model, which is seen as objectifying and reducing the body to objects and conditions to be analyzed, diagnosed, treated, and rehabilitated along with prognostications that often emphasize the negative. What the social model often lacks, however, is a view of how the individual interacts with changing societal values and how technology, medicine, and changing social norms interact to determine the extent to which disabled people can navigate through society and the extent to which they are viewed as "normal." In different times and cultures, individuals with auditory or visual hallucinations have been viewed as having distinct talents and have been seen as healers or savants. At other times, these individuals have been viewed as dangerous and valueless to society. Similarly, people with seizure disorders have been seen as having special gifts and vision; conversely, such people also have been viewed as incapable of the most basic tasks including driving.

The industrialization and urbanization of society also affect the view of disabled people as normal or abnormal increasing the requirements for social maintenance and employment. Individuals with schizophrenia reportedly do better in developing nations and agrarian areas in part because these societies have roles in which the person can fit and provide some sense of belonging and utility within their community.

Three features of human existence are frequently the subject of controversy and labeling: physical characteristics, cognitive/learning capacity, and behavior. One common characteristic that illustrates the many uses and misuses of normality is weight. What is viewed as ideal or normal body size has shown tremendous variation over time and place. In Western society, being "stout" or obese by current standards was formerly a sign of good health and wealth. Since access to a good food supply had been for millennia a sign of one's status in many societies, appearing too lean suggested poverty or ill health. Today in Western society, "thin is in" to the point of encouraging youth to be anorexic and to where liposuction to remove fat is very big business. While this culture of starvation applied primarily to women over the past three decades, it now also affects men. However, in many non-Western societies women are desired for being more full bodied, and there is likely a relationship between this and fertility. Chinese society has been characterized as being very tolerant to the point of extolling the virtue of fatness in men as they age; recent studies show that in China this is also true for women and interestingly, obese men and women among elderly Chinese have lower rates of depressive symptoms. Morbid obesity carries considerable stigma and prejudice in many countries. It is also associated with varying disability such as decreased ambulatory capacity, and when the morbidly obese person enters into health care their providers frequently mirror these societal attitudes.

Cognitive capacity, particularly as measured by intelligence testing, has survived a storm of attacks based in part on how we measure and react to definitions of normal intelligence. The concept that intelligence could be or should be tested began with a nineteenth-century British scientist, Sir Francis Galton, who had training in both biology and early forms of psychology. Galton was strongly influenced by the revolution caused by the 1859 publication of Charles Darwin's *The Origin of Species*, which examined the relationship between heredity and human ability or disability. The general attitude of the time held that the human race had a very small number of both geniuses and idiots, while the vast majority of the human race comprised equally intelligent people. This thinking is typical of the binary method of medicine, which divided the population into disease or normal with the variation of adding "supernormal" or geniuses in this case. Galton believed that mental traits are based on physical factors—inheritable traits—the same as eye color or blood type. With the help of a statistician, Galton discovered the concept of normal distribution or the bell-shaped curve, with most of the population falling between two extremes. He published his ideas on hereditary intelligence in a book titled *Hereditary Genius*, which is recognized as the first scientific investigation into the concept of intelligence. James McKeen Cattell, a student of Galton's, led a brief and intense period of intelligence testing in the United States; this testing quickly fell into disfavor when it was shown that scoring high on the Galton test did not predict whether a student would do well on schoolwork. In France, Alfred Binet devised tests of intelligence and used them to compare "average" students with known "mentally handicapped" students. He found that certain tasks could distinguish the two. Binet calculated the normal abilities for students at each age, resulting in a tool to identify the developmental age of each student.

The idea that a test could determine a child's "mental age" became extremely popular. Just before World War I, German psychologist Wilhelm Stern suggested a better way of expressing results than by mental age. Stern determined his results by finding the ratio between a subject's chronological age and mental age. A 10-year-old scoring one year ahead of chronological age (110) would be less significant than a 5-year-old scoring one year above her chronological age (120) would. Later an American psychologist, Lewis Terman, coined the term *intelligence quotient* (IQ), identifying 100 as average. This method of IQ testing was first put to mass use in placing draftees in World War I in the United States. After the war, many companies and most school systems in the United States began using some form of IQ testing.

The designers of IQ testing had reservations on the potential misuse of testing. As early as 1922, a well-known social commentator, Walter Lippmann, wrote: "One only has to read around in the literature of the subject . . . to see how easily the intelligence test can be turned into an engine of cruelty, how . . . it could turn into a method of stamping a permanent sense of inferiority upon the soul of a child." With the beginning of the civil rights movement, the potential misuse of IQ testing for racist purposes became apparent initially with African Americans and later Latinos. Questions about the reliability and validity of testing and the role of heredity versus environmental enrichment and language curtailed the widespread usage. However, school systems still use IQ testing as one factor in determining the need for special education. Such usage might be valuable, but the stigma associated with the testing implies that students placed this way are innately less intelligent and, more critically, may never be capable of being "mainstreamed" back to regular classrooms.

The concept of intelligence and its measurement has continued to evolve, despite problems and testing misuses. In 1983, Howard Gardner argued that "reason, intelligence, logic and knowledge are not synonymous," setting forth a theory of multiple intelligences. Gardner defined seven distinct intelligences: logical-mathematical, linguistic, spatial, musical, bodily-kinesthetic, intrapersonal, and interpersonal intelligences.

The concept of multiple intelligences helped broaden the idea of intelligence from a mathematical and verbal understanding to one where many inherent abilities of humans may be considered and valued. Implicit in this approach is that disability in one area of intelligence may not be associated with other areas, or more practically, individuals with certain mental disability may also have rich, useful, and enriching capacities in other mental areas.

Classifying behaviors as abnormal poses a very difficult problem for sociologists, anthropologists, and cross-cultural psychologists, and it again begs the question of the value of such classifications. Within most cultures, there are individuals who are so out of sync with the accepted range of behaviors that they pose a threat to themselves or others. Inherent in the act of classifying behaviors is the use of taxonomy of behavioral descriptions as an instrument to define and therefore punish, exclude, or incarcerate a group whose behaviors constitute a threat to the status quo or to the local governance.

For example, homosexual behaviors were frequent parts of polytheistic and pagan ceremonies, and it is likely that homosexual practices were condoned in early societies. The ancient Greeks welcomed homosexuality along with other hedonistic behaviors, though marriage and producing children held higher value, making it "normal" only as an occasional activity for young boys or for older men after they produced children. Interestingly, the Greek military viewed homosexuality as positive in that it encouraged morale and camaraderie. However, men who were exclusively passive partners in homosexual encounters were stigmatized and even banished from the military as having become women. By the sixth century, the popularity and power of Christianity led to condemnation of homosexuality as well as prostitution and other hedonistic activities, although little was done to enforce this code even among priests and monks. Tolerance of homosexuality continued in most of Europe in certain circles until about the thirteenth century. The Inquisition and the Protestant Reformation resulted in strong penalties in different European countries including castration, imprisonment, and death. The death penalty for "sodomites" was imposed in the United States by the military as early as the eighteenth century, a sentence that Thomas Jefferson changed to castration in 1779.

By the close of the nineteenth century, medicine, including the newly developed field of psychiatry, was competing with religion and law over which had jurisdiction over sexuality in general and homosexuality in particular. As with the medicalization of alcoholism, this was progressive, as a "sick person" was better than a sinner or criminal.

Some forces within psychiatry were more liberal in their view of homosexuality. In 1901, Havelock Ellis considered homosexuality to be inborn and therefore not a disease. He also recognized the contribution homosexuals made to society. Sigmund Freud saw all humans as innately bisexual and their sexual preference was made according to experiences in early development. While he advised acceptance, he noted that homosexuality stemmed from arrested development. In his "Letter to an American Mother" (1935), Freud, in keeping with his view of psychoanalysis toward promoting mental health through self-understanding, wrote about homosexuality:

> If [your son] is unhappy, neurotic, torn by conflicts, inhibited in his social life, analysis may bring him harmony, peace of mind, full efficiency whether he remains a homosexual or gets changed.

Psychiatry and psychoanalysis did not always follow Freud's more accepting view. In the 1940s to the early 1960s, these fields developed complex developmental theories explaining the pathological development leading to homosexuality. Alfred Kinsey's empirical studies of sexual behaviors of Americans revealed findings that could not be discerned by clinicians working exclusively with individuals seeking their services. His studies revealed that a significant number of his research participants reported having engaged in homosexual behavior to the point of orgasm after age 16 and that 10 percent of the males in their sample and 2 to 6 percent of the females (depending on marital status) had been more or less exclusively homosexual in their behavior for at least three years between the ages of 16 and 55.

The *Diagnostic and Statistical Manual of Mental Disorders*, second edition (*DSM-II,* 1968) of the American Psychiatric Association (APA) listed homosexuality as a disorder, but the *DSM-III* (1975) did not. This change in thinking was supported by insiders within the APA but also was in response to growing numbers of gay and lesbian advocates who protested and disrupted the APA through the 1960s and 1970s. In 1973, the APA removed homosexuality from the *DSM.* However, to permit payments for treatment by insurance companies, the *DSM-III* included the category "ego dystonic homosexuality" and listed the criteria as (1) a persistent lack of heterosexual arousal, which the patient experienced as interfering with initiation or maintenance of wanted heterosexual relationships, and (2) persistent distress from a sustained pattern of unwanted homosexual arousal. While this had impact on American opinion, it did not change the values and rules of much of the larger society including the American military, which has continued to discharge homosexuals from service. These considerations strongly influence psychiatric views of the criteria for mental illness and normality as will later be demonstrated. The World Health Organization's classification, the International Classification of Diseases (ICD), in its diagnostic manual used in much of the world, continued to list homosexuality as a diagnosis until 1992 with the publication of ICD-10.

An example from the former Soviet Union demonstrates the misuse of psychiatry to serve a government's purposes in a more striking way through its implicit authority to determine normal versus pathological behavior. By the early 1960s, one of the most prestigious psychiatric institutes in the Soviet Union added a criterion for schizophrenia very different from any previously proposed: "dissident behavior" and coined a new type of schizophrenia, which was called "sluggish schizophrenia." Using this criterion and diagnosis, a number of radicals were hospitalized in psychiatric institutions and given treatments with severe side effects under the auspices of curing them of their "illness." Many Western counties and human rights watch groups made challenges to this diagnostic method and practice. However, this policy continued for more than two decades when, with a more open emigration policy in the Soviet Union, the practice was discontinued. Unlike the case of homosexuality where psychiatry was used to bolster general public opinion, the mislabeling of dissidents as schizophrenics was not in concurrence with society but was enforced by the existing regime.

Psychiatry's role in defining normal behavior is part of the larger ways in which society and culture define what are its shared beliefs and behaviors and the "proper" way an individual conducts himself or herself within a society and family. Many aspects of social behavior are usually considered including dress, posture, hairstyle, smell, gestures, facial expression, and use of language. Cultures also have specific codes for the context within which behaviors are appropriate so that different behaviors are condoned depending on gender, age, privacy, work, home, family, friends, and strangers, for instance. Some cultures while having very strict taboos on behavior also include special days of celebration (e.g., Mardi Gras, Halloween, New Year's Eve) in which behavioral norms are deliberately flouted. Some very restrictive cultures may place an onerous burden of conformity on certain demographic groups such as women, so that any deviation from these "normal" role expectations is seen as deviant and deserving of punishment.

As psychiatry and the social and behavioral sciences consider normality, they are increasingly addressing the context of behavior. Delusions, for example, are a criterion for many psychotic disorders. However, Western psychiatry has included in the definition of delusion that it be a "false and fixed belief" and also that it is a belief not commonly held by other members of the individual's cultural group. This added definition allows many unique cultural-religious views of the world without labeling them as psychopathology. Individuals who feel they have been "bewitched," possessed by an evil spirit, or that God is punishing them for their sins are no longer diagnosed as psychotic if these thoughts are consistent with the beliefs of their cultural or religious background. Likewise, hallucinations, defined by Western medicine as a sensory experience without sensory input (e.g., hearing voices or seeing things), has usually been seen as one sign of a psychotic experience. It is now recognized that "normal" individuals partaking in religious experiences with or without hallucinogens can have hallucinations that are not part of a larger psychiatric disorder.

Beyond questions of psychiatric disorders, there are more common behaviors related to disabled individuals that are sometimes considered abnormal in a manner that threatens their dignity. These behaviors include drooling, incontinence, and being physically and cognitively dependent on others. These acts are sometimes incorporated under the heading of "activities of daily living" and if an individual cannot perform them, it is assumed he or she does not have a good quality of life or is not "normal." Rehabilitation aims to improve or restore function on all levels possible. While it is hard to reject maximizing each person's potential, dwelling on a failure to reach a certain level of performance or function perpetuates the stigma attached to disabled people. Likewise, as elderly persons lose the capacity for performing these activities they are often seen in Western society as pathological and a burden, a factor that can be associated with increased interest in euthanasia. For disabled people, as well as other marginalized groups, the political revolution they are likely to lead is one in which difference is not labeled as deviance or abnormal.

—Joseph A. Flaherty

See also Eating Disorders; Health; IQ; Models; Obesity; Psychiatry; Stigma.

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NORMALIZATION

Normalization, or the normalization principle, has been the most significant driving force in the ongoing closure of state-run or state-funded institutions for people with a disability, especially those with a developmental disability in the Western industrialized world.

Its influence is also permeating the policies of developing countries that are increasingly embracing human rights principles. For instance, the normalization principle resonates closely with the UN Standard Rules for the Equalization of Opportunities for People with a Disability.

Possibly the first reference to the concept of normalization was by the Committee for the Partially Able-Bodied, established by the Swedish Government in 1943. This committee was appointed to create better opportunities for the productive ability of partially able-bodied persons, who, because of physical or mental occupational impairment or social affliction, can be expected to have more difficulty than others in acquiring and maintaining employment. This goal was consistent with Sweden's development of modern social services to replace the earlier philanthropic and public protective interventions that were seen as inadequate. In particular, segregated services, such as institutions for people with disabilities and social disadvantage, were being rejected. The committee's report, published in 1946, stated that "this 'normalization' of conditions of life, education, employment exchange etc. of the partially able-bodied must be a great achievement."

These developments in Sweden in the 1940s concentrated specifically on people with limited impairments but had little impact on those with more severe developmental impairments. Many of this population were placed in large institutions. However, in the 1950s and 1960s the normalization principle, as presented by the Committee for the Partially Able-Bodied, was frequently cited as a principle that should also be applied to persons with intellectual and other developmental disabilities. The immediate effect was a restructuring of the institutions toward a more normal life for their residents, but this did not lead to increased contact between persons with a disability and those in the local community.

Historically, for the institutional population, the scene shifted to Denmark where a strong advocate for people with an intellectual disability, Niels Erik Bank-Mikkelsen, was instrumental through his support for parent advocacy groups in achieving an act of Parliament that used the term *normalization*. This act supported the creation of situations for people with disabilities as near as normal as possible, irrespective of whether it occurred entirely or partially within an institution or in the general community.

While the act was strongly supported by large numbers of families who wanted their child with a disability living closer to home or at home, it attracted hostility from vested interest groups, including professional staff, who feared a loss of their jobs. It was significant that the enactment of the act was helped by the ever-improving Danish economy.

When Bank-Mikkelsen spoke of normalization, he was not inferring that people with disability were abnormal and nondisabled people were normal, nor did he want to imply that the special nature of people with disabilities should be made "normal." To him, the goal of normalization was not to normalize these people but to normalize their living conditions.

Undoubtedly, Bank-Mikkelsen's passion for strong advocacy for disadvantaged people was significantly influenced by his experiences during the German occupation of Denmark in World War II. He was imprisoned for his activities in the resistance movement. Bank-Mikkelsen's work soon had an international impact. In 1962, U.S. President John F. Kennedy established an advocacy committee on mental retardation, members of which visited Denmark and other Nordic countries. Bank-Mikkelsen contributed one of the chapters of the President's Committee's final report released in 1969. He also strongly supported an international conference held in Copenhagen in 1964, which saw the formation of the International Association for the Scientific Study of Mental Deficiency (IASSMD; now the International Association for the Scientific Study of Intellectual Disabilities, IASSID).

He also played an important role in the Legal Aspects of Mental Retardation symposium held in Stockholm, Sweden, in 1967 and sponsored by the International League of Societies for the Mentally Handicapped (ILSMH; now Inclusion International). The results of this symposium strongly influenced the 1971 UN Declaration on the Rights of Mentally Retarded Persons.

Through his travels to countries including Australia, the United States, Japan, and Saudi Arabia, Bank-Mikkelsen promulgated the tenets of normalization, with particular reference to the appalling conditions he witnessed in institutions for people with an intellectual disability.

The second significant person to contribute to the development of the principle of normalization was the Swedish scholar Bergt Nirje. Nirje, whose background was in the law and humanities, was deeply influenced by the work of Bank-Mikkelsen, whom he visited in 1963 as a preamble to speaking at a Nordic conference held in Oslo in that year. The theme of this conference was "institutions for mentally retarded persons." Nirje related that he was struck by the words in the Danish law that stated "to let the mentally retarded obtain an existence as close to the normal as possible."

Positions with the Swedish Red Cross and the UN High Commissioner for Refugees that involved visiting Hungarian refugee camps in the aftermath of World War II profoundly influenced Nirje's mission to oppose large "mass managed" institutions. He too contributed chapters to the report of the President's Committee on Mental Retardation.

As ombudsman and executive director of FUB, the Swedish Association for Persons with Intellectual Impairment (1961–1970), and coordinator of training and program planning in the Ministries of Health and Community and Social Services of the Government of Ontario, Canada (1971–1978), Nirje had the opportunity to develop his conceptualization of the principle of normalization. In 1967, in a paper presented to the First Congress of IASSMD held in Montpellier, France, he introduced the concept of the "normal rhythms of life," a concept that became embedded in the eight core facets of life that became the essence of his conceptualization of normalization. To Nirje, normalization means a normal rhythm of the day; implies a normal routine of life; means a normal rhythm of the year; calls for normal developmental experiences of the life cycle; calls for the valuing of individual choices; means living in a bisexual world; means applying normal economic standards; and calls for living, learning, and recreating in facilities similar to those others in the community enjoy.

Nirje (1969) summed up these elements into his overall definition of the normalization principle that "means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (p. 181).

In 1985, Nirje refined his definition: "The Normalization Principle means making available to all persons with disabilities and other handicaps, patterns of life and conditions of everyday living which are as close as possible to or indeed *the same as* the regular circumstances and ways of life of society" (p. 67). He further elaborated this statement by pointing out that

> the normalization principle rests on the understanding of how the normal rhythms, sequences and patterns of life in any cultural circumstances relate to the development, maturity of life of the handicapped, and on the understanding of how these patterns apply as indicators for the development of proper human services and actions. (p. 67)

Integration in society, Nirje maintained, is based on the recognition of a person's integrity, meaning "to be yourself among others—to be able and to be allowed to be yourself among others."

The next significant figure to contribute to the principle was Wolf Wolfensberger, who together with Robert Kugel, then chair of the President's Committee on Mental Retardation, edited its final report published in 1969 (Kugel and Wolfensberger 1969). Wolfensberger (1972), drawing on deviancy theory, proposed a reformulation of the definition of the principle as follows: "Utilization of means which are culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible" (p. 28). He specifically indicated that this definition was for purposes of a North American audience, and for broader adaptability to the general area of human management. He suggested that the normalization principle is culture specific and what may be typical in the Scandinavian environment would not necessarily apply in other cultures. Wolfensberger's elaboration was more detailed in its recommendations to service providers and facility managers than was Nirje's approach.

Wolfensberger became closely involved with the deinstitutionalization movement in North America, as did Nirje in Sweden and Canada. However, whereas Nirje concentrated on those structures that primarily affected the day-to-day lives of the person with the disability, Wolfensberger developed a quality control system that was directed specifically to program management. He devised two instruments for this purpose: The Program Analysis of Service Systems (PASS) and Program Analysis of Service Systems' Implementation of Normalization Goals (PASSING).

In the 1980s, Wolfensberger (1983) further elaborated the principle of normalization, subsuming and replacing it with the theory of social role valorization (SRV). In his earlier formulation, deviancy theory was the driving force, but this was replaced by social role theory. He defined SRV as "the enablement, establishment, enhancement, maintenance, and/or defence of social roles for people–particularly those at risk . . . by using, as much as possible, culturally valued means" (p. 234). He suggested people's roles can be enhanced by improving both their competencies and their social image.

Normalization, in its various interpretations, is a social science theory that has had a profound positive effect on the lives of people who were once removed and segregated from society. It remains relevant for the twenty-first century as thousands of people remain in institutions across the world. However, there are forces emerging that could see a return to institutional solutions to social problems.

—Trevor R. Parmenter

See also Niels Erik Bank-Mikkelsen; Bengt Nirje; Social Model: Sweden.

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NORSE SAGAS

Norse sagas are prose narratives written in Old Icelandic between 1190 and 1230 (the last years of the Icelandic Free State) mostly by unknown authors, concerning the lives of Norwegian kings, prominent Icelandic families, and legendary Norse figures as well as stories translated from Latin saints' lives and continental romances.

The Icelandic Family Sagas are set in tenth-century Iceland and are structured on a pattern of conflict (of honor or property) and revenge. The secondary literature on origins, structure, and plot themes such as feuding largely overlooks the great number of characters with impairments and disfigurements.

In the saga world, impairments were often acquired as Viking occupational hazards. That people with such impairments as blindness or the loss of a limb or eye were regarded as disabled was a social construct that related not to the denial of civil rights but to one's ability to acquire and defend property and dependents against aggressive neighbors. The measure of an Icelandic saga hero was in how he negotiated his impairment to obviate its disabling aspect. Impairments are thus the mark of outstanding characters—they were never sentimentalized.

The saga world regarded as impairments not only the loss of a faculty or limb but also sexual and temperamental quirks and foreign ethnicities. Of the three best-known and -loved eponymous saga heroes, Njál was never able to grow a beard, Egil was seven feet tall and swarthy, and Grettir was inarticulate and had a very small penis. Among the several saga heroes who are skaldic poets, Kormák looks Irish and is sexually dysfunctional, Björn the Hítárdalur Champion appears to be homosexual, Gunnlaug Snake's-Tongue suffers serial leg impairments, and Thormód Kólbrún's-Skald has a crippled right arm and stammers. Virtually all the Family Sagas include minor characters who are blind or have peg legs, and the simpleton is a stock character frequently made to play the fall guy. Women are not usually said to have any impairment other than blindness, and deaf characters do not appear.

The saints' lives treat impairment as an opportunity for a miracle cure, while legends and romances exploit impairment for fantastical prostheses or magical means to induce or cure dumbness. A subgroup of the Family Sagas, the so-called Contemporary Sagas set in the thirteenth century, describe impairment even more frequently, though this is usually the result of extra-juridical mutilation, and here we see impairments first associated with moral deficiencies, as came to be standard in modern times.

—Lois Bragg

See also Folk Belief.

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NORWAY: NATIONAL ACTION PLANS

Action plan is a term used in many countries and in many languages, typically referring to a package of objectives and activities that are intended to combine in ways toward accomplishing a larger goal. As in many other countries, Norway has had a series of action plans in many areas of sociopolitical life. One arena where Norwegian national action plans have received much national and international attention is in the area of disability. The national action plans for disabled people refer to three sequential four-year plans, covering a total period from 1990 to 2002, and with a general goal of improving the situation of disabled people. The first two plans were written by Norway's national Ministries, whereas the third and most recent one was also acted on by the Parliament and exists in the form of a white paper (*Stortingsmelding nr 8:1998–99*).

BACKGROUND AND CONTEXT

As a follow-up to the UN International Year of Disabled Persons (1981) and the subsequent Decade of Disabled Persons (1983–1992), Norway produced a national plan with the aim of working toward the newly formulated international goals of full participation and equality for disabled people. This first plan included a set of objectives and activities, but these were formulated in quite general ways and with unclear political commitment. While the government never admitted that this plan was unsuccessful in terms of its actual accomplishments, the first four-year plan of action (1990–1993) was in part a result of the fact that very few of the intended actions in the plan for the 1980s had actually been implemented. It was noted that there was a need for a more specific description of the intended actions, as well as a clearer and more binding political commitment. It is these two elements of concreteness and commitment that have shaped what became known as national action plans.

In Norway, all services for all citizens are the responsibility of the public sectors, with primary coordination at the local municipality level (*kommune*). Action plans for the disabled are not limited to activities in the area of health and social services, but include all spheres and sectors of public life. It is the national government that provides direction and guidelines, as well as having a monitoring role. Action plans could be interpreted as a signal that the Norwegian government is taking the social and political situation of disabled people more seriously, or at least is taking the actualization of stated goals more seriously.

USER INVOLVEMENT

Participation and influence of disabled people have consistently been a central principle in these action plans. Concretely, this involvement has occurred in two ways. First, the plans themselves are developed in cooperation with disabled people and their organizations, both through direct participation and also through a series of consultative hearings. The National Union of Disabled Peoples Organizations (Funksjonshemmetes Fellesorganisasjon) and the National Council for the Disabled (Statens råd for funksjonshemmete), which includes members from disability organizations, have also been involved in the drafting of these plans. The second way that disabled people are involved has to do with the actual actions stipulated in the plans, where user participation is mandated in a number of ways. One example is that research and development activities require user-collaboration as a prerequisite for receiving funding.

PLAN CONTENT

The content of these plans for action has been twofold. The first part is more principled in nature and describes overriding sociopolitical goals and general guidelines. The second part is the actual plan of actions to be carried out, containing the concrete activities and arrangements that the government is expected to implement, usually including specified sources and mechanisms for funding. The list of actions has been quite diverse in regard to purpose, form, and scope, and the number has increased with each plan. The 1990–1993 plan had a list of 53 actions, the 1994–1997 plan had 90, and the third had nearly 150 actions to be taken. While the range of types of listed actions to be implemented is rather diverse, they can be summarized in the following major categories: specified (earmarked) funding, incentive funding, innovative efforts, research and development work, and information projects.

Examples of activities receiving economic incentives include extending the range and type of respite services available to families with a disabled family member and smaller actions such as economic support for the production of "talking books." Examples of innovative actions are the establishment of a competence center to assist those with rare diagnoses and their families and smaller projects such as sign language theater. In the area of research and development, action plans have financed a range of projects, including a national research program on disability, one on the living situations of intellectually disabled people, and a number of smaller projects. Examples of information activities include projects aimed at improving access to information, such as sign language and subtitles on television. Other types of information projects are efforts aimed at informing public servants and the general citizenry about disability issues, especially those involved in local administration and community planning.

TIME LIMITED OR PERMANENT?

The activities stipulated in these action plans were intended to be time limited. However, many of the actions were deemed as successful and have been expanded or developed into permanent arrangements. Examples include the right to have a user-controlled personal assistant and functional assistants to assist at one's place of employment. In this way, action plans can be said to be vehicles for initiating and trying out different arrangements, as experimental steps as part of a longer-term strategy and goal.

EVALUATION

While several of the larger projects resulting from these action plans have been externally evaluated, the process of action plans itself has not been assessed. However, after the first two plans, the government Ministries reviewed results and experiences and emphasized in their conclusions that action plans made it easier to start up new initiatives. In addition, many actions and arrangements might not have taken place at all were it not for the framework of guiding principles and priorities described in the plans. The dual focus on concreteness and binding commitment was also seen as important.

However, there are some likely limitations to the "action plan approach" as a way of improving the situation of disabled people. First, disability politics risks becoming something outside of, or at least alongside, mainstream public sector policy. Having a special plan for a certain group of citizens reinforces their separateness and differentness. Another limitation might be that the overall effort behind these plans has been so all-encompassing and yet so detailed that the smaller bits may be easier to implement than addressing the larger, overarching challenges. Furthermore, there have been problems at local levels in joining the various actions together into a coordinated, comprehensive strategy. There is then a risk of increasing the gap between the societal goals of full participation and equality and the vast range of specific actions to be implemented. While it is difficult today to judge the overall effect of these national action plans, the hope that the various actions and activities would somehow combine toward a larger common effort remains to be realized.

—Kristjana Kristiansen and Jan Tøssebro

See also Participation; Social Model: Sweden.

"NOTHING ABOUT US WITHOUT US"

The expression "Nothing about us without us" has become one of the rallying cries of the international disability rights movement (DRM) and disabled people's organizations (DPOs). First coined in the early 1990s, the slogan's power derives from its location of the source of many types of (disability) oppression and its simultaneous opposition to such oppression in the context of control and voice. "Nothing about us without us" was adopted as a leading slogan by Disabled Peoples' International because it resonates with the philosophy of the disability rights movement. As Ed Roberts, one of the leading figures of the international DRM, has said, "If we have learned one thing from the civil rights movement in the U.S., it's that when others speak for you, you lose" (quoted in Driedger 1989:28).

"Nothing about us without us" can be considered a demand for self-determination. Self-determination is the essential theme that runs through all the work of the international DRM, regardless of political-economic or cultural differences. Control has universal appeal for DRM activists because the needs of people with disabilities and the potential for meeting these needs are everywhere conditioned by a dependency born of marginalization saturated with paternalism. The condition of dependency is presently typical for hundreds of millions of people throughout the world. Only in the past 25 years has this condition begun to change. Although little noticed and affecting only a small percentage of people with disabilities, this transformation is profound. For the first time in the thousands of years of recorded human history, politically active people with disabilities are beginning to proclaim that they know what is best for themselves and their community. This is a revelational claim aptly capsulized in "Nothing about us without us."

Since the late 1990s, the expression has become very popular and has been used by a variety of disability groups in trainings, articles, slogans, and titles.

—James Charlton

See also Advocacy, International; Disabled Peoples' International; International Disability Organizations; Ed Roberts.

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NOVEL, THE

"His wound gives him his narrative power." Arthur Frank is speaking of Tiresias, the ancient seer, who was blinded by the gods that he might "see" the future more clearly. Procne weaves the story of her sister Philomela's rape by King Tereus into fabric, her tongue having been cut out to prevent her telling the tale. Homer may have been blind, the better to remember the tale of the tribe and translate it into heroic dactyls. Such examples from classical literature suggest that the art of storytelling is intimately linked to a narrator's disability. Frank speculates that, at some fundamental level, the figure of the "wounded storyteller" may represent a "common bond of suffering that joins bodies in their shared vulnerability." But the wound may also extend to the story itself, a tale that is often of self-inflicted blindness (Oedipus), hubris-generated madness (Lear), and socially redemptive suffering (Quasimodo, Tiny Tim). Although disabled figures seldom appear as main characters, they often appear in cameo roles as grotesques or exotics necessary to the novel's plot. Given the preponderance of disabled figures in fiction, what is the relationship between the body of the story and the story of the body?

This question has been crucial for disability studies in the humanities. Disabled figures appear in many novels, such as Melville's one-legged Ahab, the invalid narrator of Charlotte Perkins Gilman's "The Yellow Wallpaper" and the limping Baby Suggs in Toni Morrison's *Beloved,* and most novels touch, in some way, on themes of illness, disfigurement, and mental illness. Certain genres—mysteries, Gothic novels, science fiction—are built around nontraditional bodies and extreme psychological states. We may not think of Milly Theale's lingering illness in James's *Wings of the Dove* or of Bertha Mason's madness in *Jane Eyre* as disabilities, but once we do, we begin to see the extent to which novels rely on a figure of bodily infirmity or cognitive incapacity. This linkage has spawned a considerable interest in the novel within disability studies. Foundational works such as Lennard Davis's *Enforcing Normalcy* (1995), Rosemarie Garland Thomson's *Extraordinary Bodies* (1997), Diane Price Herndl's *Invalid Women* (1993), and David Mitchell and Sharon Snyder's *Narrative Prosthesis* (2000) address not only the prominence of the disabled figure in fiction but also the cultural meaning of disability in a genre founded on an ideal of verisimilitude and fidelity.

Many critics see the novel emerging in the eighteenth century as an extension of Enlightenment rationality, a vehicle for chronicling the emergence of a new middle class. The novel's ability to represent ordinary people in ordinary circumstances made it a significant genre for validating a certain type of average individual, *l'homme moyen sensuel*, as the Realists called it. But as Lennard Davis has observed, *l'homme moyen* was also a product of medical and positivistic sciences that emerged in the early nineteenth century and that reinforced certain ideas of bodily or cognitive normalcy and excluded others. The sciences of eugenics, comparative anatomy, psychoanalysis, and phrenology provided a host of new (often suspect) diagnostic methods for analyzing various types of bodies and mental states for which the new technologies of photography and film provided visual support. This nineteenth-century "hegemony of normalcy," as Davis calls it, required a nontraditional or disabled body that could serve as a negative version of the statistical average. Often the disabled figure annexed other forms of deviance—racial, sexual, political—that threatened projects of imperialism and national consolidation. Thus, the disabled figure in fiction was a site for social anxieties within modernity for which there was as yet no name.

A key optic for regarding disability in nineteenth-century fiction is through gender. As women participated more forcefully in the public sphere, they found themselves portrayed as threats to patriarchal institutions, commonly represented in terms of irrationality and hysteria (the madwoman in the attic) or physical frailty (the invalid woman). Novelists such as Nathaniel Hawthorne, Émile Zola, and Gustav Flaubert often represented women as limited by their biology or subject to "female maladies" such as hysteria and neurasthenia. To some extent, this focus on female biology and psychology was prompted by scientists who were diagnosing women's illnesses and prescribing cures, the most famous of which was S. Weir Mitchell's "rest cure." As Diane Price Herndl (1993) points out, many nineteenth-century novels are centered around an invalid or dying woman whose representation reinforces female passivity and pathology at a moment when many women were gaining political and social power. But this passivity performs a critical function, as Herndl points out, because the invalid woman can serve as a challenge to representation itself. Invalidism, whether in the historical Alice James or the fictional portrait of Milly Theale, may offer women "a coherent and simple role in a world where multiple and conflicting roles are threatening or disappointing" (Herndl 1993). The unnamed narrator of Gilman's "The Yellow Wallpaper" uses her status as invalid to question the scientific definition of female biology offered by her doctor husband.

In the modernist novel, disability often serves as a sign of lack or absence, a figure for alienation in a world dominated by instrumental reason and commodity capitalism. In Ernest Hemingway's *The Sun Also Rises,* Jake Barnes suffers from a mysterious "wound" that has rendered him impotent. Edith Wharton's protagonist in *Ethan Frome* is a man who becomes seriously disabled in a suicide attempt in response to his arid, sexless life with a disabled wife. In *Lady Chatterley's Lover,* Clifford Chatterley is in a wheelchair, the result of a war wound that has rendered him, like Jake Barnes, impotent. In William Faulkner's *The Sound and the Fury,* Benjy Compson is mentally retarded, his broken, discontinuous narrative rendering the loss of family property but also the fragmentation and commercializtion of the American South. These modern texts thematize male inadequacy through disability that is a synecdoche for larger issues of world war, urbanization, and gender uncertainty.

Contemporary novelists have used disability to question the integrity of the unitary subject whose invention had been the focus of much previous fiction. Recognizing that the "normal" body is a variable fiction, novelists have represented the disabled body as a site of stigma but also of social critique. From William Burroughs's science fiction cyborgs—part technology and part human—or Katherine Dunn's carnival freaks in *Geek Love* to Toni Morrison's one-armed Nan in *Beloved,* disabled characters challenge certain humanist definitions of identity. Burroughs's cyborgs reveal the proximity of bodies to technology in the postwar era; Dunn's chemically altered grotesques expose the fictive nature of family and social institutions; Morrison's disabled African American women call attention to bodies that have historically been marked as other, culturally ostracized within racist culture. Rosemarie Garland Thomson (1997) notes that such representations in Morrison "enable [her] . . . to represent a particularized self who both embodies and transcends cultural subjugation, claiming physical difference as exceptional rather than inferior."

The pervasiveness of disability in the novel has produced several influential theoretical studies of narrative. David Mitchell and Sharon Snyder (2000) have suggested that not only do many novels feature a disabled character, such a figure provides a kind of "narrative prosthesis" for novelistic coherence itself. On the analogy of the prosthetic limb that provides an illusion of physical wholeness for the amputee, the disabled figure provides an illusion of textual embodiment that the novel must produce. And just as the wounded hero must be "cured" or brought back to health, so the disabled figure must be eliminated for the social body to be restored. The one-legged Ahab, whose megalomaniacal pursuit of the white whale for taking his leg, must be eliminated so that Ishmael's more recognizable humanist narrative can triumph. Physical and cognitive differences are the text's "cultural other" that must be brought under control by the narrative act. In Mitchell and Snyder's theory, the interrogation of the body's materiality coincides with an interrogation of the novel's materiality, its ability to complete a story that has a wound at its center.

Lennard Davis (1995) has argued that this wound is a historical phenomenon. He notes that theories of the novel that focus on its response to material conditions of emerging capitalism fail to recognize the impact of these conditions on the materiality of the body. Davis sees the modern novel as constructed around a dichotomy of normal-abnormal identities, one reinforced by positivist science in service to a national imaginary of typicality. For Davis, the disabled figure is foundational for undermining this imaginary. Since anyone can become disabled, the ideal of an average, typical, national body is suspect. The disabled figure "dismodernizes" the modern novel, establishing its formations in modernity but recognizing its deconstructive function in relation to the modern subject produced therein.

—Michael Davidson

See also Cyborg; Feminism; Invalid Women; Modernity; Representations of Disability, History of; Representations of Disability, Social.

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NURSING

Competent nursing has been central to the care of people with disabilities for many centuries. Up until the nineteenth century, people who were sick or disabled because of old age, mental illness, or physical disability were usually cared for by their families at home. For the poor sick and destitute, institutional care existed in local charitable guest- or poor houses. Professional nursing care by skilled nurses who were paid for their work, either in these institutions or through visiting nursing associations, grew during the nineteenth century. At that time, patterns of living and the provision of health care changed as a result of broader social changes, such as industrialization, urbanization, and changing work and gender relationships.

NURSING ORDERS

Nurses' role in care for the sick and disabled originated in religious orders, founded at the time of the Reformation and Counter-Reformation. Women and men who joined religious orders actively devoted themselves to poor relief and care for the sick. They viewed the care they provided as part of their religious practice and learned nursing skills through apprenticeship. With the foundation of the Daughters of Charity in France in 1633, cofounders Vincent de Paul and Louise de Marillac set a remarkable example of organized nursing care by lay women. The Daughters of Charity gained enormous social respect. Religious calling and spiritual commitment to God legitimized their role. So strong was the example that Roman Catholics and Protestants alike adapted to this model, and charitable nursing orders spread over Europe and North America through the next centuries, reaching a peak in the Evangelical and Missionary religious revival movements in the late nineteenth and early twentieth centuries.

Within a broader nineteenth-century humanitarian reform movement, previously unspecified groups of socially marginalized poor and disabled people were differentiated into distinct categories. Separate institutions emerged, for example, for the care of the sick and incurables, for insane persons, and for prisoners. In the new capitalist and industrial world, the emerging middle classes became concerned about the growing numbers of poor, which they perceived to be a source of social instability, fueled by fears of dirt, poverty, and contagious disease. In the New World, massive immigration created its own problems. Reform-minded middle-class citizens sought new and supposedly more effective ways to help the poor through rational control and scientific efficiency. Establishing good nursing care was one of them. Numerous associations for care of the sick emerged, who involved themselves with care of the sick in institutions, but some also provided care for people in their own homes.

Modeled after Roman Catholic sisterhoods and brotherhoods, the Protestants revived the function of the deacons and deaconesses. In 1836, Pastor Theodor Fliedner established one of the most well-known associations for care of the sick and dependent, the Deaconess Institute in Kaiserswerth, Germany. Within the protected structure of a motherhouse, the institute trained both nurses and teachers to work in its facilities. The work of deaconess nurses was not limited to care of physically sick or disabled people. People with mental illness were also included in the charitable effort. Within decades of its founding, the Kaiserwerth Institute included hospital care, a school for infants, an orphanage, and an asylum for women with mental ailments.

NURSING AS A PAID PROFESSIONAL OCCUPATION

The Kaiserswerth Institute served as an important inspiration to Florence Nightingale, who spent some time there in the mid-nineteenth century. She had an influential role in spreading and transforming the disciplined religious hospital apprentice training for nurses into a nonsectarian model that was fundamental to the emergence of nursing as a paid professional occupation. Most well-known for her work in the Crimean War, Nightingale fundamentally influenced the direction of nursing and nursing education in modern hospitals. Her authority evolved against the backdrop of a profound change in the public role of middle-class women.

The nineteenth-century humanitarian impulse that generated a new concern about the well-being of the poor provided a context for new caring roles for women. Their work and education became a matter of public debate, and an expanding economy created new work opportunities for middle-class women. They actively joined the humanitarian effort to uplift the poor and to help create a respectable working class. In this way, women not only created resources for a more meaningful life, but their philanthropic activities helped them to articulate the value of women's work in asserting a moral and ethical social influence, in fighting for temperance, for example, or in reforming hospitals and asylums. Based on a middle-class domestic ideology of women's special inclination for caring work, the new opportunities for women were considered an extension of women's traditional role in their families. Teaching, nursing, and social work became new areas of paid professional work for women. The women's movement, which obtained a more organized form in the late nineteenth century, provided a context for transforming a hitherto religious legitimization for women's work into a secular one. The idea that women had a special moral capacity and compassion, and the right characteristics such as devotion, sensibility, and sacrifice for caring work in a paid capacity, complementary to public roles of men, was a deeply gendered notion, reflecting the gendered beliefs of the time.

The projected image of the middle-class woman, trained in care of the sick, who brought order, cleanliness, and discipline to the unordered environment of large urban hospitals was a powerful one, and especially attractive to reform-minded physicians, who had their own interest in hospital reform. Influenced by the ideals of science, they sought to expand the application of medical therapeutics and technology. They had an interest in enhancing their research and teaching on hospital wards and valued the assistance of trained nurses who could help them to implement new therapies and maintain order on the wards.

NURSING EDUCATION AND WORK

The expanding demand for women with training in care of the sick grew from various sources, a boosting economy, the rise of a middle class that could afford to pay for private nursing, and the expansion of hospital care for a growing urban community and industrialized workforce that could no longer be cared for in their own homes.

Physicians sought to improve the image and reality of public hospitals and asylums alike, which traditionally had a poor reputation as stigmatizing places of last resort. In making hospitals attractive to a growing middle (and reputable) working class, the civilizing role of respectable nurses, for which high social regard had already been established in nursing orders and associations for care of the sick, became an inspiration to reform-minded doctors. The slight difference was that they were particularly interested in training these women themselves and bringing the nursing staff under their own control.

Initially, their interest matched feminist attempts to create work opportunities for women. The combined efforts of doctors, hospital administrators, and respectable ladies to reform hospitals resulted in the introduction of hospital-based training schools of nursing, a highly attractive model of nursing education that spread throughout the world, attracting large numbers of young, middle- and working-class women. The arrangement was that the women lived and worked on the hospital grounds, their reputations carefully protected through a disciplined system of supervision and regulations, in return for a nursing diploma after initially two, but later three, years of training. Doctors taught them the medical knowledge deemed appropriate and necessary, and usually a nurse superintendent oversaw the management of the school under the authority of the medical director of the institution. Soon, however, nurses expressed awareness of the challenges associated with a hospital-based program of education. Work conditions of the new student nurses did not differ much from their counterparts in domestic servant roles in terms of pay and working hours. The work nurses took up in private duty upon graduation was largely unprotected. This situation prompted nurses to organize themselves into professional associations and seek legal and social protection from the state through registration laws and licensing regulations.

NURSES AND CARE OF THE MENTALLY ILL

The introduction of diploma-based nursing education forcefully continued the cultural connection between nursing work and care of the sick and disabled. The introduction of trained nursing in asylums forms a salient example. Institutional care for the mentally ill became firmly established in the industrializing world in the nineteenth century. However, despite initial optimism about the improvement new institutions would bring, asylums soon grew into overcrowded, lower-class institutions for indigent insane and their social reputation was very poor.

When scientific psychiatry grew as a medical field in the late nineteenth century, psychiatrists had a vested interest in enhancing the status of asylums and introducing new therapies such as bed rest and hydrotherapy. They began to model the asylums after the influential example of the general hospital. A crucial factor in this transformation was the availability of competent personnel who could assist them in making the new therapies work. Inspired by the impact of the role of middle-class women in hospital reform and the effect of hospital nurse training schools, asylum physicians also began to argue for the establishment of mental nurse training. Nurses, trained in care of the sick, began to provide day-to-day care of the mentally ill, and asylums opened their own mental nurse training programs.

The care of large groups of mentally ill patients with difficult and often unpredictable behavior remained a burdensome task, however, and the limitations of high turnover of personnel and demanding work conditions characteristic of the general hospital nursing workforce were probably even more prominent in the asylums. At the turn of the twentieth century, a large part of the asylum population consisted of demented elderly, for example, who came to the asylum in the last years or last months of their life. Behavior of demented, confused, or agitated patients was difficult for nurses to handle, and communication with this population was a complex matter. Patients in a delusional, manic, or agitated state could be dangerously violent or unpredictable in their behavior. Asylum work was strenuous and not without risk. More stable patients, however, usually took part in hospital work and made an extensive contribution to the asylum economy. A gradual decrease in mortality rates, as in Dutch asylums, likely indicated that to some extent mentally ill patients did benefit from more competent and compassionate care, although generally circumstances in asylums remained challenging, reflecting the broader social difficulty of caring for the mentally ill.

Although the disadvantages of large institutions did not disappear with the introduction of systematic training of personnel, nursing work provided an opportunity for a decent social position for large groups of middle- and working-class women and men. The popularity of this training model for nurses may indicate that it served first and foremost as a new way to staff institutional care for the sick and disabled. This model of combined nursing education and work gradually changed in the second half of the twentieth century, as nursing education and work increasingly began to be separated and the necessity of a more advanced education for nurses became essential for expanding health services in the second half of the twentieth century.

PUBLIC AND MENTAL HEALTH MOVEMENTS

The devastating impact of World War I, with its aftermath of labor unrest and economic depression, combined with widespread tuberculosis and high infant mortality rates, reinforced the idea that in a democratic society basic needs of citizens had to be taken care of independent of the ability of individuals to pay for health services. Starting in the nineteenth century and expanding in the first half of the twentieth century, Western industrialized nations began to provide more consistent protection of its citizens through state regulated security and insurance plans for unemployment, old age, sickness, and disability. Although models and programs varied between countries, some form of regulated health insurance financed through private or public funds became the norm and had a permanent impact on the provision and development of health services and disease prevention.

Closely related to this idea was the belief that science, generating more effective and efficient ways to manage the social problems created by dependency, provided the foundation on which social policies and solutions should be based. The public and mental health movements arising in the first part of the twentieth century were a case in point. They reflected the growing confidence that professional and scientifically based efforts to enhance the health of the people, physically and mentally, would ultimately result in a productive and healthy population. Nurses took up an essential role in these movements, expanding and re-creating more independent careers in public and mental hygiene work, such as children's bureaus and vaccination programs, school health programs, visiting nursing societies, tuberculosis prevention, child guidance clinics, but also in factories, insurance companies, and boards of health and education.

CHANGES FOLLOWING WORLD WAR II

Following World War II, a growing health agenda originated from various sources. Increased international economic and social collaboration in health matters was reflected in the foundation of the World Health Organization (WHO) in 1948. The WHO noted that "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (Howard-Jones 1981:472). The new availability of antibiotic drugs fueled increased confidence in the advancement of medical knowledge and technology. Increasing national wealth provided an economic basis for expanding health programs. In the mid-twentieth century, hospital and medical care insurance legislation facilitated an enormous growth of hospitals and medical care services and generated an unprecedented demand for health care personnel.

During the 1940s and 1950s, every industrialized country faced an enormous shortage of nurses. As a more acutely ill patient population filled hospital wards, traditional patterns of staffing hospitals by continuously turning over nursing student personnel no longer matched required levels of care and clinical observation. More graduate nurses became employed in the hospital, while continued demand for more caretaking personnel was also filled through new diversification of the nursing workforce. As of the 1960s, academically based nursing education became more widespread, while new programs for nurse assistants and licensed practical nurses were also established to complement the work of the traditionally registered nurses. Nursing homes emerged for the care of chronically ill and disabled people, and the lower-qualified group of nurses became the workforce of choice in these new institutions.

While nursing adapted to increased demand, coming to terms with the new diversity in educational preparation of nurses was a complicated process. Through national and international nursing organizations, such as the International Council of Nurses (ICN), nurse leaders sought to establish minimal educational guidelines for professional nurses and expand nurses' role in health service, policy, and research, while seeking to maintain control over a continuously expanding nursing workforce. The higher complexity of nursing care required for a patient population that experienced new illnesses for which in the past no medical treatment had existed was not always well understood among health policy makers. Moreover, as health care advanced, chronic illness and permanent disability rendered new demands for skilled long-term care. The gendered context in which professional nursing emerged during the nineteenth century had generated beliefs that made it persistently difficult to articulate at a social level the essential value of nursing care in all of these situations.

Defining the responsibilities of the nurse, which had been a long-standing matter of debate within nursing organizations, regained relevance as the function of the nurse had to be articulated in new twentieth-century contexts. Virginia Henderson (1969:50), an influential nursing leader in the United States and a clinical nurse researcher, developed a powerful and influential statement that captured the essential role of the nurse in the assistance of dependent and disabled individuals:

> The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to a peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge.

Her view, articulated in *Basic Principles of Nursing Care,* became the basis for the ICN's vision on nursing and was translated into 12 languages, serving as a guide for nurses around the world.

PRIMARY HEALTH CARE

Not only the view on health and health services changed profoundly during the twentieth century but also the perspective on sick and disabled people themselves. Health is increasingly considered a basic human right. Moreover, health consumers now actively participate in health care politics, raising awareness and advocating for equal access and improvement of service. A strong consumer movement now advocates for consumer rights, resources, and responsibilities.

Demographic changes and a rapidly growing elderly and chronically ill population have shifted the emphasis of health services from merely disease prevention to health promotion. The argument that hospital-based care and medical services alone are not enough to maintain people's health gained momentum as of the 1970s. An emphasis on primary health care has emerged, in which community-based care and promotion of a healthy lifestyle have obtained central stage, enhancing an active role of people in maintaining their own health. Primary health care is a broad-based approach to health services in which promotion, prevention, cure, rehabilitation, and palliative support are equally valued. Nurses, both in staff positions and in specialized advanced practice roles such as clinical nurse specialist or nurse practitioner, have an essential role in patient advocacy and in bringing about the primary care philosophy.

CURRENT AND PERSISTENT CHALLENGES

Currently, nurses consider enhancing the integration of people with disabilities in the community and improving their quality of life essential tasks. As part of their academic education, nurses have gained knowledge and expertise in research and policy development. Nursing research is now a fundamental component of nursing practice. Over the past decades, nurses have made substantial contributions to knowledge of chronic illness and disability, supporting people with disabilities in improving their health and living conditions. Both nurses, as providers, and persons with chronic illnesses and disabilities, as consumers, experience the unrelenting reluctance of society at large to value the public need of basic care. As a nursing shortage once again is looming around the world, largely as a result of the profound effects of cost-containment and restructuring of health care during the 1990s, which eliminated thousands of nursing jobs, the persistent difficulty as much as the profound necessity of finding a balance in evaluating the cost and value of nursing care remains a prominent health care issue.

—Geertje Boschma

See also Health Care and Disability; Medicine.

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O

OBESITY

Obesity is a condition characterized by a larger-than-average amount of body fat (excess adipose tissue). While fatness has been associated with wealth and prosperity in historical contexts where continued existence was predicated on access to food, *obesity* is a medical term used to pathologize the fat body in a context of abundance of resources. In contrast to overweight, which is a Body Mass Index of 25–29 (BMI, or weight in kilograms divided by the square of height), obesity is a BMI of 30 or greater. (BMI problematically does not consider muscle mass and is only a crude measure of weight.) Obesity is considered a public health crisis/epidemic in the affluent West in the early twenty-first century, with more than one-third of all adults and one in five children categorized as obese. There was a huge jump in National Institutes of Health estimates of the prevalence of obesity in the United States from the 1960–1980 period, when 15 percent of adults were obese, to over 30 percent in the 1980–2000 period. However, the federal government's lowering of the baseline of standards for obesity made 35 million people who had not been considered fat before suddenly very much so.

The management of obesity fuels a multi-billion-dollar diet and fitness industry, extensive pharmaceutical research and development, lobbying for taxes and advertising bans on certain foods, efforts to improve nutritional labeling, and other interventions aimed at slimming down the public. The medical establishment links obesity to a host of health problems, including high blood pressure, diabetes, heart disease, stroke, gall bladder disease, and cancer of the prostate, colon, and breast. Sedentary lifestyles and increased consumption of inexpensive, fatty, processed foods are typically hailed as contributing factors, though heredity and genetic factors are thought to play some part as well. However, much medical research conflates obesity with these factors, further suggesting a causal relationship between obesity and the aforementioned health problems. Critics point out that the correlation is far too often misinterpreted as causation, and they propose instead that the stresses resulting from living in a society that stigmatizes fatness as unhealthy, immoral, and disgusting may in fact be the cause of ill health.

Since the early 1970s, members of several U.S. size-acceptance organizations, most prominently the National Association to Advance Fat Acceptance (NAAFA) and the Fat Underground, have been working to change the way society perceives of fatness, to cast off its stigma, and to combat discrimination. Their actions have been instrumental in the inclusion of obesity in the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. Fat Americans are legally protected against discrimination so long as their condition substantially limits at least one of their major life activities or is perceived as doing so. Nonetheless, controversy abounds about whether the condition of obesity, over which individuals are usually thought to have some personal control, should be protected, and very few anti-obesity discrimination cases have been successfully argued. Several places in the United States have taken the plight of fat people who suffer discrimination more seriously, with Michigan, Washington, D.C., and Santa Cruz and San Francisco, California, offering anti-size discrimination statutes for protection.

—Kathleen LeBesco

See also Americans with Disabilities Act of 1990 (United States); Health Promotion; Normality.

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OBSESSIVE-COMPULSIVE DISORDER

Obsessions or compulsions, or more commonly both, are the hallmark of obsessive-compulsive disorder (OCD). Obsessions are recurrent and persistent ideas, thoughts, impulses, or images that are intrusive and inappropriate and cause marked anxiety or distress. Common obsessions include fears of harming other persons or sinning against God. Compulsions are repetitive, purposeful, and intentional behaviors or mental acts performed in response to obsessions or according to certain rules that must be applied rigidly. They are meant to neutralize or reduce discomfort or to prevent a dreaded event or situation, even though the sufferer generally knows the irrationality of these acts. Obsessions create anxiety, which is relieved by compulsive rituals such as checking, washing, counting, confessing, hoarding, and rearranging objects with symmetry and precision. These symptoms can cause functional disability as severe as psychosis and can make it virtually impossible to function at work or at home.

To receive a diagnosis of OCD, a person must have either obsessions or compulsions that cause marked distress, consume more than one hour daily, or significantly interfere with the person's normal routine, occupational functioning, or usual social activities and relationships. The person must recognize that the obsessions and compulsions are unreasonable. Many psychiatrically normal individuals—particularly children—have occasional obsessional thoughts or repetitive behaviors, but they tend not to cause distress or disability. Many people double-check locks or avoid stepping on cracks. These rituals are viewed as acceptable and desirable and are easily adapted to changing circumstances. To the obsessive-compulsive person, however, rituals are a distressing and unavoidable way of life. Data indicate that as many as 2–3 percent of the general population meet criteria for OCD at some point during their lives. Men and women are equally likely to develop OCD, although men have an earlier onset.

Recent developments in the treatment of OCD have improved outcomes and instilled a greater sense of optimism. The mainstays of treatment are pharmacotherapy and cognitive-behavior therapy. Behavior therapies, which tend to be more successful for ritualizers, emphasize exposure paired with response prevention. Proponents of behavior therapies state that 60–70 percent of the patients who persevere with the treatment improve markedly. New generations of drugs work well at relieving both obsessions and compulsions in nearly 75 percent of patients. Treatment is long term because patients tend to relapse when the drug is discontinued, often within weeks. Patients who complete a course of behavior therapy are less likely to relapse.

—Ahmed Okasha

See also Behavior Therapy; Behavioral Disorders; Psychiatric Disorders.

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OCCUPATION

In the context of disability and rehabilitation, the term *occupation* is most widely used and discussed in the field of occupational therapy. While various definitions exist, occupation generally refers to engaging in work, play, or activities of daily living. Work refers to activities (both paid and unpaid) that provide services or commodities to others, such as ideas, knowledge, help, information sharing, entertainment, utilitarian or artistic objects, and protection. Activities such as studying, practicing, and apprenticing improve abilities for productive performance. Thus, work includes activities engaged in as a student, employee, volunteer, parent, serious hobbyist, and amateur. Activities of daily living, play, and work interweave and sometimes overlap in the course of everyday life. Play refers to activities undertaken for their own sake. Examples of play are exploring, pretending, celebrating, engaging in games or sports, and pursuing hobbies. Play is the earliest occupation, persisting throughout life. Activities of daily living are the typical life tasks required for self-care and self-maintenance, such as grooming, bathing, eating, cleaning the house, and doing laundry.

Occupation is recognized as a basic human need and as a determinant of well-being. This need is reflected in the strong drive to do things and the fact that people flourish by engaging in practical, productive, and playful pursuits. The need for occupation entails the urge to do things, to discover, to exercise capacity, and to experience oneself as competent. It is considered to be the product of an evolutionary process in which the complex nervous system of humans gives them a pervasive need to act.

The term *occupation* derives from the Latin *occupare* and connotes taking hold of (i.e., occupying) time and place. Modern discussions of occupation highlight the fact that occupations are how persons fill their time. Humans mark the passage of temporal cycles by what they do. Such terms as *mealtime*, *playtime*, and *workweek* illustrate how the patterns of time and doing are intertwined. Human awareness of the future also means that much of what people do in the present is aimed toward some state of affairs they wish for at a future point. Therefore, occupations not only fill and mark time but also shape the course of people's lives over time. To a large extent, people engage in their occupations so as to locate themselves in an unfolding narrative with an eye toward a particular direction or outcome for that life story.

Occupation is also how persons make their place in the social world. Most of the occupations that people do are conducted among and with others. Occupations express and maintain the social fabric since they not only follow normative ways of doing things but also serve to perpetuate those same social patterns they reflect.

Occupation, disability, and rehabilitation were historically linked in the moral treatment movement of the seventeenth century. Moral treatment saw mental illness as a result of persons' loss of connection to the occupations that made up the mores or folkways. This perspective presaged contemporary views of disability as an interruption of a person's participation in life activities. Moral treatment emphasized using occupations (i.e., work and leisure activities) as ways to encourage and enable people to reconnect with the social world around them. The idea of using occupation as a therapeutic tool has continued in occupational therapy and other disciplines that use activities as a means of habilitation and rehabilitation.

—Gary Kielhofner

See also Employment; Job Training; Occupational Therapy; Rehabilitation; Work Incentives.

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OCCUPATIONAL THERAPY

Occupational therapy is a health-related profession that primarily serves persons with disabilities. It is concerned with the well-being of persons in their everyday occupations (i.e., work, play, and daily living tasks). The profession sees occupation as a necessary aspect of life, contributing to physical, emotional, and cognitive well-being. Occupational therapists work with individuals whose participation in occupation is threatened or hampered by impairments and/or environmental barriers.

The origins of occupational therapy are the eighteenth-century moral treatment approach. Moral treatment was a European movement that saw mental illness as a form of demoralization emanating from disruption of a person's connection with the mores or customary activities of society. Moral treatment consisted of inviting and supporting participation in everyday activities as a means of "remoralizing" individuals by reintegrating them into ordinary routines of living. Moral treatment exported to North America and practiced in the eighteenth and early nineteenth centuries. In the mid-1800s, overcrowding and underfunding of state hospitals led to its virtual demise.

In the early 1900s, a diverse group of people (architects, physicians, nurses, and leaders from the settlement movement and industrial arts) began developing a form of treatment that used participation in work, crafts, leisure activities, and self-care as a form of therapy. These early leaders included the psychiatrist Adolf Meyer and social activist Eleanor Clarke Slagle. William Rush Dunton, another psychiatrist and a descendent of Benjamin Rush (a physician and statesman who introduced moral treatment to the United States), was responsible for introducing and spreading literature and concepts from European moral treatment into occupational therapy. The early practice of the field (which quickly spread from application with persons who had mental illness to a variety of other impairments) focused on helping patients reclaim function and achieve satisfying everyday lives through active participation in work, self-care, and leisure tasks during their rehabilitation.

In mid-twentieth century, the field became more closely aligned with medicine and the medical model. As a consequence, more attention was paid to remediation of underlying impairments that contributed to disability. In the 1970s and 1980s, this emphasis on impairments was increasingly criticized from within the field. Consequently, leaders sought to return occupational therapy to a more holistic practice centered on the client's participation in everyday life occupations.

The contemporary focus of the field is, therefore, on the client's challenges or difficulties with participation in occupations. Occupational therapy services seek to enhance individuals' performance and satisfaction in work, play, and activities of daily living through reducing impairments and through personal and environmental adjustments. Services are offered to clients who range from preterm infants to the very old and to persons with any type of physical, sensory, cognitive, or emotional impairment. More recently, services are offered to persons whose work, play, and activities of daily living are disrupted by war, poverty, violence, and other social injustices. Occupational therapists are also increasingly involved with providing services to promote wellness and prevent loss of function.

Since the aim of occupational therapy is to enable persons to have satisfying and productive engagement in occupation, occupational therapists are trained to understand and address the interrelated biological, psychosocial, and environmental factors that contribute to occupational problems. The common denominator of occupational therapy practice is involvement of persons in occupations as a means to enhance their well-being. The profession is based on the premise that when humans engage in occupations using their physical and mental powers, they can positively affect their biological and psychological status. Consequently, occupational therapy focuses on empowering clients to actively influence their own rehabilitation process and outcomes, but selecting their own objectives for the kind of lives clients want to lead.

Occupational therapy ordinarily consists of one or more of the following elements. First, therapists provide direct opportunities for clients to perform occupations with an aim toward achieving personal change (e.g., development of new skills, learning to compensate for a permanent impairment, increasing self-confidence, and discovering new ways to achieve satisfaction in performance). The occupations that are used as therapy can include a wide range of activities (e.g., sensory-motor play, crafts, work tasks, group projects, leisure activities, school/classroom tasks, and self-care activities such as dressing or bathing).

Second, occupational therapists provide and train clients in the use of various technical devices that extend limited capacity or compensate for lost capacity. This technology ranges from simple adaptive equipment that has been modified to accommodate motor limitations to complex, computer-based equipment that is used for communication and environmental control.

Third, therapists help clients remove barriers to engaging in occupations by modifying how tasks are completed or through modifications of the environment. Tasks are modified through such strategies as simplifying steps, providing special sensory or memory cues, or altering expectations for outcomes. Environmental modifications include such things as removing architectural and structural barriers in the physical environment and changing attitudes of others toward disabled persons in environments where the person carries out occupations (e.g., home, school, and workplace). More recently, occupational therapy has increasingly included advocacy for social and policy change as a strategy for removing environmental barriers.

Fourth, therapists may enable persons to engage in occupations through counseling and problem solving that encourage the client to choose and participate in occupations. Because occupational therapy is based on the client's active involvement in doing things, the field pays particular attention to the client's perspectives and experiences in order to facilitate this involvement. Client centeredness is an important theme in occupational therapy.

In addition to working with individuals, many therapists have agencies, organizations, and entire communities as their clients. They may provide consultation services on program design, optimal environments, training and development of staff and families, prevention programs for workers, and education programs for community members, all within the context of maximizing occupational functioning of the target group.

There are occupational therapists practicing in more than 60 nations worldwide. Education ranges from occupational therapy assistants who earn two-year associate of arts degrees to therapists who earn professional doctoral degrees. In the United States, a graduate degree will be required for entry into the profession in 2007, but the most common educational background worldwide is the bachelor's degree. The World Federation of Occupational Therapists is a major international body that recognizes educational programs, although most countries have their own credentialing of educational programs and qualified therapists.

—Gary Kielhofner

See also Aids for Activities of Daily Living; Occupation.

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O'CONNOR, FLANNERY (1925–1964)

American author

Flannery O'Connor was born in Savannah, Georgia, the only child of a devout Catholic family. This background, as many critics have argued, shaped her later fiction writing as part of the southern grotesque. Her father was a realtor and her mother was a member of a prominent political family (her grandfather had been mayor of Milledgeville, Georgia, for many years). She graduated from Georgia State College for Women in 1945 and then attended writer's workshops at the University of Iowa. In 1950, she experienced her first bout with lupus—a debilitating blood disease that she inherited from her father. O'Connor used crutches for mobility from 1955 onward.

From the beginning, O'Connor's work demonstrated a somewhat perverse relationship between religious and disability themes. In her second novel, *The Violent Bear It Away* (1960), the main character, Francis Marion Tarwater, becomes a minister in his youth and later baptizes and drowns Bishop, the "idiot" son of his uncle. The act is performed in eugenic-like style as one of mercy to save the cognitively disabled character from Satan's temptations. Likewise, in her famous short story "A Good Man Is Hard to Find," a malignant criminal named "The Misfit" explains that the easy expendability of human life was brought about by Christianity when Jesus was raised from the dead. This miraculous act precipitated attitudes of false reverence for death and afterlife as mere inconveniences that can easily be overcome. In the story "Good Country People," the female protagonist dons an artificial leg as the result of a hunting accident. When she tries to sexually engage a country Bible salesman named Manley Pointer, he runs off with her prosthesis as punishment for her "licentiousness." Thus, O'Connor spent much of her writing career demonstrating the degree to which humans will torture, injure, and kill each other as an expression of their investments in religious "morality."

In the 1950s, she reflected directly on the social fate of disabled children by arguing that sentimentality expressed toward them—that which would deny their difficulties and suffering in a hostile world—is akin to beliefs that sent individuals to the gas chambers during the Holocaust. Furthermore, O'Connor insisted that the parents of disabled children would hesitate to dismiss such a comparison of cultural attitudes toward disability even though her parallel may seem extreme to many. In making this argument, the disabled author identified sentimentality as a key antagonist of disabled people with respect to more meaningful engagements with the experience of impairment. O'Connor died in 1964 at the age of 39 following an ill-fated surgery that reactivated her lupus.

—David T. Mitchell

See also Novel, The; Religion.

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ONTARIANS WITH DISABILITIES ACT OF 2001 (CANADA)

The recognition that people with disabilities are entitled to full citizenship and that government has an obligation to take steps to make that vision a reality is a relatively recent development in Canada. It reflects a transition from the view that people with disabilities are inadequate and require charity and beneficence to an acknowledgment that the obstacles for full inclusion are barriers that prevent people with disabilities from fully participating in all aspects of society.

The Charter of Rights and Freedoms provides constitutional protection to persons with disabilities by prohibiting discrimination on the basis of disability. Provincial and federal human rights legislation also prohibits discrimination on the basis of disability in a number of key areas including employment and the provision of goods and services to the public. However, the charter and human rights legislation require individual complaints to be filed for each act of discrimination and involve a lengthy legal proceeding. While human rights legislation may allow for systemic litigation and proactive approaches to prevent and remove barriers, the lack of a comprehensive barrier-removal statute was identified as an important deficit preventing the full participation of persons with disabilities. Requiring individuals to file complaints is difficult where people are afraid to disclose that they have a disability.

Between 1995 and 2001, the Ontarians with Disabilities Act committee, a province-wide coalition of people with disabilities and organizations representing people with disabilities, was formed to lobby for comprehensive barrier-removal legislation in Ontario.

Legislation was introduced in November 2001 and went into effect on September 30, 2002. It requires the provincial government, municipal governments, hospitals, educational institutions, and public transit organizations to develop barrier removal plans within one year. The plans must set out how organizations intend to identify existing barriers, how they plan to remove those barriers, and how they intend to prevent the creation of new barriers. There is no specific obligation in the legislation to remove a certain number of barriers or types of barriers within any time frame. The plans are to be developed in consultation with people with disabilities. The plans must be filed with the newly created Accessibility Directorate and will be available to the public. The legislation does allow the government to develop regulations and guidelines on the plans, but to date none have been developed. As of January 2003 the enforcement provisions of the legislation had not been proclaimed.

The legislation also permits the government to extend its application to the private sector, but again, this has not been done. The government is seeking voluntary compliance by the private sector. There are a number of other obligations placed on the provincial government, such as ensuring that all of their websites meet accessibility standards.

The legislation does not create an independent body, but it does enshrine in legislation the Accessibility Directorate as a part of the public service. It also creates a provincial Accessibility Advisory body, as well as requires municipalities of more than 10,000 people to create their own advisory councils.

The legislation specifically states that it does not in any way diminish or affect the rights of people with disabilities under the Ontario Human Rights Code.

The definition of *disability* in the Ontarians with Disabilities Act is inclusive and specifically includes mental disability and brain injury. The definition in the Ontario Human Rights Code was amended to be consistent with the definition in the Ontarians with Disabilities Act.

The legislation also requires that people with disabilities and other stakeholders must be given an opportunity to consult on any proposed regulations developed under the act. It allows for the development of guidelines and standards, although there are no timelines in place for them to be developed.

In a provincial election held in October 2003, the Ontarians with Disabilities Act was raised as an issue with the new government promising to strengthen the legislation within its first year in office. Consultations started in January 2004, and the legislation was passed and went into effect in 2005.

—*Patti Bregman*

See also Disability Law: Canada.

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OPPRESSION

Oppression occurs when individuals are systematically subjected to political, economic, cultural, or social degradation because they belong to a specific social group. In 1970, Paulo Freire argued that the experience of oppression is marked by dehumanization, conquest by the oppressed group, dividing and ruling by the oppressed group, manipulation, cultural invasion, "forcing the oppressed group to adopt the beliefs of the oppressors," exploitation, marginalization, power inequities, and violence.

OPPRESSION AND THE COMPLEX DISABLED PERSON

Oppression is often a topic when minority groups and the dispersion of power are discussed. In the African American civil rights movement, the women's movement, anti-apartheid movements, and many civil and human rights movements globally, oppressed people have sought to redistribute power and increase equality, all citing a common theme of oppression.

Many parallels have been drawn between the black community and the disability community in North America. The idea of the minority model being applied to both groups is anchored in the social model that has flourished in British and American disability studies. This model argues that social attitudes rather than physical or mental inabilities are the primary source of problems confronting disabled people. In addition, disability theorists argue that many aspects of the physical and social environment are determined by public policy and that policy is a reflection of pervasive societal attitudes and values. This may have a distinct impact on those who have intersecting identities that may be targets for oppression.

Consider, for example, a black woman who is disabled as defined by Western disability theorists. Persons such as this, who are members of more than one minority group, often experience tension, and they rank their membership in such groups in terms of the characteristics they consider most appealing and most central to their identity. What is appealing to a person is often dictated by the culture that the individual identifies with. Often, even within minority groups, the dominant culture influences beliefs about what characteristics are of value. Cultural invasion is a phenomenon discussed by Freire (1970) where the invaders, "persons outside of the oppressed group," penetrate the cultural context of another group, disrespecting the latter's potentialities. In this invasion, the invaders impose their views of the world—right and wrong, good and bad, inferior and superior—on those whom they invade, and they inhibit creativity by curbing expression of the less powerful group. Those invaded are then expected to pick up the values of their oppressors and accept them as their own. Many disabled blacks have internalized the views of the dominant group concerning both race and disability.

Oppression is expressed in the above instance by locating the sources of oppression within the body of the disabled person, thereby blaming the individual for experiences of oppression, because his problems are housed within him. This is done in an attempt to remove societal responsibility for barriers that may be placed on the oppressed group. The internalization of race hatred has been argued well; however, less theorized is the acceptance of dominant cultural views concerning disability status and the effect this has on the experience of oppression for persons who hold multiple minority status.

It is not enough that the skin is a culprit; now the biological traits beneath the skin have been targeted. Such an argument is not new to blacks as it was seen in the measuring of black skulls to prove innate inferiority and a lack of humanness in an effort to legitimize mistreatment of blacks based on race. Over the years, black theorists and scientists have taken up this argument to disprove it, but the same has not been successfully done for disability, and blacks have not openly recognized this similarity in a way that would spark revolution as it did in race politics. In turn, the dominant culture's ideas of the "normal-functioning body and mind" have become mainstream in black communities, and these ideas lend themselves to inadvertent oppression from a group that is familiar with the trauma of daily oppression.

Although incorporation of dominant beliefs toward the disabled has occurred, it is not an absolute within the black community. Blacks are also influenced by a historic ostracism based on race, and they have learned to accept a wider range of difference as normal and acceptable. Thus, disability oppression is often seen enforced on those whose differences lie outside the range that blacks have carved out as normal and functional, and it places those on the fringes at high risk for "majority norm enforcement."

If ethnicity complicates disability, then adding gender to the equation can certainly offer an additional dimension. Rosangela Berman Bieler, a Brazilian disabled woman, argued in 1998 that in spite of the similar discrimination that disabled men and women face, there is a point where they differ; that difference is seen in the cultural norms accepted by majority society concerning sexuality and affection in regards to disabled women. In a society where body defines you, the black and disabled female finds her body on the lowest stratum of beauty in terms of the dominant culture's standards.

Women of color with disabilities are not unique in their struggle to fight the stereotypes of asexuality and abnormality concerning the disabled female body, but an ethnic female does face the added stigma of being an "other," already considered less than the dominant culture's acceptability for beauty. Thus, not only does the disabled black woman receive societal messages that she is less than female because of her disability, she also receives the message that she is less than female because she is black. As a trinity, disability, blackness, and femaleness represent a union of oppression that is focused on the body of an individual who can be devalued from many angles. Her image is tarnished by her triple minority status, and it is acceptable to treat her as less than human.

THE UNIQUENESS OF DISABILITY OPPRESSION

Though oppression based on race and gender has similarities to oppression experienced by those who are disabled, disability oppression is unique in some respects: People are born black, or female, but can become disabled at any time in their lives. There is a fear associated with the unknown, and to distance oneself helps to keep a separation between what one currently is and what one does not want to be. This distance is seen in North America and also globally, and the fear of becoming disabled helps to keep disability oppression grounded in many cultures. The establishing of oppression based on the fear of a shift in social category separates disability-based oppression from race-based oppression; in other words, people do not wake up after 20 years of being white and suddenly possess the characteristics of blackness.

An additional unique characteristic of disability-based oppression is the need that a disabled person may have for personal assistance. This opens doors of oppression in different ways than does race or gender. Consider an individual who needs daily assistance with bathing or dressing. If the personal assistant refuses to help, or is late and services are not rendered, the disabled person is in a situation of less power, of less authority, of "dif-ability," and is thus oppressed based simply on the need for personal assistance. These occurrences are specific to those who have disability status.

CONCLUSIONS

When grappling with the existence of oppression, we must be informed by our surroundings, by the oppression that others have experienced and navigated through, while also being aware of the nuances that are present in oppression experienced in the context of disability. Oppression is not just an experience but also a social phenomenon that has been globally expected. There is always a group that assumes a subordinate position. The disabled community faces multiple levels of the expression of oppression, because disability inhabits locations that cross and encompass gender, race, socioeconomic status, disability type, lifestyle, age, religious beliefs, and nationality. It must be realized that disability oppression is not housed in genetics but lives in the cultural norms that have been accepted as mainstream beliefs in the societies in which we live. Mainstream cultural norms concerning disability must be altered in ways that will help eliminate disability oppression as a standard experience for the disabled.

—Nefertiti L. Nowell

See also Attitudes; Disability Culture; Disability Pride; Gender; Normality; Racism.

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ORALISM

Oralism refers to one of the two principal approaches to and philosophies of teaching language to the deaf; it is contrasted with manualism. Oralism assumes that speech is the most evolutionarily advantageous form of language and that the ability to use and/or understand spoken language is what separates humans from lower species. Thus, oralism devotes considerable attention to teaching deaf and hearing-impaired people not only how to produce speech but also how to read lips. Manualists take the opposite position, regarding sign language (in its various forms, from American Sign Language to Signed English, and their national variants) as "natural" languages, possessing all the important characteristics of any language, such as morphology, syntax, and markers for semantic and rhetorical intensifiers and connotations. In its earliest years, manualism also carried with it an evangelical mission, as a way of spreading gospel to those ordinarily considered excluded from its transmission.

In the nineteenth century, when the great debates between oralists and manualists first took shape, one of the most famous proponents of oralism was Alexander Graham Bell, whose invention of the telephone was in part a by-product of his work on creating communication systems for the deaf (Bell was married to a deaf woman). His father, Alexander Melville Bell, a famous teacher of elocution, developed a system called "Visible Speech," designed to assist in teaching deaf people how to acquire spoken language. The Alexander Graham Bell Association, a foundation named after him, continues today and is committed to furthering Bell's conviction that the proper way for deaf and hard-of-hearing (their term) people to communicate is through spoken language.

There were eugenic and racist elements to the oralism versus manualism debates, as well. Bell, for example, believed that manualism needed to be done away with in large part because it encouraged inbreeding between deaf people, thus leading to a greater possibility (in the case of hereditary deafness) of the continuation of deafness, since manualism allowed deaf people to remain segregated from the hearing. Also, by the end of the nineteenth century, it was the case that there was a racial gulf between oralists and manualists, and only people of color were being taught exclusively through manualist approaches (presumably because educators either believed them incapable of learning through oralist methods or because they did not see the reason for nonwhites to have the skills they associated with spoken language).

Oralism also became a platform for the development of the teaching of deaf people as a form of "women's work" in the United States: Because of the American Civil War, men, who were the principal teachers up until that time, were called to battle, and women took over some of these roles. After the war, the lowering of the age at which deaf children began to receive instruction and the economic advantages of assigning such work to women helped increase the role of women in this arena.

In recent decades, as deaf people became Deaf (i.e., assumed a cultural identity that involved pride in their status), oralism has become once again a more criticized approach to language education. Such larger educational movements as mainstreaming and inclusion are often seen as vestiges of or returns to the precepts of oralism, in that they do not create a space for Deaf people to enact their own linguistic culture and that they privilege speech over sign. Similarly, more recent debates over cochlear implant surgeries, particularly for children during their most sensitive years for language acquisition, revives the binary division between speech and sign that oralism raised almost two centuries ago.

—Bruce Henderson

See also Alexander Graham Bell; Deaf, History of the; Deaf Culture; Speech and Language Pathology.

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ORTHOPEDICS

The practice of orthopedics has a long history. From its first inception in France in 1741 to the present, orthopedics is a specialty that has evolved to fit the changing nature of disabling conditions with the rise of technology.

Despite its long history, prior to the nineteenth century very little orthopedic surgery was performed. Generally, orthopedics was confined to the correction of deformities by means of external apparatus, reduction in the case of dislocation, and amputation. With developments in other spheres such as anesthetics, antiseptic techniques, and X-rays, more surgical means were at the disposal of orthopedists. In the nineteenth century, orthopedics began to formally establish itself as a specialty, particularly in the United States. The American Orthopaedic Association was founded in

1887, its German counterpart in 1901, and the British Orthopaedic Association was established in 1918.

Specialist hospitals and clinics such as the Boston Orthopedic Institution and Fracture Clinics in Manchester and Liverpool were established in the late nineteenth and early twentieth centuries. While new techniques were created, such as surgery for open reduction of congenital dislocation of the hip and bone lengthening with direct skeletal traction, it was during World War I that orthopedic surgery came to the fore. Orthopedic surgeons' skill prevented permanent disability from skeletal injuries, halted deaths from gas gangrene through amputations, and mediated highly complex procedures on nerves and tendons. The need was so great that American orthopedists were imported even before the United States entered the war in 1917.

After the war, the orthopedic surgeons' focus concentrated once more on civilians. Hospitals that had housed disabled ex-servicemen were turned into institutions for disabled workmen and children. Surgery was conducted on tubercular joints so prevalent in Britain and other disabling conditions such as clubfoot. In the United States, until the development of vaccines in the late 1950s, orthopedists treated those who had contracted and recovered from paralytic polio with a variety of methods. As previously mentioned, discoveries in other spheres have had an impact on orthopedics; for instance, the development of sulphonamides and penicillin in the late 1930s and 1940s decreased the risk of bone infection in compound fractures.

The late 1950s and 1960s were a time of great change in orthopedics. Although artificial joints had been designed and implanted since the late nineteenth century, it was in the late 1950s that Sir John Charnley, at the Wrightington Hospital in Wigan, England, perfected his two component combination plastic and stainless steel hip replacement. His new procedure changed much of the focus of orthopedics to implanting devices that replaced worn joints affected by osteoarthritis. This innovation was taken up around the world, and other artificial joints were designed. Successful replacement knees were first inserted in 1968 and were followed by the shoulder, elbow, ankle, and hand. In Switzerland, the AO (Arbeitsgemeinschaft fur Osteosynthesefragen; Association for the Study of Internal Fixation) revolutionized fracture care, rejecting plaster casts for surgical intervention with a system of screws and plates. New materials have been developed for joint replacement surgery including titanium, combination alloys, and ceramics. High technology now plays an important role in joint replacement with new techniques such as minimally invasive surgery (MIS), which usually results in a shorter recovery time for the patient. These innovations have created even more specialization in orthopedics, which now includes approximately 12 specific areas of subspecialization including sports medicine and arthroscopy, trauma, tumor, and metabolic disease. Manufacturers play an important role in the marketing and promotion of orthopedic products, a multi-billion-dollar business.

—Julie Anderson

See also Accidents; Arthritis and Cartilage Diseases and Injuries; Disabled Veterans; Dwarfism; Surgery and Disability.

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British Orthopaedic Association, http://www.boa.ac.uk/

ORTHOTICS

See Mobility Aids

OSTEOPOROSIS

Osteoporosis (porous bone), named in the 1820s by Alsatian pathologist Jean Georges Chrétien Fréderic Martin Lobstein "the Younger," is characterized by low bone mass and deteriorated bone tissue, causing fragile bones and increased risk of fracturing. Bone compression or fracturing most frequently affects the hip, spine, or wrist and causes loss of height and/or kyphosis (dowager's hump). Persons with severe osteoporosis may experience spontaneous and/or traumatic bone breakage; pain; mobility limitations; physical, emotional, or psychological disabilities; or death.

In 1940, Fuller Albright, a Boston endocrinologist, discovered a link between estrogen loss at menopause and "thin bone." Albright initiated estrogen treatments to osteoporotic women. Its use became widespread only in the mid-1960s when Robert A. Wilson, a Brooklyn gynecologist, promoted estrogen therapy, newly available in pills, as a cure for all menopausal deficits in popular and medical media. Researchers in the late 1970s associated estrogen treatment with reproductive system cancers, and its use declined. Osteoporosis remained obscure until 1984, when a Consensus Conference through the U.S. National Institutes of Health declared estrogen and calcium standard treatments.

Historically, osteoporosis was mostly associated with older women, but others at risk include aging men, persons with eating disorders, pregnant teenagers, and female athletes. Men generally have higher bone mass, lose bone density at a slower pace, and develop bone loss at older ages. Controversy remains about whether osteoporosis is a disease or a natural concomitant of aging.

Genetic, behavioral, and environmental factors and their interactions contribute to osteoporosis. All racial groups are susceptible, although incidence varies. Peak bone mass (PBM), the amount of bone tissue attained by adulthood, is a major determinant of fracture risk. Smoking, excess alcohol, excess caffeine, lack of or excess exercise, and lack of sunshine deplete bone tissue. Secondary osteoporosis may result from other illnesses (e.g., end-stage kidney disease), medical treatments and practices (e.g., removal of ovaries, institutionalization), specific drugs (e.g., long-term steroid use), and other hormonal and nutritional deficiencies (e.g., vitamin D, calcium, parathyroid hormone, calcitonin, and fluoride).

Bone densitometry proliferated during the late 1980s; campaigns to promote screening to measure bone mineral density (BMD) of older women further increased recognition of this "silent" epidemic and the estimates of persons affected. Definitions of osteoporosis and osteopenia (borderline low bone density) based on BMD criteria established by the World Health Organization resulted in the diagnosis of millions of asymptomatic patients. More than half of all women and about one-third of all men over age 50 are predicted to experience osteoporotic fractures during their lives. Incidence and cost estimates are widely employed by commercial, medical, and advocacy interests to influence governments and consumers.

Since the late 1990s, nonestrogenic drugs (e.g., bisphosphonates) have been widely prescribed to prevent and repair bone loss. In 2003, in the United States, the Women's Health Initiative clinical trials indicated increased risk of cancer and heart disease from use of estrogen with progestin. Postmenopausal women with osteoporosis are now advised to avoid long-term hormone replacement therapy.

Despite widespread bone densitometry testing in North America, many cases go undiagnosed, even when serious bone fracturing has occurred. Science cannot yet accurately predict which individuals with low BMD will develop fractures or become disabled, but geneticists and molecular biologists are pursuing subcellular studies. Programs to prevent falls play an important role in reducing incidence of broken hips, which often lead to disability and/or death in seniors.

North American patient activists and medical experts established voluntary agencies (e.g., National Osteoporosis Foundation, Osteoporosis Society of Canada) in the 1980s, which lobby governments, educate the general public, and provide services for persons with osteoporosis.

—Elaine Berman

See also Aging; Aging, International; Hip Fracture.

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OUTCOME MEASURES

Functional disability and quality of life are key outcomes that influence patients' demand for care, as well as their compliance and satisfaction with treatment. Over the past few decades, there has been a shift from traditional physician-focused assessment, with its dependence on physiological and radiological measurement, toward methods based on the belief that patients can provide accurate and meaningful assessments of their own health. Such measurements have found a natural home in the field of disability, where clinician-based assessments can give only a limited picture of the impact of illness on individuals. Indeed, clinical assessments have tended to overestimate the adverse effects of disability on self-reported quality of life. For example, in one study over 80 percent of patients with spinal cord injury anticipated average, or better, quality of life, while less than one-fifth of those treating them rated their potential health state so positively. Such a mismatch in perceptions of the impact of disability means that appropriate outcome measures must be developed that assess what is important to patients in terms of their own health-related quality of life.

Results from studies of patients with disabilities have often shown that they view their health in a positive way and that their self-reported quality of life is often very comparable to similarly aged people not reporting any disabilities. Manifestly, however, the impact of disability can also have dramatic negative consequences for patients, and appropriate outcome measures can be useful to assess patients' reactions to treatment and therapy. For example, the quality of life of stroke patients has been found to decrease over time, despite clinical assessments remaining stable. In trials of interventions, patient-based outcome measures can be used to assess their efficacy, and they provide an important addition to clinical assessments.

The increasing use of subjective health indicators has been reflected in the number of research papers reporting aspects of subjective health status or *health-related quality of life*. This reflects a growing interest on the part of physicians and health researchers in using the patient's viewpoint in formulating treatment plans and monitoring the quality of medical care outcomes. As more of the population experience the limitations of aging, chronic illness, and disability, due to increased lifespan, a need has developed for a more humanistic form of health care that incorporates a systematic assessment of the patient's perceptions.

Interest in subjective patient-based assessment accords with the World Health Organization's (WHO) now classic characterization of health, which incorporates autonomy and physical, mental, and social well-being and not merely the absence of disease. Health-related quality of life is a concept that attempts to encompass the spirit of the WHO definition of health by incorporating both personal health status and social well-being in assessing the health of individuals and populations. Although there is no agreed-on single definition of health-related quality of life, researchers for the most part concur on the components that should be included, such as general health, physical functioning, emotional state, subjective well-being, and social support.

Indicators of health-related quality of life typically incorporate patient views gained from interviews and/or focus groups. It is essential that, once a set of questions has been identified, the instrument has good psychometric and statistical properties. An instrument that evaluates outcomes of treatment must measure reliably and accurately what it purports to measure. Minimally, outcome measures should manifest the following attributes.

1. *Reliability.* The instrument should produce the same, or very similar results, on two or more administrations to the same respondents, provided, of course, there is good reason to believe that the health status of the patients has not changed. The difficulty with such a method of validating a questionnaire rests on the uncertainty of whether results that may indicate a questionnaire is unreliable are in fact an indication of real change in health status. Due to the potential difficulties in gaining an accurate picture of reliability in this way, many researchers adopt the Cronbach's alpha statistic, to determine internal reliability. Internal reliability refers to the extent to which items on a scale are tapping a single underlying construct, and therefore there is a high level of interitem correlation. Assuming that such high levels of interitem

correlation are not a product of chance, it is commonplace to assume that a high alpha statistic indicates the questionnaire is tapping an underlying construct and hence is reliable. However, due to many potential sources of variability, high internal reliability reported in only a single study should be viewed cautiously.

2. *Face validity.* Face validity refers to whether items on a questionnaire appear to make sense and can be easily understood. An instrument that contains ambiguities or illogical response categories is very unlikely to either be reliable over time or manifest high levels of internal consistency. In studies that are undertaken cross-culturally, it is essential that translations of an instrument have been validated and that translations of items should retain the original meaning.

3. *Content validity.* This refers to the choice of appropriate items in a questionnaire. Items included in a measure should reflect the underlying domain being measured.

4. *Criterion validity.* This is the ability of an instrument to correspond with other measures. However, finding a "gold standard" instrument is rare, and only really possible in instances where a shorter-form measure is being created from an established longer instrument. For example, results of the eight-item SF-8 have been compared with results from the 36-item SF-36 Health Survey.

5. *Construct validity.* This refers to the ability of an instrument to reflect previously hypothesized patterns of data. For example, physical health typically deteriorates with age, and any questionnaire designed to measure this should reflect this pattern in its results.

6. *Sensitivity to change.* Measures must be responsive, that is, sensitive to meaningful change. When evaluating health care interventions, responsiveness is a crucial aspect of a measures utility. It is possible, for example, to have measures that are reproducible and valid but not responsive. Gordon Guyatt and colleagues (Guyatt et al. 1989) give the example of the Sickness Impact Profile (SIP) in a controlled trial of different strategies for managing back pain. They found that while many parts of the SIP were useful in evaluating change, others were not. For example, they found that no respondent, either at baseline or at follow-up, endorsed the item "I do not feed myself at all, and must be fed," which produced results that are clearly reproducible but not informative in the context of that particular trial. Such unresponsive items cannot prove useful in detecting changes over time as a function of treatment. Consequently, when selecting a measure for inclusion in an evaluative study, researchers should select instruments that contain appropriate items for the patient group and that are likely to detect changes.

7. *Interpretability.* It is essential for measures to provide meaningful data. For example, in terms of change scores a number of instruments provide guidelines for interpreting changes that are important to patients, rather than simply being statistically significant. Minimally important differences (MIDs) are those changes that patients themselves have judged as being small but meaningful. These MIDs can be useful both for interpreting results of longitudinal data, and calculating sample sizes for trials.

The most commonly used measures are generic instruments that have been designed for use in any illness group, population, or sample, for example, the SF-36 and SIP. Such measures have gained widespread use, and consequently substantial amounts of data exist on reliability, validity, and sensitivity to change. Furthermore, data from general populations exist, enabling comparison of results with normative samples. Any given disease-specific measure is, by its very nature, less widely used but more likely to reflect concerns typical of the specific illness group for which it was designed.

—Crispin Jenkinson

See also Functional Assessment; Quality of Life.

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PAIN

Chronic pain may well be the most common cause of recurrent and permanent disability in the developed world today. According to a 1999 Gallup survey, 89% of Americans suffer from pain at least once a month, and 43 percent—some 83 million—report that pain frequently affects their participation in some activities. More than 26 million (15 percent) describe their recurrent monthly pain as severe. Pain accounts for an estimated 20 percent of health care visits and 10 percent of prescription drug sales. Yet less than 1 percent of the U.S. National Institutes of Health's budget supports research into the mechanisms and management of pain.

Pain is classified as chronic rather than acute when it persists beyond the normal healing period for any illness or injury and appears likely to recur or continue indefinitely. The insurance industry defines three months as the minimum for chronicity, but a period as short as two or three weeks can establish a chronic condition in many instances. Several organic diagnoses such as arthritis, cancer, diabetes, and herpes are associated with severe chronic pain.

Many Americans suffer, however, from disorders defined by the pain alone. These include migraine and other forms of chronic headache; low back pain; abdominal and pelvic pain; temporomandibular joint disorder; trigeminal neuralgia, an intense stabbing pain throughout the facial area, triggered by the fifth cranial nerve; fibromyalgia, defined as widespread musculoskeletal pain, often accompanied by fatigue; phantom limb pain; carpal tunnel syndrome (repetitive strain); and the causalgiform disorders (in current terminology, chronic regional pain syndrome [CRPS]). The latter are characterized by persistent burning pain, usually located in an extremity, which may be referred elsewhere in the body; allodynia, or painful sensation in response to an innocuous stimulus (such as light touch); and hyperesthesia, or severely painful sensation in response to a mildly painful stimulus (pressure or pinprick).

Regardless of its specific location and nature, chronic pain often takes over the sufferer's life. The individual finds it difficult and tiring to work, exercise, and participate in normal activities; withdraws from other people; and becomes both anxious in expectation of severe pain and depressed by its unrelenting persistence. Although many treatments are available, there is no one therapy that works in all cases, and many patients become angry and frustrated at what they perceive as the indifference or ignorance of the medical profession.

HISTORY

Nineteenth-century British, German, and French physicians were the first to recognize the problem of chronic "pains without lesion" and attributed them to a functional disorder or persistent irritation of the nervous system. Johannes Müller's concept of *Gemeingefühl*, or "cenesthesis," an individual's ability to correctly perceive internal sensations, was another of the creative etiologies proposed. S. Weir Mitchell, the American neurologist who observed many Civil War soldiers afflicted with causalgia, phantom limb pain, and other painful conditions long after their original wounds had healed, wrote movingly of their suffering. He described classic causalgia (the burning pain following a nerve injury) as “the most terrible of all the tortures. . . . Under such torments[,] . . . the most amiable grow irritable, the soldier becomes a coward, and the strongest man is scarcely less nervous than the most hysterical girl.” Despite the odd and often hostile behavior of his patients, Mitchell was convinced of the reality of their physical suffering.

However, by 1900, specific diagnostic tests and signs had redefined the practice of neurology, leaving little room for unexplainable chronic pains without other physiological symptoms. At the same time, practitioners of psychiatry and the new field of psychoanalysis found that “hysterical” pains offered potential insights into mental and emotional disease. The contributions of neurophysiologists such as Charles Sherrington supported the concept of *specificity:* that “real” pain was a direct, one-to-one response to a specific harmful or noxious stimulus (although Sherrington himself insisted that the central nervous system integrated neural response from the periphery). The corollary of specificity theory was that individuals who reported pain in the absence of an evident cause were delusional, neurotically obsessed, or malingering (often the conclusion of military surgeons or those treating workmen’s compensation cases): Their pain was “in the brain.” As John Homans wrote of causalgia-like disorders in *The New England Journal of Medicine* in 1940, “That there is something basically at fault about the nervous system of certain of the individuals affected, is probable. Some . . . have grudges against the world, or are perhaps stupid, or even criminal.”

This disparaging attitude toward patients with chronic pain persisted well into mid-century. A few researchers and clinicians—the surgeons Rene Leriche and William Livingston, the neurologists Alfred Goldscheider and Rafael Lorentè de No, and the anesthesiologist Emery Rovenstine—proposed alternatives to specificity theory or attempted new treatments before 1940. In the 1890s, Goldscheider endorsed Sherrington’s insistence that the central nervous system integrated inputs from the periphery and proposed that pain was a result of the brain’s recognition of spatial and temporal *patterns* of sensation. Leriche, based on his work with injured men during World War I, suggested that a nerve injury that damaged the myelin sheath surrounding the sympathetic nerves might create some kind of artificial synapse between these and contiguous sensory nerves, leading to sensations of pain in response to normal stimuli and internal physiological activity. Livingston, who worked with patients with industrial injuries in the 1930s, diagrammed a feedback loop within the nervous system, which he termed a “vicious circle,” theorizing that continuing severe pain over a period of time led to functional and organic changes in the nervous system, producing a chronic pain state.

These ingenious ideas were largely ignored until World War II, when, for the first time in history, organized teams of clinicians had the opportunity to observe and treat large numbers of men with similar injuries. Henry K. Beecher, a Harvard anesthesiologist serving in Europe, was startled to realize that soldiers with serious wounds seemed to be in much less pain than surgical patients recovering consciousness in the recovery room. The GIs were slow to request morphine and often appeared quite relieved by a cigarette. Beecher theorized that, whereas pain for the surgical patient meant disruption of normal life and fears of serious illness, the soldier’s painful wound meant his release from the battlefield to a hospital and increased chance of survival. The human experience of pain, he suggested, had to result from the fusion of a physical sensation and a cognitive and emotional “reaction component.” The assumptions of specificity theory, based on laboratory experiments in which the reaction component was relatively neutral, could not be applied therefore to the understanding of clinical pain.

At Madigan Army Hospital in Washington state, the young anesthesiologist John Bonica participated in regular lunchtime discussions with colleagues—a neurologist, an orthopedist, and a psychiatrist—about the difficult pain disorders they encountered. He left army service with the conviction that interdisciplinary collaboration in both clinical and basic research would be essential to improving medical understanding of pain. Both Bonica and Livingston, who called the war years dealing with nerve injuries at Oakland Naval Hospital "the most exciting and productive of my life," founded multidisciplinary pain clinics at their home institutions in 1947. In 1953, Bonica brought together much of the current state of knowledge in his magnum opus *The Management of Pain.* One of the important points made in this book, paralleling Beecher's work, was that all clinical pain included both physiological and psychological components.

The Dutch neurosurgeon Willem Noordenbos extended the theory of pain as an integration of multiple inputs into the nervous system in his short but classic 1959 book, *Pain.* His model of a multisynaptic afferent system was "an extremely complicated nerve net in which, within limits, everything synapses more or less with everything else." His ideas appealed to the Canadian psychologist Ronald Melzack (who had been Livingston's fellow) and the British physiologist Patrick Wall, two self-described iconoclasts who met at MIT in the late 1950s. They drew together Goldscheider's, Livingston's, and Noordenbos's ideas with the available research evidence, rethought the problem, and proposed the gate control model of pain in their now iconic paper, "Pain Mechanisms," in 1965. Although the theory itself proved to be incorrect, the implication that laboratory and clinical observations together could demonstrate the physiological basis of a complex neural integration mechanism for pain perception inspired and challenged a young generation of researchers.

THE PAIN FIELD

Drawing on the upsurge of interest in pain generated by Wall and Melzack, John Bonica organized a meeting of 300 researchers and clinicians at an isolated convent in Issaquah, Washington. Under his leadership, this conference gave birth to an interdisciplinary organization, the International Association for the Study of Pain (IASP), and a new journal edited by Wall, *Pain*, marking the emergence of pain science as a professional field. National chapters of the association have been organized throughout Europe and Latin America; in Asia, Australia, and New Zealand; and in several African countries. The American Pain Society (APS) was founded in 1977. In 2003, the IASP had more than 6,700 members, representing more than 100 countries and 60 disciplinary fields. The next 30 years saw much new research on the problem of pain, stimulated by the availability of a dedicated research journal and by regular professional meetings and opportunities for interdisciplinary discussion between clinicians, neurophysiologists, biochemists, pharmacologists, molecular biologists, and psychologists.

Two major findings have emerged from this research. First, severe pain from an injury or other stimulus, if continued over some period, can alter the neurochemistry of the central nervous system, creating a sensitization of the central nervous system and significant neuronal changes that will endure after the initial stimulus is removed and that is perceived by the individual as chronic pain. Gary Bennett and Xie Yu-Kuan demonstrated this phenomenon dramatically at the National Institutes of Health (NIH) in 1989, using a rat with a constricted sciatic nerve. In 2004, Min Zhou and a team at Washington University in St. Louis identified two enzymes in the forebrain, adenylyl cyclase 1 and 8, that play an important role in central sensitization.

The second finding is that pain perception and response differ with gender and ethnicity and with learning and experience. Women appear to suffer pain more often and with greater emotional stress than do men, but some evidence shows that they may cope with severe pain more effectively. African Americans show a higher vulnerability to chronic pain and a higher level of disability than do white patients. These observations are borne out by neurochemical research; for example, Jon Levine and Christine Miaskowski at UCSF found in the early 1990s that males and females have differential analgesic responses to different types of opioid drugs.

In another set of experiments at NIH in the late 1990s, M. A. Ruda and her colleagues showed that animals that experience pain when very young show neuronal changes at the molecular level and appear more sensitive and hyperesthetic as adults. The clear inference of these studies is that no two individuals experience pain the same way. The clinical observations of Mitchell, Beecher, Livingston, and others are thus borne out by research evidence. Pain is in the brain after all, but in a physiological as well as psychological sense.

TREATMENT

Effective treatment of many chronic pain disorders remains problematic. There are more options than in the early 1900s, when opiate drugs or disabling surgery were the only alternatives, but no one method seems to work in all cases. Morphine and its relatives, including oxycodone, hydropmorphone, meperidine, propoxyphene, and codeine, remain the most consistently effective analgesics known. Since the introduction of the World Health Organization (WHO) analgesic ladder in 1986, an international group of pain specialists and policy advocates, led by Jan Stjernswärd, Mark Swerdlow, Robert Twycross, Kathleen Foley, Vittorio Ventafridda, David Joranson, and June Dahl, has campaigned for the removal of legal and attitudinal barriers to opiate use in severe chronic, particularly cancer, pain. But many patients and clinicians associate these drugs with an unacceptable loss of mental clarity and control. Drug regulatory authorities in most countries fear diversion to the criminal market and restrict and discourage the prescription of opiates. In the late 1990s, the diversion and illegal recreational use of Oxycontin, a slow-release formulation specifically designed for use in chronic pain, prompted a new outburst of public and regulatory concern in the United States.

Surgeons have progressively refined sympathectomies and other techniques—ligature, resectioning, or crushing of the nerve fibers—for blocking the transmission of pain signals to the spinal cord and brain since the 1870s, but in the 1920s, a few pioneers, including Leriche and Livingston, advocated the use of serial anesthetic blocks as a more humane therapy for intractable chronic pain. Livingston found that multiple injections of procaine, sometimes as many as eight over a period of two years or more, often ended the "vicious circle" and resulted in permanent remission. These methods were refined by Rovenstine, Bonica, Swerdlow, and other anesthesiologists and became the staple practice of pain clinics in the United States and the United Kingdom in the 1950s.

The search for pharmaceutical alternatives to the opiates has continued. Although many morphine derivatives were isolated by the 1960s, none had been found that combine analgesic efficacy with a complete lack of addictive potential. Clinical observations in patients with depression meanwhile had demonstrated that the tricyclic antidepressants, such as amitriptyline and imipramine, could relieve headache, postherpetic neuralgia, and other types of persistent pain. More recent research has suggested a number of new pharmacological strategies to develop drugs that will block or inhibit specific steps in sensory, inflammatory, or sensitization neural pathways: These include COX-2 inhibitors and N-methyl-D-aspartate (NMDA) antagonists.

Psychologists have developed alternatives to drugs for the treatment of chronic pain, based on learning and behavioral theory. Soon after the publication of the gate control model, Richard Sternbach argued that an individual's perception of and response to pain were learned from prior experience—and, by implication, could be relearned. In the early 1970s, the psychologist Wilbert Fordyce and his colleagues at the University of Washington developed a therapeutic program based on operant conditioning, which helped chronic pain sufferers to work their way back to normal functioning by gradually increasing levels of activity. This method has often proved successful but is expensive and requires significant time investment. Cognitive-behavioral therapy, a related modality that emphasizes the teaching of self-management skills, emphasizes the patient's own agency. The individual who has learned to cope effectively with his or her pain, using relaxation, distraction, and controlled exercise, is able to function better, may suffer less from anxiety and depression, finds the pain less intensive and less disabling, and discovers ways to lead a productive life. Yet some observers have criticized these learning-model programs for shifting so much of the therapeutic responsibility to the patient.

PAIN IN THE TWENTY-FIRST CENTURY

As the twenty-first century begins, pain has increasing salience as a scientific and health problem. In the late 1990s, the American Pain Society (APS) popularized the use of "Pain as the Fifth Vital Sign," and a campaign led by June Dahl prompted the Joint Commission for the Accreditation of Health Care Organizations (JCAHCO) to include pain assessment as a required standard. The U.S. Congress declared 2000–2010 the "Decade of Pain Control and Research" as a result of strong advocacy by pain professional groups, such as the APS and American Academy of Pain Medicine, and patient support groups, such as the American Chronic Pain Association. The Pain Care Policy Act, reintroduced in 2005 as H. R. 1020, would establish a new National Center for Pain and Palliative Care Research at the National Institutes of Health and a national awareness campaign within the Department of Health and Human Services.

Yet most medical students still learn little about pain; many medical specialists, in fields such as cardiology, oncology, gynecology, and gastroenterology, still pay relatively little attention to their patients' pain, and despite its high prevalence and debilitating effects, there is no definitive and completely effective treatment for chronic pain.

—Marcia L. Meldrum

See also Complementary and Alternative Medicine; End-of-Life Care; Health Care and Disability; Palliative Care.

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PALLIATIVE CARE

The term *palliative care* describes an orientation to the care of persons with life-limiting illness that encompasses physical, social, psychological, and spiritual dimensions. It is closely associated with the development of hospice services and is a model of care that has operated beyond the narrow confines of the formal health care system to involve local communities, charitable and philanthropic giving, and the efforts of volunteers. Palliative care services have considerable potential to serve the needs of people with disabilities with advanced illness, although so far and in most cases, they have tended to focus on the care of those with malignant conditions, to the exclusion of those with other needs.

The World Health Organization (WHO) first defined the term *palliative care* in 1989. The most recent definition of palliative care to appear from the WHO, published in 2002, states that palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life and may also positively influence the course of illness; and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

There is a global need for improved end-of-life care. Around the world, more than 1 million people die each week. It is estimated that 60 percent of these could benefit from some form of palliative care. Yet at the moment, only a tiny minority of dying people ever receive the support of hospice and palliative care services. Palliative care is hugely underdeveloped in most resource-poor countries, and it is still significantly constrained in many countries with otherwise "advanced" health care systems. There is a significant shortage of political leaders and "product champions" with an interest in palliative care and a dearth of national and international policies to promote its development. The creation of a trained multidisciplinary workforce to deliver clinical care, educational programs to support them, and an evidence base to highlight both unmet need and the efficacy of existing provision are all additional challenges. It is estimated that hospice or palliative care services now exist or are under development on every continent of the world—in around 100 countries. The total number of hospice or palliative care initiatives is in excess of 8,000, and these include inpatient units, hospital-based services, community-based teams, day care centers, and other modes of delivery.

The first attempt to develop a modern approach to hospice and palliative care was led by Dr. Cicely Saunders at St. Christopher's Hospice in South London, which opened in 1967. Based initially around an inpatient unit, soon followed by a home care service, it also delivered education programs and undertook research into the care of terminally ill people. From the outset, ideas developed there were applied differently in other settings. Within a decade, it was accepted that the principles of hospice care could be practiced in many locations: in acute and oncologic hospitals, in home care and day care services, and through ambulatory, outpatient, and "drop-in" services. Such approaches brought the new thinking about dying into the very heartlands of acute medicine and into domiciliary and long-term care settings.

Professional recognition of this emerging area of expertise was necessary if the work was to spread and the influence of hospice philosophy was to go beyond the confines of the voluntary hospice movement. Some claimed that specialization, the integration of palliative care into the mainstream health system, wider "coverage" of services, and the development of an "evidence-based" model of practice and organization were crucial to long-term viability. Meanwhile, others mourned the loss of early ideals and regretted an emphasis on physical symptoms at the expense of psychosocial and spiritual concerns. During the 1990s, there were claims that forces of medicalization and routinization were at work and even that the putative "holism" of palliative care philosophy masked a new, more subtle form of surveillance of the dying and bereaved in modern society.

At the same time, two forces for expansion were also clearly visible. First was the impetus to move palliative care further "upstream" in the disease progression and to make it available to those at earlier stages of a life-threatening illness, thereby seeking integration with curative and rehabilitation therapies and shifting the focus beyond terminal care and the final stages of life. Second, there was a growing interest in extending the benefits of palliative care to those with diseases other than cancer, to make "palliative care for all" a reality. So far, there has been greater success in the first of these; palliative care has found its way into the curriculum of health care professionals working in many settings, its services are delivered alongside and sometimes closely integrated with mainstream provision, and the palliative care "approach" is being fostered in many settings. Too often, however, access to specialist palliative care is confined to those with a cancer diagnosis.

Health and social care staff working in palliative care require training in the particular needs of people with disabilities in relation to advance health care planning, options for hospice and palliative care, and special concerns in consenting to care. People with disabilities, as well as their family members, companions, and surrogates (where applicable), require information and guidance on their rights to make informed health care decisions and on the availability of hospice and palliative care to manage pain and distressing symptoms, as well as psychosocial and spiritual distress in the context of advanced illness.

The lack of engagement between disability studies and studies in palliative care is striking. Yet both fields reveal some of the properties of social movements. In their early decades, modern hospice and palliative care services in the West were supported by wider forces: consumerism and increasing calls for autonomy among the users of health and social care; demographic trends, which created substantial numbers of individuals able to volunteer their labor in local hospices; and greater affluence, which led to an increase in charitable giving. This movement may well have contributed to a new openness about death and bereavement that was in evidence in the late twentieth century (in Britain, for example, the first person ever to be seen to die on television was in the care of a hospice). Inspired by charismatic leadership, the hospice movement condemned the neglect of the dying in society, called for high-quality pain and symptom management for all who needed it, sought to reconstruct death as a natural phenomenon rather than a clinical failure, and marshaled practical and moral arguments to oppose those in favor of euthanasia.

Hospice care and palliative care have a shared and brief history. The evolution of one into the other marks a transition that, if successful, could ensure that the benefits of a model of care previously available to just a few people at the end of life will in time be extended to all who need it, regardless of diagnosis, stage of disease, social situation, or means.

—David Clark and
Carol Thomas

See also Death; End-of-Life Care; Pain.

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PANIC DISORDER

Panic disorder (PD), a commonly observed mental disorder affecting up to 3 percent of the general population, is one of the most disabling conditions among the so-called common mental disorders. Approximately 60 percent of people suffering from PD show a severe or moderate level of disability and reduced quality of life, with relevant difficulties in important areas such as work, social relationships, marital life, and leisure. Disability related to PD may be due to several factors. First, the nature of symptoms themselves can result in overwhelming anxiety that impairs functioning, as can the fear of recurrent attacks and the presence of "anticipatory anxiety" (i.e., the anxiety related to the expectation of a new attack). Second, the frequency of "comorbidity" with other disabling anxiety or depressive disorders, particularly agoraphobia, complicates up to two-thirds of PD cases. Agoraphobia is characterized by anxiety about being in places or situations from which escape might be difficult or embarrassing (i.e., open or restricted spaces, crowded places, travelling in a bus, etc.) and by avoidance of such situations, with a consequent, often marked, restriction in lifestyle of people affected. Major depression is a frequent consequence of untreated panic disorder, and this adds to the symptom picture and adds considerable social-occupational disability. Finally, the chronic or recurrent nature of the disorder (up to 70–80 percent of cases) often leads to suicide attempts and to reduced self-esteem, which compounds the disability.

—Bernardo Carpiniello

See also Mental Illness.

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PARALYMPICS

The Paralympic Games or the Paralympics are the international multisport competitions for athletes with disabilities, which take place every two years, alternating between summer and winter sports. Roughly 4,000 athletes from around 140 countries compete in approximately 20 sports in the summer Paralympics, while roughly 500 athletes from around 40 countries compete in approximately four sports in the winter Paralympics. The *Paralympic movement* is a term that refers to the collective parties who contribute to the worldwide development of sports for persons with a disability, from developmental to the elite sport level. Historically, the idea stems from the use of sports for rehabilitation, but due to the increased participation and recognition of sports for persons with disabilities, the Paralympics and the Paralympic movement now play a vital role in facilitating sporting opportunities for all persons with disabilities and contribute to changing societal attitudes and perceptions of individuals with disabilities. In the past 50 years, this movement has seen a significant increase, and today, thousands of athletes participate in more than 300 international competitions every year.

HISTORY OF THE PARALYMPIC MOVEMENT

In 1944, Sir Ludwig Guttmann promoted sport as a form of recreation and rehabilitation therapy for World War II veterans with spinal cord injuries in Stoke Mandeville, England. In 1948, he organized a sports competition for athletes with disabilities, and with the gradual inclusion of other countries into these competitions, the Paralympic movement began. Olympic-style games for athletes with disabilities were organized for the first time in Rome in 1960. A number of different disability groups were merged in competition in 1976, and in the same year, the first Paralympic Winter Games took place. The number of participating athletes has consistently increased at every event since.

The Paralympic Games are multidisability, multisport competitions and have become the second largest sporting event in the world, only after the Olympic Games. The Paralympic Games have always been held in the same year as the Olympic Games, and since the Seoul Games (summer, 1988) and the Albertville Winter Games (1992), they have also taken place at the same venues. In 2001, an agreement was signed between International Olympic Committee and the IPC under which the city chosen to host the Olympic Games will also host the Paralympics. The Italian city of Turin will host the 2006 Olympic and Paralympic Winter Games, and in the summer of 2008, both the Olympics and Paralympics will be held in Beijing.

The word *Paralympic* was originally a pun combining *paraplegic* and *Olympic,* but with the inclusion of other disability groups and the close associations with the Olympic movement, it now relates to *parallel* and *Olympic,* to illustrate how the two movements exist side by side. Most sports at the Paralympic Games are the equivalent to the Olympic sports, but four sports are unique to the Paralympic Games (boccia, goalball, powerlifting, and wheelchair rugby). For current information about the Paralympic sports (summer and winter), please visit the International Paralympic Committee (IPC) website at www.paralympic.org.

To create a level playing field, Paralympic athletes are classified into one of six disability groups. The six disability groups are amputee, cerebral palsy, intellectual disability, visually impaired, spinal injury, and *les autres* (conditions that do not fit into the traditional classification system). In some sports, athletes compete in a class according to functional ability, for example, in Swimming. This means that an athlete who uses a wheelchair for mobility may compete not only against other wheelchair athletes but also against amputees or those with cerebral palsy, if they have the same or similar functional ability. In Athletics, however, classification is disability specific. This means that the disability groups only compete against other athletes with the same disability, for example, amputees against amputees.

As athletic opportunities have expanded and sport for persons with disabilities has matured, so have the number of participants at all levels of competition and the individual accomplishments of athletes with disabilities. Outstanding performances by athletes at Paralympic events are often only slightly behind those of able-bodied athletes and constantly improving.

THE INTERNATIONAL PARALYMPIC COMMITTEE

The IPC is the international representative organization of sport for athletes with disabilities. It supervises and coordinates the Paralympic Games and other multidisability competitions such as the World and Regional Championships as well as developing sporting opportunities around the world for athletes of all levels.

The IPC was founded on September 22, 1989, as an international, nonprofit organization formed and run by around 160 National Paralympic Committees (NPCs) and 5 disability-specific international sports federations (IOSDs). The organization has a democratic constitution and structure, made up of elected representatives. The current president of the IPC is Phil Craven, a former Paralympian and former president of the International Wheelchair Basketball Federation.

The IPC has a number of objectives and functions. Overall, the IPC aims to promote, without discrimination, the practice of sports for people with disabilities and to seek the expansion of sport opportunities for people with disabilities from a developmental to an elite level. To achieve these aims, the organization must coordinate the calendar of international and regional competitions, liaise with the IOC and other international sports bodies, and develop and encourage educational programs, research, and promotional activities. The IPC also currently serves as the International Sports Federation for 13 of the 26 sports. Other sports are either governed by independent sport federations or are part of a disability-specific IOSD program. All of these activities allow the IPC to achieve its mission: "To Enable Paralympic Athletes to Achieve Sporting Excellence and Inspire and Excite the World."

Until 2005, the IPC was composed of the General Assembly (its highest decision-making body); the Executive Committee; the Management Committee; the Headquarters in Bonn, Germany; and the various standing committees and commissions. In 2005, the IPC underwent some structural changes; the Executive Committee was replaced by a Governing Board, and all members of the Governing Board are now directly elected by the General Assembly. There are four advisory councils in addition to several standing committees and commissions. They are governed under a new IPC constitution and a new electoral system. This will lead the 13 IPC sports toward more self-sustainability and eventually independence from the IPC. In addition to the NPCs and IOSDs, the sports and regional bodies will also become full members of the IPC. It is hoped that these changes will allow the IPC to lead the Paralympic movement more effectively and consistently in the future.

—Miriam Wilkens

See also Classification in Paralympic Sport; Physical Activity; Recreation; Sports and Disability; Sydney Paralympics.

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PARALYSIS

Paralysis, the relative absence of intentional movement of a part of or the whole body, has an impact on the social order. As Harold Garfinkel teaches, the entire social world, including the built environment, is based on an upright, bipedal, mobile body, with eyes in the front of the skull. Garfinkel illustrated this to his students by taking them to Rancho los Amigos, a hospital specializing in the rehabilitation of patients with spinal cord injuries. The objective was to learn the changed spatial perspective of the patients.

There are many causative conditions leading to paralysis. Among these conditions are stroke, spinal cord injury, a wide variety of congenital and neuropathic conditions and diseases, brain injury, and a host of other causes.

Paralysis is highly variable. Some people have a contracture in the shoulder and cannot move an arm. Others may suffer arthritis in the hip and cannot use a leg. Still others suffer from systematic neurological disease or injury and are totally dependent on others for movement, eating, toileting, cleaning, communicating, and, in some cases, breathing. For the most part, those who are totally dependent on others are the focus of this entry, which details the social impact of living within a paralyzed body. First, conversation and gaze will be topicalized. Second, lack of mobility will be discussed. Finally, the hope of practical sociology will be elaborated on behalf of paralyzed subjects.

This entry focuses on the interactional difficulties that have devastating economic consequences for totally and dependent paralyzed people. Most dependent paralyzed people lose their jobs and company or institutional medical insurance. The income stream plummets. People have to sell their homes and draw down their financial assets. Then, they move to apartments, often publicly assisted, and change to public medical insurance. These apartments are far from family support and lead to a sense of isolation and acute depression.

Families of dependent paralyzed subjects, who suffer the evaporation of financial resources, are extremely fragile in the United States. There is a frequent expression of resentment and cruelty toward paralyzed subjects. Some family members deal with their feelings by ignoring the subject, even when the subject requests assistance. Some declare ignorance as an excuse for not assisting in the care of paralyzed subjects. The care often falls on the parent or spouse. These caretakers are isolated within their family and suffer from the absence of psychological help and physical help.

CONVERSATION AND GAZE

General Properties of Being Voiceless

Paralysis of the voice and sound-making muscles radically distances the subject from participating in the social world. The paralyzed subject cannot solicit and maintain the attention of others by making sounds. Since the majority of social institutions are accomplished by speech, the paralyzed subject is routinely left out of these collaborative enterprises (e.g., conversations, parties, family, medical care, employment, organizations, friendships, banking and investment, and a host other everyday routines).

Here are some examples. In the daily flow of domestic activity in a house or apartment, the body without a voice quickly gets routinized as an object with no social reference. No one informs the body without a voice what is going on in the other parts of the dwelling and what people are doing. People will pass by, their eyes averted, and not address the voiceless. Questions about activities in the house, communicated by alternative means, are treated as pesky and are not answered. The subject without a voice soon comes to see himself or herself as treated like a piece of furniture.

Not only is the paralyzed subject removed from the ongoing interaction in the house, but the voiceless is subject to actions that are determined by others and not sanctioned by the voiceless. The voiceless subject will be moved, told “you are crooked,” and then quickly and sometimes violently moved into the caretaker’s perceived appropriate position. This will happen regardless of whether the voiceless subject is comfortable.

The caretaker(s) will frequently substitute their own judgment for that of the voiceless subject. The subject will be told he or she is fine and in no need of action, when in fact the subject is in immediate need of action. The words “you are fine” are often uttered in the face of an apparent request for action. Substitution of judgment can take many permutations, with people speaking and acting for the paralyzed subject without permission. The result is a decrease in the subject's autonomy.

If the subject demonstrates any displeasure with the failure to take proper action, such as getting red in the face or shaking the few working muscles, the caretaker will often infantilize the protest. The subject will be told, "You are not being a good boy." Caretakers will collaborate in characterizing the subject as "not a good boy" in endless rounds of conversation.

Adverse characterizations of the subject or patient are frequent in caretaking but routinely overlooked. Caretakers' utterances of phrases such as "you would be better off dead" or "death will be a gift" are not infrequent. Subjects' wives, husbands, children, and extended family members are not immune from getting involved with the talk of death, uttering phrases such as "why don't you just die!"

This kind of talk and reflexive attitude can infrequently lead to violence against and even the death of the paralyzed subject. Violence is usually written off as a result of stress, and there is certain stress within the family of the paralyzed subject. However, the focus on stress misses the widespread ambiance of the rhetoric of resentment, burdenship, and anger. Beyond the family and friends, this rhetoric of denunciation and violence seems widespread in general American culture.

Conversation

Sometimes, conversations are essential and cannot be avoided. If the paralyzed subject is lucky enough to be employed, most often in his or her preparalyzed position, the work product is produced by communication. Those who use the strength of their bodies are disqualified from employment as soon as they become paralyzed. Truck drivers, construction workers, repairmen, waiters, professional athletes, restaurant cooks, and others are out of luck if they become paralyzed. Only knowledge workers can continue to be employed after paralysis.

Knowledge workers, or those who are not employed in positions of physical labor, produce and distribute knowledge. Such work requires attending meetings and engaging in conversational interaction with others. The work is often computer based. Subjects with spinal cord injuries who can talk are able to do most of this work. Spinal cord injuries, especially at a lower level in the spine, do not affect the ability to carry on conversations. Those who suffer from neurological diseases or conditions that more generally affect movement in the body, including speech production, face a predicament in the information business. They cannot enter into conversations, produce utterances, or verbally acknowledge what they are told.

Conversation is a series of sequentially arrayed turns at talk. The turns are temporally tight, meaning there is no gap between them. The lack of a gap is a mutually read indication that each speaker is referring to the last turn or a formulated previous turn. The pace of natural conversation presents a huge problem for those who rely on computer-assisted speech and the few who use lipreading as their form of communication. Most people see computer-assisted, synthesized speech as a panacea for people with damaged speaking abilities. First, the person cannot type fast enough to keep up with the pace of conversational turn taking, with the exception of "yes" or "no." Any elaborate response cannot be formulated quickly enough to be designed to the previous turn at talk.

Some suggest that responses to verbal exchanges can be designed in advance. But stock answers do not respond to the particular verbal formulation of a questioner. Stock replies do not have built-in recipient design: The formulator of a question or a turn in conversation can easily anticipate the next turn at speaking, an answer built specifically to the previous turn at speaking, or to the inquiry. Preformulated turns at talk cannot adapt to the particular words used and to the specific setting of a verbal exchange. These predesigned turns at talk feel like heavy weights, encumbering natural conversation.

The ability to type is variously affected by paralysis. Some have full use of their arms and hands and can type as quickly as they are able. Such individuals have fewer problems keeping up with the pace and reference of a conversation. Others, including those who have neurological diseases or brain injuries, have more impaired arm and hand-finger movement.

Typing may be limited to a single finger input, to a scanning of words or letters. An orally held stick that is pushed onto letters on a keyboard may be used as a typing device. Head movement can be used to input letters; blinking of the eyelids can be used to input letters. There is a growing amount of technology that comes to the communicative aid of paralyzed people.

Still, despite these advances in technology, alternative computer input devices are painstakingly slow and cannot keep up with the pace of natural conversation. These devices, as cleverly engineered as they are, are frustrating to use because the conversational pace moves so quickly: By the time the computer speaks, the interlocutors have lost the specific turn at talk, and the reference of the comment is tapped out by an alternative device.

Finally, there are those paralytics who rely on lipreading to communicate. Lipreading is not fast but offers the maintenance of mutual gaze between conversationalists and the expression of facial gestures, intensifying the communication and slowing down the transition to the next turn at talk. Lipreading requires a lip-signer and a lip-reader, a person who assembles words or letters into sentences and then speaks the sentences on behalf of the lip-signer. This person is usually called a translator and is a side participant in the ongoing conversation. The translator can often connect the paralyzed subject's slowly formulated turn at talk to a previous turn at talk, to which the paralyzed subject designed his or her response. The role of an effective translator is difficult because the translator has to keep track of the ongoing conversation and translate what the paralyzed subject wants to say at the same time.

Translators can be great facilitators of communication, but it is also possible for translators to interfere with what the paralyzed subject intends to say. Once the translator becomes familiar with the subject's thought patterns, phrases, and vocabulary, the translator can and often does answer inquiries posed to the subject without getting input directly from the subject. This often leads to charges leveled by the subject that translators are speaking for him or her, saying things not intended. Control of communication is a continuing issue for paralyzed subjects.

MOBILITY

Paralysis is a big problem in a world constructed on mobility: in houses, offices, educational institutions, markets, planes, trains, motor vehicles, and social relations. As mentioned earlier, the whole constructed world is based on an upright postured and bipedal individual. Paralyzed subjects face a deficit in this world.

The paralyzed subject in a wheelchair, as well as his or her caretakers, becomes cognizant of every surface feature—for example, sand, grass, up and down hill angles, steps, rugs, step-downs and step-ups, uneven sidewalks, ice and snow, oil, curbs, edges of sidewalks, and other terrain. All of these details constitute hazards to safe wheelchair transportation. Nearly every wheelchair occupant has experienced being dumped out of the chair, landing violently on the concrete.

Just as automobile drivers are of varying quality, wheelchair pushers are spread out along the quality continuum. There are some pushers who regularly go over curbs and sidewalks, letting the wheelchair turn over. Others appear to have a spatial perception problem, regularly driving the paralyzed subject's knees and feet into walls and tables.

Often, those who push wheelchairs lack the American middle-class sense of personal responsibility and may repeatedly push the paralyzed subject's knees into solid objects. Wheelchair pushing often becomes an instrument of cultural and class differences.

Because the paralyzed subject cannot move, transfers are another area of danger for the subject and those who perform the transfer. The sites where transfers commonly take place are from wheelchairs to bed, from wheelchairs to the shower and toilet, and from wheelchairs to easy chairs. Paralyzed subjects frequently are dropped, and those facilitating the transfers hurt their backs and joints. Fortunately, there are mechanical lifts that help those who perform transfers to avoid the danger of injury. However, not all people can afford mechanical lifts.

Difficulty in movement contracts the spatial and social world. Previous routines of shopping, going to the bookstore, seeing a movie, going on vacation, and going to parties, barbecues, supermarkets, and meetings are seen as gigantic achievements. As such, they are avoided personally and perceived as an avoidable drain on caretakers. Despite this trend to avoid the above social situations, the paralyzed subject may desire to go to parties, for example. However, invitations are few, and when they come, they have the caveat, "I have steep steps to get into my house." Nevertheless, there are certainly enjoyable occasions at wheelchair-accessible houses and at hotels. But for the most part, there is a perceivable decline in invitations to social events. If the paralyzed subject had been a partygoer before, a feeling that one's social life has collapsed is inevitable.

The cure for feeling isolated and estranged from social life is to open one's home to parties and family social gatherings. Assuming the house has been modified to the requirements of a disabled, paralyzed person, it is a wonderful place to enjoy the fruits of social gatherings. However, remodeling houses for the disabled takes significant amounts of money. Few paralyzed subjects have access to these financial resources.

PRACTICAL SOCIOLOGY

Paralyzed subjects are great practical sociologists. They quietly and repeatedly observe the everyday routines of their households and of the individuals who are their caregivers. They are absorbed by these routines and family activities because they can interfere with getting attention. It takes attention and regard to participate in social settings. Getting this attention and participation is often problematic for paralyzed subjects.

Most paralyzed subjects did not realize before paralysis how much household activity is repeated in the same way, even institutionalized. This includes the routines of going to the toilet, preparing and eating food, reading the daily newspaper, cleaning rooms, going to bed and waking up, and the various tolerable limits in being called by the subject. There are certain times that are off limits, when the subject cannot call a caregiver, such as sleeping, no matter how many hours, and eating, showering, toileting, and free time.

Even gaze patterns are socialized. For most people, gaze is embedded in the project at hand because people have limited peripheral vision. Peripheral vision is developed through circumstantial training, such as hunting or operating a small sailboat. Paralyzed subjects notice how directed gaze is to the task at hand. They experience repeated frustration with signaling and maintaining mutual gaze. They attempt to set a behavioral code, such as the violent shaking of the head, as a solicitation for mutual gaze. However, this code is frequently overridden by emerging circumstances. The code is practically useless.

The situational opportunity for paralyzed subjects to develop into practical sociologists provides some hope and an instrumental sense of life. From observation and memory, they can anticipate problem settings and instruct their primary caregivers to ensure successful participation. They can also communicate what not to do. These "not to do's" have to be communicated neutrally and in a gingerly fashion, avoiding any sense of personal attack.

Although not every paralyzed subject has the patience and sense of a growing base of knowledge, practical sociology is the best way to avoid and repair most of the dire circumstances described here. Practical sociology does not require formal education in sociology, but it assumes a contemplative attitude. However, paralysis is often the harbinger of contemplation.

—Albert B. Robillard

See also Disability Management; Health; Mobility Aids.

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PARENTAL ADVOCACY

An advocate is defined as "one that pleads in another's behalf" and is often compared to a lawyer (*American Heritage Dictionary of the English Language* 1992).

In the case of parental advocacy for children with disabilities or special needs, the advocate is often responsible for pleading on behalf of a child from multiple perspectives. A traditional perspective would assume that the parent is responsible for "pleading on behalf" of the child in tandem with professional therapist(s) (e.g., the assumption being that there is only one perspective to consider, that of the child's success and "cure"). Current approaches through the field of disability studies allow for the incorporation of multiple perspectives on a "cause." By promoting parental advocacy, we can ensure that perspectives on the individual as a child, a family member, and a student or learner, as well as a person with a disability, are respected.

The treatment of children with disabilities has long been an issue requiring parental advocacy but has only recently been legitimized through public policies relevant to education and quality of life. Reading historical documents serves as a reminder of just how recently individuals with disabilities were stigmatized, and significant assumptions were made regarding future capabilities and life trajectories, based on initial status at birth or diagnosis at a young age. Parents were often encouraged to "give up" on their young children with disabilities and to "cut their losses" by institutionalizing children. A growing realization on the part of both parents and educators that such programs often were not in the best interests of the child and family has resulted in legislation that guarantees a "free and appropriate" education "in the least restrictive environment" to children age three and above and encourages states to identify high-risk children and children with disabilities from ages zero to three as well.

The growing fields of disability studies, special education, and child development/developmental psychopathology have all begun the process of researching how one determines the best educational programs for children across a wide range of developmental concerns and disabilities, but there is much work to be done in documenting which programs work for whom and how different programs meet the specific concerns of children and their families in terms of both educational and functional success. Within this cultural context (a relatively new area of study, with limited data on program success), what is the best way for parents to advocate for children and families?

PARENTAL ADVOCACY NEEDS

For any advocate to plead one's case, he or she needs information. This applies to parents of children with special needs in a broad variety of arenas. We compiled the following list of *some* types of information required by parents to be effective advocates for their own child and family:

Disability-specific information (the ability for parents to get such information will vary dramatically based on their child's identified special needs, as well as the age of the child. In some cases, diagnoses of children will not be made until the grade school level, if at all, making appropriate information-seeking difficult if not impossible.)

Knowledge of public policies and the child and family's legal rights, as well as the changes with age (Section 504 or the Rehabilitation Act; the Individuals with Disabilities Education Act [IDEA] and its components, including Individualized Educational Programs [IEPs]; Least Restrictive Environment; the Family Education and Privacy Act [FERPA]; most recently, the No Child Left Behind Act [NCLBA] and its implications for special education students; and potentially many other relevant policies dependent on the child's disability)

School district–specific information (within the legal parameters of the policies mentioned above, what are the offerings of the family's home school district? What is the range of possible placements? How do they change from pre-K to primary to middle and high school? How does the school district deal with behavioral or discipline issues for children with IEPs? How are children made eligible for special services within the district? How are school year programs extended through the summer to provide continuity? How are school or program transitions handled within the district? What types of assistive technologies are available?)

Statewide policies (statewide assessment, qualifications for state funding and special education initiatives)

"Out-of-the-box" information—Many types of "suggested" programs for children with special needs

(particular types of massage, yoga, or physical therapy for motor-related disabilities or regulation disorders; particular listening therapies for sensory or auditory processing disorders; etc.), as well as general programs of enrichment (music, fine arts, etc.), may be useful. Parents need information both about offerings of these programs, as well as data on effectiveness/actual effectiveness, and whether any data are available.

"Impact" and networking information—Finally, parents often find it useful to know about supportive services and resources in their own community (e.g., parent support networks) and more nationally (informational websites or chat groups).

As should be obvious from above, there is an overwhelming amount of information required to be an effective parental advocate for a child with special needs. Making the job even harder are some of the emotional issues regarding parental advocacy. Most parents did not expect to be raising a child with special needs, and there is a significant adjustment period required to cope with discovery of the child's needs. When one seeks information or services for a child with special needs, one suddenly enters a world of experts, from varying disciplines, with much jargon. Many parents are afraid of asking the "experts" questions, either because of potential reprisal (perhaps the district or private professionals will not treat my child nicely if I am seen as a "difficult" parent) or due to discomfort with feeling or being perceived as "stupid." Through parent information and support groups established throughout the country and funded by the federal government, parents are learning how to share information about their child with special needs, ask questions of professionals and school personnel, and bring relevant and important information about their child to the table.

Parents play a key role in providing information about the child's abilities, strengths and weaknesses, and interests. They have a unique expertise with regard to their own child and his or her role in their family. Parental insights complement information obtained by the school or the service provider and provide a broader picture of the child's capabilities and needs. Identifying specific ways for parents to be involved in the process is essential for developing a good educational program. The importance of collaboration on the part of parents and professionals, as well as key advocacy roles for both groups, cannot be overemphasized.

WHEN ARE PARENTAL ADVOCACY EFFORTS NEEDED?

Although parenting and advocating for a child is an ongoing process, there are certain distinct times when particularly intense efforts are needed. For example, two such times are (1) the period during which identification or "diagnosis" of a child's special needs occurs and (2) the yearly review or IEP meetings that document a child's educational progress and form plans and goals for the coming educational year. In addition to these two times, there is the ongoing supervision of the child's program, in terms of both meeting the child's educational and experiential goals, as well as the effect of the program on the child and family.

IDENTIFICATION OR DIAGNOSIS

In some cases, identification of special needs occurs at or prior to birth. In other cases, there is a growing realization either on the part of the parent or in an initial preschool or primary school experience that something is just "not right." Many parents discuss having gnawing levels of concern regarding specific behaviors, only to be reassured by pediatricians or other medical specialists. This is in part due to the very broad range of behavior in early development, which makes more subtle variations that may be indicative of special needs harder to detect. Most special educators, parents, and textbooks dealing with this issue recommend that in a "gray" instance, primary care professionals refer parents to early intervention specialists who can conduct evaluations and either reassure parents or provide needed services.

It is also the case that the reverse can happen—professionals at school or medical professionals can notice possible areas of developmental delay or learning differences and raise concerns to parents who have not yet been concerned (anecdotally, many parents of firstborn children with special needs mention this and state they had no "barometer" on which to judge their child's differences).

Once a developmental delay or other learning or social, emotional, or behavioral issue has been identified, parents are likely to be provided with a referral for evaluation. Key components of the parents' job at this point are twofold: (1) coordinating all needed evaluations and (2) providing accurate and complete information as part of the evaluation process. In general, gathering reliable data from children can be difficult; this is true for typically developing children and even more so for children with special needs. Indeed, the more profound the special need, the more potential for misinterpretation of child behavior and communication attempts. This makes the parents' role as "data provider" all the more essential. A good evaluation should include a parent interview both regarding the child's general abilities (birth history, meeting of developmental milestones, etc.) as well as a sense from the parent of just how typical the child's behavior has been during the evaluation and whether the child has demonstrated his or her true abilities, knowledge, and learning styles.

YEARLY REVIEW/IEP MEETINGS

Once a child is "in the system" (e.g., has received a detailed evaluation and been determined eligible for services), an initial IEP meeting will be held to create the child's program for the current or coming school year. In subsequent years, annual reviews and/or IEP meetings will be held to document progress toward educational goals and to form plans for the coming year. Parents must be notified about this meeting and may make plans to attend along with any key individual or individuals they would like to bring.

For most parents, IEP meetings are among the most stressful places they find they must advocate for their child. Anecdotally, many parents cite as particularly stressful the "litany" of data about their child and the technical format, focused primarily on weaknesses rather than strengths, given that the purpose of the meeting is to define need for services. Many parent information centers offer training on preparing for a meeting, particularly on the art of representing your child and family, as well as the importance of asking questions and getting accurate information. In addition, websites and information centers provide detailed checklists for preparation for IEP meetings, as well as reinforcing particular aspects of the family's rights (e.g., timing of information and receipt of reports, ability of parents to attend a meeting but withhold signature until all information is satisfactorily available for the child's program, etc.).

In summary, this entry merely scratches the surface for key factors underlying the necessity of parental advocacy in forming appropriate educational and quality-of-life goals for children with disabilities. Key needs of parents for information and support are discussed, as well as key times when parental advocacy efforts may be most important. An additional critical factor to be considered is the importance of advocacy and collaboration from other sources, such as the school and the community. A critical factor in future efforts should be the collection of evaluative data, both by individual and group methods, to ensure that we are all advocating for the best possible start for our children.

—Roberta L. Paikoff, Marian Casey, and Rhonda Wodlinger-Cohen

See also Advocacy; Childhood, Youth, and Adolescence; Family; Individualized Education Plan (IEP); Parenting; Special Education.

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Parent Advocacy Coalition for Educational Rights, www.pacer.org
Wrightslaw, www.wrightslaw.com

PARENTAL NARRATIVES

Mrs. Merrick explained that the appearance of her son, known as "The Elephant Man," was the result of her being frightened at a Victorian circus; Carry Nation explained that her husband's drinking led to their daughter's many health problems; Michael Bérubé explained that his son's Down syndrome was determined by the random replication of chromosomes at his conception. In all eras, parents of children with disabilities have explained. They have written and spoken their explanations as parental narratives, a genre somewhere between autobiography and biography, between memoir and witness. It is an enduring genre, often sharing shelves with adoption stories, mourning parent stories, and other vernacular efforts to recall the process of loving a child through unusual or difficult circumstances.

Several categories of parent narratives of disability can be identified. Inspirational or sentimental narratives are generally upbeat, intended to comfort and encourage others, especially other parents but also a more general readership, which may account for the frequent success of such books. A classic in the category, Dale Evans Rogers's *Angel Unaware,* published in 1950, was a best-seller for years; its frankly religious tone can strike many readers today as heavy-handed, but the book's ultimate message—that Robin Rogers's short life was worthwhile, her presence in the home a joy to her parents—countered medical advice and even other parents' more tragic constructions of disability in mid-twentieth-century America. The latter category, the parent confessional or pathographical narrative, is personal to the same degree as sentimental narratives but with the intent of warning other families and sharing grief. Heartbreaking accounts of learning the child's "hopeless" diagnosis are characteristic of this genre, for example, in Pearl Buck's *The Child Who Never Grew* (1950) or Michael Dorris's *The Broken Cord* (1989). Other parents take a more practical how-to approach to their story, attempting a more neutral voice as they pass along advice to a readership of new parents. Charles R. Callanan's *Since Owen,* from 1990, is among these works. Finally, more and more, some parents use their experience with a disabled child as a springboard toward exploring broader social or philosophical issues. Kenzaburo Oe's (1995) *A Healing Family* and Michael Bérubé's (1996) *Life as We Know It* are two recent exemplars of this approach. All these categories share the underlying impulse to say what others cannot or will not about disability and its effect on family life.

Such testimonies are not universally embraced. They are dismissed as unreliable evidence or, at best, anecdotal, imprecise, and self-serving documents. The ethical problem of consent is raised: Is the disabled child capable of giving informed consent for very personal details of her or his life to be revealed in print? And if so, is the parent's role too powerful, the relationship too emotionally fraught, to allow that consent to be given freely? Other critics fear that such narratives will be taken as sufficient substitutes for firsthand accounts of disability. Still others find that, by the time a parent is ready to write a memoir, his or her advice may no longer be useful to a new generation of parents encountering a much-changed landscape of laws, programs, and social attitudes.

Others, however, see parent narratives of disability as serving an array of useful functions. As Rapp and Ginsberg (2001:543) point out, because "the knowledge of what is entailed in caring for such children remains absent from the mainstream discourse, underscoring a sense of social segregation or stigma," parental narratives may bridge a destructive gap in common awareness. Parental narratives written in or recalling earlier times may work as a record of past conditions, valuable to historians but also to policymakers seeking models or measuring change. Parents themselves often report that the writings of other parents are more accessible, supportive, and relevant to their day-to-day decision making and coping than other formats, and parental narratives have historically encouraged, or even (in the case of *Angel Unaware*) directly funded, parent advocacy on behalf of social inclusion and community-based programs. As parental narratives are often (but not always) written in the context of developmental disability, they may add to a literature otherwise short on vernacular accounts.

The parental narrative literature is well developed in the United States and seems to continue growing: In 2002 alone, at least a dozen new parental narratives were published by American presses. Furthermore, online support groups are inviting millions of connected parents to tell their stories to each other, through listserv posts and web pages, unmediated by editors or publishers. What is less common is the parental narrative written in a non-Western cultural context (Kenzaburo Oe's work being a notable exception here); parents in emerging economies, finding their traditional sources of support lost without a strong system of alternatives in place, cannot access a rich array of published narratives for making sense of their circumstances. A wider range of cultural stories would also work to place existing Western narratives in a broader context than is now fully possible. Another opportunity for comparison is beginning to emerge in narratives written by adult children about their parents' disabilities (for example, Alzheimer's), a reversed situation that may produce an equally intense literature. The dimensions of intimacy, caregiving, and power inherent in family life, as they are experienced in the presence of disability, will thus long remain a fertile, complicated, and ethically challenging source of personal narrative.

—Penny L. Richards

See also Models; Novel, The.

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▣ PARENTING

A common misconception is that there are relatively few parents with disabilities. This assumption appears to perpetuate social obstacles—a lack of appropriate and accessible resources for parents with disabilities and their families. In fact, in the United States, parents with disabilities represent 15 percent of all parents of children younger than age 18. However, 24 percent of single parents, 18.7 percent of African American parents, and 16.3 percent of Hispanic parents have disabilities.

There is an overall lack of detailed national, regional, or local data on U.S. parents with disabilities and their children. Targeted national disability surveys, such as the National Health Interview Survey, focus primarily on the impact of the adult's disability on major life activities—such as work, education, managing a home, or personal care—but do not investigate the impact on parenting activities. As a consequence, national disability statistics provide only broad estimates of the numbers of disabled parents but little detail about their family lives. In addition, disabled parents and their children remain invisible in most public and private data systems' tracking services to parents or disabled adults in the United States. As a result, the need for specialized or accessible services for parents with disabilities tends to be underestimated.

An analysis of the 1993 Survey of Income and Program Participation, U.S. Census Bureau data by Linda Toms Barker and Vida Maralani, distinguished disabilities in parents as 40 percent sensory, 26 percent physical, 24 percent psychiatric, and 16 percent cognitive. The literature on parents with disabilities reflects a tendency to overgeneralize about them, often in a pathological direction. That is, negative assumptions about parents with emotional, psychiatric, or cognitive disabilities are generalized to parents with physical disabilities. Concerns about parents with acute disabilities such as a recent spinal cord injury are generalized to parents who have long-term stable disabilities, with coping skills and resources that have developed over many years. A focus on variation in disability issues should not obscure the profound effect of cultural, environmental, and psychosocial issues in the lives of parents with disabilities.

Unfortunately, parents with disabilities and their children face many social obstacles: Public policy and appropriate resources lag far behind the social changes that have led to the apparent increase in the numbers of parents with disabilities. The largest study on parents with disabilities to date was done for Through the Looking Glass by Maralani and Toms Barker and yields data from a national sample of 1,175 parents with disabilities. Although participants in the study tended to have more education, employment, and income than most individuals with disabilities, 23 percent had household incomes under $15,000 and 43 percent under $30,000. The many social obstacles and the lack of public resources mean that parents with disabilities and deaf parents in the United States face more out-of-pocket costs than other parents, while their incomes are lower.

In the national survey, transportation was cited by 83 percent as a problem for them as parents. Problems in housing accessibility was another key area that affected parenting. Another access problem was identified regarding adaptive parenting equipment, such as adapted cribs. Such equipment is still essentially unavailable on the market and is seldom reimbursed by public or private health or disability funding systems. Of the 240 parents answering what prevented them from obtaining such equipment, around half did not know how to find information about such equipment and had no way to pay for it. During pregnancy or childbirth, 62 percent of parents had found a lack of disability expertise on the part of professionals, attitudinal problems, and/or interference in the right to become a parent.

Deaf parents also report social obstacles. Ninety percent of deaf parents have hearing children and face significant communication problems with their children's schools, as well as a lack of culturally and linguistically appropriate services for their families.

Mothers with disabilities may face more complex social obstacles. Research by the Center for Research on Women with Disabilities (CROWD) at Baylor College of Medicine found that women with disabilities in the United States are more likely to remain in abusive relationships due to dependency. They report longer durations of physical and sexual abuse compared to women without disabilities and different forms of abuse, such as the withholding of personal assistance or adaptations. Intervention programs report that trauma and abuse experiences are particularly prevalent in mothers with intellectual disabilities. Despite these problems, CROWD research found that traditional shelters and agencies for battered women were generally not accessible for women with disabilities. Specialized services for mothers with disabilities in the United States seldom effectively address trauma issues.

In the U.S. survey of parents with disabilities, it was particularly concerning that 16 percent of these predominantly physically disabled, well-educated middle-class parents reported efforts to remove children from their custody. The literature on parents labeled with developmental disability cites a 25 to 60 percent rate of removal of their children. While 28 percent of adults labeled with "developmental disability" or "mental retardation" have children, only 14.4 percent of these adults have children living with them, apparently reflecting this high removal rate.

Through the Looking Glass's National Resource Center for Parents with Disabilities has identified significant problems in family courts and the child protection system for parents with disabilities. In child protection systems, there has been a tendency to assume that parents with cognitive or emotional disabilities cannot parent or benefit from services, based solely on their diagnoses. In family courts, there is often the assumption that marital custody by a parent with a physical or vision disability is "not in the best interest of the child," even when the primary relationship is between this parent and child. Both systems often do not evaluate actual parent-child interaction (or do so inadequately) and are unaware of disability adaptations, community supports, and relevant research. These problems are compounded by the lack of disability-appropriate preventive intervention in the United States. Similar problems in practice have been described by Gwynnyth Llewellyn in Australia (see McConnell and Llewellyn 200) and Tim and Wendy Booth in England (see Booth and Booth 1994).

The National Task Force on Parents with Disabilities in the United States has identified additional underlying social obstacles. Policies, programs, and funding streams tend to focus only on the parent or the child, rather than emphasizing the family as a unit. Relationships and interaction between parent and child should be more of a focus in research, evaluation, and services. Personal assistance services (PAS) usually only serve the individual with the disability but will not provide any assistance related to care of an infant or child. Both PAS and the availability of parenting adaptations are affected by the lack of inclusion of baby care or parenting as an "activity of daily living."

Since parents with disabilities are faced with so many social and environmental obstacles, adaptation emerges as a theme in their everyday family lives. In the 1980s, Through the Looking Glass documented the natural reciprocal adaptation process between parents with physical disabilities and their babies. This research evolved into a number of studies focused on developing and evaluating the effect of baby care adaptations for parents with physical disabilities. The studies found that such equipment can have a positive impact on parent-baby interaction, in addition to reducing difficulty, pain, and fatigue associated with baby care. By reducing the physical demands of caregiving, the equipment can be instrumental in preventing secondary disability complications. Prevention of secondary injuries prevents additional stress on the parent-child relationship. The equipment has also appeared to have a significant role in preventing or alleviating depression associated with postnatal exacerbation of disability, such as in multiple sclerosis. The research and clinical experience with parenting adaptations makes it clear that one cannot assess the potential of a relationship between a parent with a significant physical disability and an infant without first providing whatever adaptive techniques and equipment make it possible for interaction to occur and the infant-parent relationship to develop.

The incorporation of cognitive adaptations into prevention services for parents with intellectual disabilities has also been clinically documented as crucial to effective practice. Adaptations in communication are essential when evaluating or intervening with parents with cognitive or learning disabilities, visual disabilities, and deafness. Without adapted communication, parents may be mislabeled as "unable to benefit from services" and therefore vulnerable to loss of custody. Inappropriate and disrespectful services can create rather than resolve problems in parenting by individuals with intellectual disabilities. The Booths have eloquently described such problems with practice in England (Booth and Booth 1994).

Adaptations can remove disability obstacles to fair evaluation and effective services for parents with disabilities and their children. Disability-appropriate early intervention can achieve positive outcomes even in the most stressed families.

Parents with disabilities and their children demonstrate resilience and adaptability in the face of considerable social obstacles. However, parents with disabilities and their children are much more alike than unlike other families; parenting is about loving, guiding, caring, and nurturing, disability status aside.

—Megan Kirshbaum

See also Children of Disabled Parents; Childhood, Youth, and Adolescence; Family.

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PARKINSON'S DISEASE

Parkinson's disease (PD) was described in 1817 by James Parkinson, a London physician, whose "Essay on the Shaking Palsy" reported his observations on six patients. It is a disease of the brain characterized by degeneration of nerve cells (neurons) in an area of the midbrain known as the substantia nigra, which produce the neurotransmitter dopamine and transport it to the basal ganglia. The latter are paired groups of nerve cells in the base of the brain involved with movement. Parkinson's disease typically begins between ages 55 and 60 years. It is a common disease, affecting 1 to 3 percent of those older than age 60, and each year, between 5 and 25 new cases per 100,000 population are diagnosed.

The diagnosis is made be observing the characteristic signs described by James Parkinson. The classic triad includes slowness of movement (bradykinesia or akinesia), a slow tremor of the hand at rest, and a ratchety-like resistance when a limb is passively moved, known as cogwheel rigidity. Additional features include small handwriting (micrographia), a flexed posture, decreased facial expression, a soft-monotone voice, shuffling gait, and, as the disease advances, impaired balance with falls.

The cause of most cases of PD is not known. Approximately 5 percent of patients have PD on a primary genetic basis. These include an autosomal dominant gene, which codes for the protein α-synuclein, among others, and the *parkin* gene, which causes autosomal recessive, young-onset PD. Yet, most cases of PD are sporadic, and genes appear to play a contributory role but are not directly causal. Epidemio logic studies have demonstrated that environmental factors, such as being raised in a rural environment, drinking well water, having a prior head injury, and exposure to pesticides, are putative risk factors for PD, but none has been shown to be directly causal.

The treatment of PD is based on the deficiency of dopamine in the basal ganglia. The mainstay of therapy is levodopa, which is converted to dopamine by the remaining nigral neurons. It is combined with carbidopa to prevent nausea. As PD advances, the response to levodopa diminishes, and many patients no longer have a smooth transition between dosages, leading to fluctuations. During periods when levodopa is working, there is relative freedom of movement, alternating with times when levodopa does not work, characterized by an exacerbation of symptoms, including immobility. These fluctuations, known as "on-off," are further complicated by periods when there is an exaggerated, unwanted response to levodopa, producing excessive twisting movements known as dyskinesias.

In addition to levodopa, a number of other therapies can either be used alone or as adjuncts to levodopa. Dopamine agonists work directly on the dopamine receptor and, like levodopa, are often used as initial therapy. Anticholinergics are the oldest agents used for PD and help restore balance in the basal ganglia between dopamine and another neurotransmitter, acetylcholine. Amantadine is an antiviral agent, which was discovered serendipitously to have antiparkinsonian activity. Other medications are available to enhance the effectiveness of levodopa. When the symptoms of PD, particularly movement fluctuations, cannot be controlled adequately with medication, surgery is an option for selected patients. This involves inserting a permanent electrode into the basal ganglia and connecting it to a battery, a procedure know as deep-brain stimulation.

With modern therapy, most people with PD live a normal or near-normal lifespan. Yet, disability increases as the disease advances, while its rate and degree vary greatly among patients. There are currently no treatments that slow progression, but that is one of the most active areas of research. Throughout the course of PD, medical and surgical therapies are enhanced by rehabilitation directed at improving strength, flexibility, endurance, gait and balance, speech, swallowing, and the activities of daily living.

Although motor problems and their treatment are the main focus of managing PD, equal attention must be paid to the psychological and cognitive well-being of patients, as well as the needs of caregivers. Depression is very common in PD and is considered to have an organic basis and not simply a reaction to disability. With advancing disease, many patients develop cognitive impairment and often frank dementia, further contributing to disability and caregiver distress. The diverse and progressive symptoms and signs of PD emphasize the importance of a multidisciplinary approach for successful management.

—Stephen G. Reich

See also Epidemiology; Neurological Impairments and Nervous Disorders.

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▣ PARTICIPATION

Participation has become a core concern of disabled people and disabled people's organizations because of the discrimination, barriers, and segregation that historically they have experienced and seek to overcome. Disabled people's political participation can only adequately be understood within a broader understanding of ideas of participation. *Participation* is a complex, ambiguous term without an agreed-on definition, to which disabled people have added their own meanings. Disabled people internationally have developed three particular focuses for their participation. These are as follows:

> participation in the support they receive, to ensure it meets their needs and is consistent with, rather than restricts, their human and civil rights (this aim is embodied in the disabled people's development of the international independent living movement);
>
> participation in society more generally, to ensure that disabled people are able to live in mainstream society on equal terms with nondisabled people, with equal access to mainstream employment, education, health, and other services and opportunities, instead of being segregated in separate structures and provision;
>
> political participation, to afford disabled people the same democratic rights as nondisabled people and equal opportunities to influence and take part in public life. These concerns are reflected in the rights-based approach of the disabled people's movement and its emphasis on disabled people's rights and responsibilities based on equal citizenship.

THE NATURE OF PARTICIPATION

Participation implies active involvement in the public and social sphere and refers to a range of involvements that individuals and groups may have in organizations, institutions, and decisions affecting them and others. There are many approaches to and understandings of participation and involvement. These have most often been framed in terms of the degree of involvement people have—from zero to control; from tokenism, through consultation, to a primary say in decision making. This was notably expressed in Sheri Arnstein's (1969) "Ladder of Citizen Participation." Participation is crucially judged by the extent to which people can exert influence and bring about change.

The concept of *public participation* developed in the context of land-use planning in the 1960s, became a key concern of community development, and is central in a growing number of discussions and developments, including the emergence of new social movements, postmodernism, public policy and services, the rekindling of interest in citizenship, "human need," "social exclusion," and the search for a new more participatory politics.

Because participation is an inherently political concept, it is contentious, without a clear or agreed-on definition. There is also no consensus about terminology, with different words used, including *citizen participation, self-advocacy,* and *consumer involvement,* sometimes synonymously, sometimes to impart different meanings.

COMPETING APPROACHES TO PARTICIPATION

Generally framed in terms of "consumer" or "user involvement," the idea of participation reemerged internationally toward the end of the twentieth century as a key idea, policy, practice, and goal, particularly in the fields of public policy, health, and welfare. This renewal of interest in participation relates to two frequently opposed and broader developments. First is the development of increasingly powerful and influential movements of disabled people and other long-term recipients of health and social care, with their own democratically constituted local, national, and international organizations and groupings. Second has been shifts in ideology and economics, which have resulted in a expansion of interest in the market and individual responsibility, linked with the philosophy and rhetoric of consumerism, highlighting individual choice and involvement.

This has resulted in two competing understandings of user involvement, which are often confused—the first from the disabled people's and related movements, committed to people speaking for themselves and securing and safeguarding their human and civil rights, choices, and quality of life, and the second from states and service systems, including private providers, reflecting consumerist concerns of improving the efficiency, effectiveness, and economy of services. The first approach starts with people's lives, the second with the concerns of service systems. These two approaches to participation—the "democratic" and the "consumerist"—do not sit comfortably. One is managerial and instrumental in purpose, without any commitment to the redistribution of power or control; the other is liberational, with a commitment to empowerment.

They are also associated with different strategies for participation. The consumerist preoccupation with service user feedback is reflected in an emphasis on consultation and data collection exercises focusing on the planning, management, and market testing of specialist services. The frequent experience of disabled people is that such exercises have very limited effects on improving their lives and support while making significant demands on them. Their concern is with bringing about direct change in people's lives, through collective as well as individual action. The disabled people's movement bases its approach to participation on the social model of disability, using both constitutional and direct action. It has prioritized independent living, civil rights legislation, and the provision of adequate support for organizations controlled by disabled people themselves.

DISABLED PEOPLE AND PARTICIPATION

Participation makes possible the negotiation of different, often competing interests. Participation is also an idea inseparable from issues of power and inequalities of power. As a constituency, disabled people are still relatively disadvantaged, in terms of income, class, status, and power. This is one reason why it is helpful to consider *who* is being involved, when exploring the policy and practice of participation. The equal inclusion of people in participatory developments has so far been a major and unresolved problem. The evaluation of participation is still at an early stage. Different approaches to participation also frame people in different categories. Thus, public policy initiatives have generally been framed in terms of "public participation"; regeneration, community, and international development initiatives have been framed in terms of "community" involvement; and health and welfare initiatives have been framed in terms of "user" and "patient" involvement. Typically, disabled people have not been equally included as members of the public and communities and therefore may not be equally represented in such categorization. Thus, policy for participation can reinforce the broader exclusions and discrimination that disabled people face.

Disabled people, like some other new social movements, have developed an approach to participation based on identity. They also emphasize participation in their own self-organization, highlighting their local, grassroots, and "bottom-up" approach to collective action. In their self-organization, they have generally developed their own representative structures to ensure accountability, but they also emphasize and prioritize the role of direct democracy in their broader collective action and campaigning.

While participation is generally associated with the public sphere, it is also affected by people's circumstances and responsibilities in the *personal* sphere. This can limit the participation of many groups, notably women, because of the care and support responsibilities that continue to be placed on them disproportionately and disabled people, if they are denied appropriate personal support or their access requirements are not met.

Two components are essential if disabled people are to have a realistic chance of participating and all groups, regardless of the nature of their impairment, are to have equal access to involvement. These are *access* and *support*. Both are essential. Experience indicates that, without support, only the most confident, well-resourced, and advantaged people and groups are likely to become involved, while without access, efforts to become involved are likely to be arduous and ineffective. Access includes equal and ongoing access to the political structure at international, national, regional, and local state levels and to other organizations and institutions that affect people's lives. Support includes increasing people's expectations and confidence; extending their skills; offering practical support such as child care, information, advocacy, and transport; enabling people to get together in groups; and ensuring that women, minority ethnic groups, and others facing discrimination can get involved on equal terms.

PARTICIPATION IN CONTEXT

While participation is generally presented in positive terms, it also has a regressive potential. Participatory initiatives can frequently serve to obstruct rather than increase people's involvement. They are sometimes used to tokenize and co-opt people, delay decisions and action, and legitimate predetermined agendas and decisions. This has been identified as a major problem in international development, where indigenous involvement sometimes serves to put a participatory gloss on policies imposed from outside, beyond local control. This relates to a more general and fundamental tension that exists when arrangements for participatory or direct democracy exist in political structures based primarily on a system of representative democracy. So far, little work has been done to explore if and how these two approaches to political participation may be reconciled. As a result, some disabled commentators see participation as a necessary but not sufficient condition for their liberation, arguing for an emancipatory, as well as a participatory, politics.

—Peter Beresford

See also Decision Making; Patient-Professional Relationships; Political Participation; Voting.

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PASSING

Although passing originally defined any form of pretense concerning identity, its meaning today refers increasingly to identity disguise motivated by social injustice and oppression. Passing is one strategy for managing what Erving Goffman (1963) calls the stigma of spoiled identities—those identities discredited by law, opinion, or social convention. For example, when in the minority and powerless, Jews pretend to be Christians, blacks pass as white, gay and lesbian people masquerade as heterosexual. Similarly, people with disabilities find ingenious ways to conceal their impairments and to pass as able-bodied. Disabled people who pass are often accused of leading an existence that endorses deception, accommodation, and betrayal, despite the fact that passing is necessary only because of the inequality and injustice of society. They supposedly deceive society at large, acquiesce to its injustices for personal gain, and betray other disabled people who are unwilling to pass. A more complex consideration of disability passing, however, focuses on the psychological and physical price paid by those who pass as well as on the knowledge they have acquired about the organization of human society. On one hand, to free themselves from curiosity, prejudice, economic disadvantage, and violence, disabled people develop sophisticated tactics designed to help them blend into society, but these tactics may also exact a heavy toll on individuals both mentally and physically, leading to psychological crises and secondary health problems. On the other hand, passing represents a vivid understanding of everyday life and its conventions. Those who pass treat social situations that others consider natural and normal as calculated, artificial, and subject to manipulation, thereby demonstrating their knowledge about social organization and human perception. Passers are skillful interpreters of human society. They recognize that in most societies, there exists no common experience or understanding of disability on which to base their identity. For where a common acceptance of disability exists, passing is unnecessary.

Passing is one strategy useful to manage the loss of self created by the oppression of people with disabilities. Temporary passing is empowering, producing brief moments of freedom from the prejudice and morbid curiosity often found to surround disability. Pretending to be able-bodied is one way of performing normalcy, of inserting oneself in society and escaping the alienating experience of being disabled. In the long term, however, disabled people who try to pass may feel guilty or become depressed about constructing their acceptance by society on the basis of pretense. They also internalize prejudices against disability, seeing their hidden identity as wrong, lacking, or shameful. For both the physically and mentally disabled, passing often requires overcompensation that exacerbates already existing conditions. A woman with chronic fatigue or post–polio syndrome may extend herself to the limits of endurance to maintain the appearance of able-bodiedness, but the result will be a worsening of her condition, sometimes permanently. The college student with a learning disability may discover that passing adds levels of unbearable stress to an already difficult classroom situation. Moreover, those who pass often find that keeping their secret requires solitude. Passing is a solo experience for most people. The feelings of relief that accompany coming out as disabled often derive from the discovery that one is no longer alone and that other disabled people exist on whom one may depend for acceptance, friendship, and love.

Passing requires a working knowledge of human society often unavailable to the majority of people. It entails a conscious engagement with and obedience of social rules, creating the impression of being able-bodied by close attention to the details of everyday life. Passing also requires individuals to make quick calculations in unexpected situations to avoid exposing their identity. Those who pass have a gift for dealing with unstable social situations from which we all might learn; they create a zone of comfort that blankets disability with the appearance of normalcy, making an art of helping nondisabled people feel more comfortable with the presence of disability. Passing also depends on special insights about the ways that human society and perception are organized. A blind woman pretends that she can see by giving the impression that she is sighted. Her role-playing is intentional and precise and will be successful only if she has both acute knowledge of the behaviors that define sightedness and the capacity to reproduce them. Sighted people need not pretend to see and would not be able to do so if required because the knowledge of seeing is unnecessary to their existence. A deaf boy may pass by asking questions to which he already knows the answer and by attending to subtle cues about how he should react in conversation, while a hearing person has no need to learn such nuanced behaviors. Passing involves playing roles, but its essential character is less a matter of deception than of an intimate knowledge of human ability and its everyday definition. Those who pass understand better than others the relation between disability and ability in any given situation. As careful strategists of social interaction, they know what sightedness looks like, though they may be blind; they know what conversation sounds like, though they may be deaf.

The limits of disability passing are often thought to rely on the visibility of an impairment. People with visible disabilities do pass, however, and often with relative ease because a common knowledge of disability does not exist in many situations. Both this ignorance about disability and the general anonymity of modern life produce opportunities for passing. People in public, disabled and nondisabled alike, prefer not to be noticed, with the consequence that disabled people may pass as able-bodied simply by obeying the unconscious laws of anonymity. Moreover, people with disabilities are often recognized by their tools rather than their impairments. A power chair of unusual design may not present as a wheelchair. A blind person without a white cane or whose guide dog is not the expected breed may not be perceived as blind. Similarly, when people with disabilities make their behavior conform to expectations about disability and then reverse these expectations, their status as disabled is placed in doubt. The individual who enters a bookstore in a wheelchair but stands to take a book off a shelf will confuse those who lack knowledge about disability. Passing demonstrates that the visibility or invisibility of an impairment is a less significant factor in the recognition of disabled people than the fact that a common experience of disability is rarely available in society.

Disabled people who pass understand more vividly than others that society possesses no common experience of disability. The lack of common knowledge underwrites passing, for widespread understanding and acceptance of disability would render passing not only impossible but unnecessary. While people with disabilities who pass have an understanding of both disability and its able-bodied counterparts, able-bodied people often have little idea of the conventions shaping either their own abilities or the disabilities they shun. The sighted are blind to blindness, and the hearing, deaf to deafness. When the able-bodied attempt to pass as disabled, for example, they rarely succeed, producing unconvincing versions of disability recognizable only by their exaggeration, and yet disabled persons are able to pass where the nondisabled fail. Disabled people who pass have a double experience of the oppression of disability from which both disabled and nondisabled people might learn. Like all disabled people, those who pass experience the oppression of disability on a daily basis, but they also have an intimate knowledge of just how little the habits of everyday life relate to disability. If their knowledge of human society were more widespread, disabled individuals tempted to pass might move from the desire to pass to the desire to unlearn passing and call upon others to recognize and accept their disabilities.

—*Tobin Siebers*

See also Inclusion and Exclusion; Stigma; Visibility and Invisibility.

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PATIENT-PROFESSIONAL RELATIONSHIPS

Patient-professional relationships involving disabled people and their health care providers is an area characterized by diverse perspectives. Research has shown that patients' relationships with professionals are critical to the outcomes of their health care. In addition, these relationships often influence patients' willingness to return for health care should the need arise. A number of theoretical models have been developed and used to build and maintain positive patient-provider relationships. These include models of patient-provider communication, interactive reasoning models, and client-centered models, among others. According to these models, key elements of the patient-provider relationship include the necessity for rapport, empathic understanding, mutual trust, empowerment, and reciprocal communication. However, models of the patient-provider relationship tend to differ with respect to the degree to which they emphasize a directive versus a nondirective or client-centered approach to interaction.

In directive approaches, the professional assumes the role of expert, and his or her role is to provide an informed viewpoint, structure, and direction to the treatment process. Providers who favor a directive approach also tend to favor a problem-solving, logical-deductive approach to treatment. Client-centered or empowerment-oriented approaches tend to be less directive and less structured. Professionals in favor of these approaches tend to seek the patients' views about the presenting concerns and encourage patients to control and direct their own care.

For disabled people, the nature of their relationships with health care professionals is critical. The attitudes and emotions that accompany these relationships, as well as the settings in which these interactions take place, affect the degree to which health care is viewed as relevant, useful, and ethical. A number of researchers, educators, and activists have examined and critiqued relationships between disabled people and health care professionals. Some of the more prominent voices in this analysis include Ian Basnett, Sally French, John Swain, John McKnight, Susan Wendell, Susan Lonsdale, Barbara Altman, and Peter Coleridge, among numerous others. Existing literature from this perspective includes testimonials and research reports that highlight the negative aspects, weaknesses, and areas for improvement within patient-professional relationships. These reports range from expressions of marked dissatisfaction with professionals to analyses and discussions of injustice, stigmatization, and victimization by professionals toward disabled people.

Like many relationships, the evolution of patient-professional relationships has involved a number of interacting variables. These include the personal characteristics and individual differences among and between professionals and patients. Larger contextual forces are also involved that address the societal norms of power, control, and hierarchy characteristic of the medical model of care. This model focuses on treatment or cure of damaged or failing body parts or systems. The implication of such an approach for disabled individuals is that body parts or systems that do not function as well as those of the nondisabled need to be remediated or fixed. If the impairment cannot be fixed, then the individual is somehow lacking or not whole.

Examples of these experiences are provided by number of writers and researchers, including but not limited to Susan Wendell (1996) and Susan Lonsdale (1990). Susan Lonsdale has interviewed a number of disabled women and found that they related many harmful experiences of hospital treatment and medical care. Visits to health care professionals were described as frightening in childhood. Women recalled being asked questions that were experienced as inappropriately personal and insensitive. They recalled being photographed unclothed and being pressured to walk naked in front of medical students. Peter Coleridge (1993) believes that the self-image of many disabled people has been damaged from their frequent involvement with professionals. This harm occurred particularly during childhood when necessary experiences of play, enjoyment, and discovery were attenuated or altogether replaced by stress, medical exams, and rehabilitation programming.

The negative impact resulting from objectification of the body and the medicalization of disability is also experienced by individuals with fluctuating or broadly defined chronic illnesses, such as arthritis, lupus, and multiple sclerosis. Individuals with these conditions, which are sometimes referred to as emergent or invisible disabilities, have been labeled as being depressed, anxious, or otherwise neurotic. Because their symptoms do not fit into neat diagnostic slots, professionals opt for psychiatric diagnoses of their secondary concerns and do not accurately assess the underlying disability. This invalidation is also evident in the early diagnostic labels given for less visible disabilities. For example, multiple sclerosis was once referred to as malingerer's syndrome or housewife's syndrome. Similarly, people with difficult-to-diagnose or poorly understood conditions, such as chronic fatigue syndrome, chronic pain, and fibromyalgia, have often faced ridicule, misdiagnosis, denial of care, and other stigmatizing attitudes and behaviors from professionals. For example, individuals with invisible disabilities have described a number of difficulties obtaining social services. Caseworkers with no knowledge of these conditions have denied benefits based on judgments that these conditions are not legitimate disabilities. These problems have a sharp impact on patient-professional relationships and can harm patients at a time of great vulnerability. Yet, it is not simply that professionals deny that these are disabilities or refuse services, important though those are. The larger issues of how disabilities are recognized and legitimized for treatment by society and the health care professions are relevant. To some extent, professionals reflect the societal awareness at the time. This is a problem since society can delay in understanding and recognizing emergent disabilities, especially ones that are not readily visible such as chronic fatigue syndrome. Thus, professionals are not the only individuals who bear the responsibility to address and correct this process.

For example, on average, individuals with chronic fatigue syndrome and fibromyalgia have seen 10 or more physicians, and it has taken five years or more to obtain a diagnosis. Many with these conditions have been told erroneously that their conditions were due to stress, mental illness, or lifestyle. The implication of these messages is that that the person's experience of his or her condition is not valid, that the individual is to blame for his or her condition, and that it is the responsibility of the individual to overcome it. As a result of these experiences, many people with poorly understood disabilities have developed a tendency to mistrust and doubt their health care providers. Discrimination is often multiplied for disabled people of lower socioeconomic status, as well as for those who are considered members of racial and ethnic minority groups.

As a support group facilitator, the second author has had many conversations involving the same recurrent theme—mistrust of health care providers. One individual with fibromyalgia commented, “Doctors don’t know what they’re doing. . . . Every time I ask my doctor something he has to pull out a book and look it up, or, says I don’t know, or that’s a bad idea!” A law enforcement officer with an invisible disability related during one physician’s appointment that he asked his doctor about an alternative medicine therapy. The physician remarked, “I think you’re reading too much.” Another person related that three separate physicians are treating her because she does not believe any one physician knows how to help her.

Moreover, patients report that health care providers are often not aware of the physical and logistical challenges they face, including challenges involving mobility and transportation, limited or absent health care insurance, job schedules, and economics. Failure to arrive at scheduled appointments on time is often not tolerated or is interpreted by professionals as selfishness, disorganization, or noncompliance with treatment recommendations without appreciation of challenging complexities in the environment.

In addition, a number of disabled individuals have encountered paternalistic attitudes in their relationships with health care providers. Many report not being asked for input or concerns about health care or service needs. The professional reviews the patient’s situation, makes a determination, and sets a plan of action. Then the patient is directed to follow a protocol. Another example of paternalism is evidenced in attempts by professionals to protect patients by failing to provide them with complete information about their condition or by deliberately excluding them from involvement in key decisions. For example, some patients have learned by accident that health care providers or legal advisers have “sugarcoated” or hid the severity or consequences of a situation because they felt that they (the professionals) knew what was best for the person. For example, a disabled woman was going through a difficult divorce. Her attorney insisted on closed-door negotiation with her ex-husband, his parents, and his attorney but advised the woman not to attend because he thought the situation would be too stressful for her because of her disability. Years after the divorce was finalized, this woman is still discovering the adverse consequences of her lack of direct involvement in these negotiations. Many of these consequences involve economic issues.

Medical perspectives that grow out of societal attitudes toward persons with disabilities can have a negative effect in patient-professional relationships. Contemporary writers argue that pejorative and misinformed notions of disability, often characterized as the tragic view (or personal tragedy view) of disability and impairment, have been reinforced by health care professionals. This view and its reinforcement have developed through health care workers’ professional training, through their traditional approaches to practice, and through their biased interactions with disabled individuals. Health care professionals’ contact with persons with disabilities is often limited to times when disabled individuals are most recently injured or acutely ill.

This tragic view holds that disability is something that should be avoided, reduced, rehabilitated, eliminated, or normalized by adopting as much of the lifestyle and behavior of a nondisabled person as possible. This view of disability is so prevalent that it has affected decisions and values about birth and the right to life. Writers have argued that the abortion of impaired fetuses is not commonly challenged within the United States. Gynecologists are now being sued if they do not appropriately screen for and detect impairments and abnormalities, including having one extra finger or toe. Physicians and society as a whole put pressure on women to undergo prenatal screening and to terminate pregnancies in which medical pathology has been detected. Notwithstanding considerable scientific evidence to the contrary, the idea that disabled people and their parents cannot sustain a joyful, fulfilling, or adequate quality of life is prominent within the tragic viewpoint.

RESEARCH

Individuals writing from the perspective of disabled people are not alone in their observations. Similar observations have been made in a smaller body of research and writings documenting the attitudes and behaviors of health care professionals. The literature indicates that the power imbalance that characterizes the medical model of care may, in part, contribute to the injustice, dominance, and delegitimization experienced by disabled people in their relationships with health care professionals. Writers and researchers such as Sally French, John Swain, and John McKnight have defined and discussed extensively the elements of power that are central to patient-provider relationships. The first involves the power of knowledge and skills possessed by professionals by virtue of their education and training. Professionals possess the power to evaluate the impairments that disabled people have and label their problems and needs based on their own perceptions of those needs. They also recommend specific treatments and evaluate the compliance and effectiveness of those recommendations.

According to Heather Coates and Alan King (1982), the professional's observations are often viewed as accurate, objective, and therefore superior, whereas the patient's perceptions are viewed as subjective and therefore inferior. Professionals not only possess power when working as individuals within clinical settings, but some groups, particularly physicians, also possess power collectively in that they are viewed as a high-status and economically and politically influential group within society. Professionals are more often consulted in the process of making public policy decisions that have a wide range of social and economic implications, including decisions involving abortion, genetic and stem cell research, cloning, and the sale of tobacco, alcohol, and other products, just to name a few. Professionals, rather than patients, are also called upon to make decisions that help insurance companies decide whether a patient deserves benefits or whether that patient is capable of returning to work.

As observed by Barbara Altman, Sally French, and others, practices that involve professional power encourage, maintain, justify, and enforce the dependency of disabled individuals on professionals and professionally driven institutions. Nursing homes, residential facilities (such as those for foster children or individuals with chronic illness, mental illness, or developmental disabilities), and day care programs, many of which provide specialized forms of transportation, embrace rigid treatment protocols, structures, and routines and fail to involve consumers meaningfully in daily decisions, and operations serve to foster and reinforce this dependency. These structures can encourage dependency, resentment, or both within patient-professional relationships. Systems and practices that are set up to encourage dependency have secondary effects on some disabled people. These consequences may involve internalized oppression in which the disabled person accepts his or her role as a dependent, disempowered individual. Ultimately, this process makes it more difficult for the recommendations made by professionals to be successfully embraced, and it makes it more difficult for the disabled person to achieve independence.

Over the past four decades, there have been efforts to counteract existing social norms through movements such as the disability rights movement, the independent living movement, and the patient power movement. These social movements are covered elsewhere in the encyclopedia.

WORK IN PROGRESS

Disability advocates and progressive health care educators and providers have formed a number of initiatives to improve patient-professional relationships. Values emanating from these movements and from client-centered models of care emphasize nonhierarchical, egalitarian relationships between consumers and professionals in which the role of the professional is limited to providing the patient accurate and balanced knowledge and information. Key decisions pertaining to health care, treatment, and participation in all other domains of life are within the control of the patient. Other recommendations to improve patient-professional relationships that have emerged from these movements and have been put in place to some extent include training health care professionals to understand the broader psychological, social, and economic influences of health and disability outside the health care system. For example, health care professionals from all disciplines have benefited from increased understanding of the role of physical aspects of the environment that prevent access to full participation in community and occupational settings. A final contribution that has emerged from these movements is the recommendation and practice of employing more disabled individuals in the roles of health and social service professionals.

One significant step toward incorporating these recommendations into real-world practice has involved the establishment of centers for independent living and other centers that embrace peer-facilitated models of care and the empowerment of disabled people by disabled people. Many disabled people prefer professionals who treat them as partners in their health care, legal situations, and in their search for social services. Many patients take the time to learn as much as they can about their disability, legal issues, treatment advances, and research updates. The most empowered patients expend the energy to learn about disability-related social services and attend self-help or support groups.

It appears that the most satisfied patients are the ones who feel empowered and know how to advocate for themselves in their relationships with professionals. Relationships with professionals work when disabled individuals have health care providers, legal advisers, and social service advocates who not only appreciate these qualities but also promote them. Individuals fortunate enough to find such relationships discover that they can have useful and relevant conversations with the various professionals in their lives. They can express their ideas and concerns about their situations in a trusted atmosphere without fear of being ridiculed.

In general, advocacy groups promote the value that patients take charge of their disabilities and become an integral component of their health care. In sum, health care professionals can occupy an important role in the lives of disabled individuals, and the way in which they regard and choose to relate to disabled individuals inevitably affects their well-being in emotional, social, economic, and political arenas. Well-intended professionals can provide valuable services that are nonetheless useful in the context of asymmetric relationships. There are some circumstances and cultures in which people may not be ready or accepting of an egalitarian or empowering approach. In sum, professionals who are sensitive to these issues and able to custom-tailor their approach to the client's needs may share in the most positive outcomes with their clients.

—Renee R. Taylor and
Sabrina Dudley Johnson

See also Attitudes; Decision Making; Health Care and Disability.

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Research Group on Rehabilitation and Independent Living, www.rgril.ku.edu

PATIENTS' RIGHTS

When people with disabilities enter a hospital setting, they expect to be talked over, around, and about based on a perception by medical staff that they, by the virtue of their disability, are not capable of thinking or talking for themselves. This behavior on the part of medical staff is historic and reflects society's attitude about disability and infirmity. As a practical matter, rehabilitation hospitals present less discrimination than acute hospitals because rehabilitation settings are more used to dealing with people with disabilities.

People with disabilities and the organizations that represent them have been working over the past 40 years to change people's attitudes about disabilities. One of the major methods of choice has been to use the law to improve wheelchair accessibility, to eliminate discrimination in employment, to provide equal access to services to all people with disabilities, and to ensure communications access throughout the new electronic world. Unfortunately, we as a society were not able to reduce discrimination against people with disabilities without resorting to the use of the law, but that is how it is getting done. In what follows, I offer several examples of legal and institutional documents, which enumerate patients' rights in a disability context. Together they suggest a range of societal reactions motivated to protect the rights of those with disabilities both in a medical setting and in society at large.

When Americans with disabilities think about their legal and civil rights, they consider two milestones in federal law related to services and nondiscrimination. The two milestones are Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990. The Rehabilitation Act affects only recipients of federal funding, including most hospitals. The law, with respect to services, states that

> no otherwise qualified individual with disabilities . . . shall, solely by reason of his disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance. (29 USCA § 794, Section 504 of the Rehabilitation Act of 1973, as amended)

The regulations provide further clarification.

The kinds of discriminatory acts prohibited include actions that

> (1) directly or through contractual, licensing, or other arrangements, on the basis of disability:
>
> (i) Deny a qualified person with disabilities the opportunity to participate in or benefit from the aid, benefit, or service;
>
> (ii) Afford a qualified person with disabilities an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others;
>
> (iii) Provide a qualified person with disabilities with an aid, benefit, or service that is not as effective as that provided to others;
>
> (iv) Provide different or separate aid, benefits, or services to persons with disabilities or to any class of persons with disabilities unless such action is necessary to provide qualified persons with disabilities with aid, benefits, or services that are as effective as those provided to others;
>
> (v) Aid or perpetuate discrimination against a qualified person with disabilities by providing significant assistance to an agency, organization, or person that discriminates on the basis of disability in providing any aid, benefit, or service to beneficiaries of the recipients' program or activity;
>
> (vi) Deny a qualified person with disabilities the opportunity to participate as a member of planning or advisory boards; or
>
> (vii) Otherwise limit a qualified person with disabilities in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.

In addition,

> In determining the site or location of a facility, an applicant for assistance or a recipient may not make selections (i) that have the effect of excluding persons with disabilities from, denying them the benefits of, or otherwise subjecting them to discrimination under any program or activity that receives Federal financial assistance.

In 1990, the ADA built on Title V of the Rehabilitation Act of 1973 and declared that regardless of funding, the provision of services available to the general public could not discriminate against people with disabilities. The ADA states the following:

> No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation. (42 USCA §12182(a), Americans with Disabilities Act of 1990)

And through regulation:

> (a) Prohibition of discrimination. No individual shall be discriminated against on the basis of disability in

> the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to), or operates a place of public accommodation.
>
> (b) Landlord and tenant responsibilities. Both the landlord who owns the building that houses a place of public accommodation and the tenant who owns or operates the place of public accommodation are public accommodations subject to the requirements of this part. As between the parties, allocation of responsibility for complying with the obligations of this part may be determined by lease or other contract. (28 CFR 36.201, DOJ, Nondiscrimination on the basis of disability in places of public accommodation)

Many states have a "Patient's Bill of Rights," applicable to both patients with and without disabilities, which builds on the Rehabilitation Act and the ADA. As an example, the Massachusetts "Patient's Bill of Rights" follows the subsequent concepts.

MASSACHUSETTS GENERAL LAWS, CHAPTER 111, SECTION 70E

"'Facility' shall mean any hospital, institution for the care of unwed mothers, clinic, infirmary maintained in a town, convalescent or nursing home, rest home, or charitable home for the aged, licensed or subject to licensing. . . ; any state hospital. . . ; and any private county or municipal facility."

"The rights established . . . shall apply to every patient or resident in said facility. Every patient or resident shall receive written notice of the rights established . . . upon admittance into such facility. . . . In addition, such rights shall be conspicuously posted in said facility."

"Every . . . patient or resident . . . shall have, in addition to any other rights provided by law, the right to freedom of choice in his selection of a facility, or a physician or health service mode."

"Every . . . patient or resident . . . shall receive from a person designated by the facility an itemized bill reflecting laboratory charges, pharmaceutical charges, and third party credits and shall be allowed to examine an explanation of said bill regardless of the source of payment."

"Every Patient or Resident of a Facility Shall Have the Right:

(a) upon request, to obtain from the facility in charge of his care the name and specialty, if any, of the physician or other person responsible for his care or the coordination of his care;
(b) to confidentiality of all records and communications . . . ;
(c) to have all reasonable requests responded to promptly and adequately within the capacity of the facility;
(d) upon request, to obtain an explanation as to the relationship, if any, of the facility to any other health care facility or educational institution insofar as said relationship relates to his care or treatment;
(e) to obtain from a person designated by the facility a copy of any rules or regulations of the facility which apply to his conduct as a patient or resident;
(f) upon request, to receive from a person designated by the facility any information which the facility has available relative to financial assistance and free health care;
(g) upon request, to inspect his medical records and to receive a copy thereof, the fee for said copy shall be determined by the rate of copying expenses;
(h) to refuse to be examined, observed, or treated by students or any other facility staff without jeopardizing access to psychiatric, psychological, or other medical care and attention;
(i) to refuse to serve as a research subject and to refuse any care or examination when the primary purpose is educational or informational rather than therapeutic;
(j) to privacy during medical treatment or other rendering of care within the capacity of the facility;
(k) to prompt life-saving treatment in an emergency without discrimination on account of economic status or source of payment and without delaying treatment for purpose of prior discussion of the source of payment unless such delay can be imposed without material risk to his health, and this right shall

also extend to those persons not already patients or residents of a facility if said facility has a certified emergency care unit;

(l) to informed consent to the extent provided by law;

(m) upon request to receive a copy of an itemized bill or other statement of charges submitted to any third party by the facility for care of the patient or resident and to have a copy of said itemized bill or statement sent to the attending physician of the patient or resident; and

(n) if refused treatment because of economic status or the lack of a source of payment, to prompt and safe transfer to a facility which agrees to receive and treat such patient."

"Any person whose rights under this section are violated may bring in addition to any other action allowed by law or regulation, a civil action."

The Massachusetts statute also establishes patients' rights in the doctor-patient relationship that mirror those enumerated above.

As a result of the various state and federal laws defining "patients' rights," hospitals have made public, through postings and pamphlets, their own patients rights policies. A typical policy, developed by the Spaulding Rehabilitation Hospital in Boston, is set forth as follows.

SPAULDING REHABILITATION HOSPITAL PATIENT BILL OF RIGHTS

"Spaulding Rehabilitation Hospital is committed to providing you with quality care and respecting your rights as a patient. The hospital completely supports the law known as the Massachusetts Patient's Bill of Rights. The following are your rights as a patient, established by the provisions of that law.

"Every patient or resident shall have the right:

- Upon request, to obtain from the facility in charge of his/her care the name and specialty, if any, of the physician or other person responsible for his/her care or the coordination of the care;
- To confidentiality of all records and communications to the extent provided by law;
- To have all reasonable requests responded to promptly and adequately within the capacity of this facility;
- Upon request, to obtain an explanation as to the relationship, if any, of the facility to any other health care facility or educational institution insofar as said relationship relates to his/her care or treatment;
- To obtain from a person designated by the facility a copy of any rules or regulations of the facility that apply to his/her conduct as a patient or resident;
- Upon request, to receive from a person designated by the facility any information that the facility has available relative to financial assistance and free health care;
- Upon request, to inspect his/her medical records and to receive a copy thereof in accordance with Chapter III, Section 70, of the Massachusetts General Laws, and the fee for said copy shall be determined by the rate of copying expenses;
- To refuse to be examined, observed, or treated by students or any other facility staff without jeopardizing access to psychiatric, psychological, or other medical care and attention;
- To privacy during medical treatment or other rendering of care within the capacity of the facility;
- To prompt, life-saving treatment in an emergency without discrimination on account of economic status or source of payment, and without delaying treatment for purposes of prior discussion of the source of payment unless such delay can be imposed without material risk to his/her health, and this right shall also extend to those persons not already patients or residents of a facility if said facility has a certified emergency care unit;
- Upon request, to receive a copy of an itemized bill or other statement of charges submitted to any third party by the facility for care of the patient or resident and to have a copy of said itemized bill or statement sent to the attending physician of the patient or resident;
- If refused treatment because of economic status or the lack of a source of payment, to prompt and safe transfer to a facility which agrees to receive and treat such patient. Said facility refusing to treat such a patient shall be responsible for ascertaining that the patient may be safely transferred; contacting a facility willing to treat such patient; arranging for transportation; accompanying the patient with necessary and appropriate professional staff to assist in the safety and comfort of the transfer, assure that the receiving facility assumes the necessary care promptly, and provide pertinent medical information about the patient's condition; and maintaining records of the foregoing.

The physician shall provide every patient or resident in the facility essentially the same rights."

There is a relationship in a rehabilitation hospital between dignity and rights. It is often said that one must "check one's dignity at the door" when checking into a hospital. The personal privacy of people in the hospital setting is frequently compromised during the provision of hospital services. Respecting the dignity of people in the hospital setting, through the exercise of courtesy, confidentiality, compassion, and the empowering of patients to make informed choices regarding their treatment, is essential in ensuring the rights of all people in the rehabilitation setting.

—Elmer C. Bartels

See also Americans with Disabilities Act of 1990 (United States); Decision Making; Rehabilitation Act of 1973 (United States).

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PEDAGOGY AND CURRICULUM DESIGN

Across the United States, disability studies courses continue to multiply in academic departments within institutions that have established disability studies programs and those in which program development is not currently a goal. Course offerings are found in the humanities, the social sciences, medicine, applied health and rehabilitation sciences, psychology, philosophy, architecture, law, policy, and business. Until recently, disability-related content was the exclusive domain of medicine, education, and the social sciences. Infused by the current wave of disability studies in the humanities, disability is now more likely to be understood as a product of cultural rather than purely biological forces. Recent course offerings include the following: Disability and Literature; Disability in American History; Cultural Studies/ Body Studies; Extraordinary Bodies; Disability and Culture: Race, Gender, and Sexuality; Women and Disability; Disability in Film; and Crip Cultures & Disability Studies. Judging by the titles alone, this sample evidences a strong bias toward the cultural branch of disability studies, but undoubtably, titles can be deceiving.

ACADEMIC COURSES AND PROGRAMS

In many universities, the process for new course creation can impede the development of new courses if it threatens existing, state-approved, or professionally sanctioned content. However, courses can be updated with little or no fanfare and pasted into an existing course title. For example, Normality, Abnormality, and Society, offered in the philosophy department at the University of Hawaii, Hilo, is suggestive of the first wave of disability studies when professionals set the parameters for inquiry into disability informed by a prevention/treatment/remediation paradigm. However, despite its retrograde title, the course, taught by Ron A. Amundson, a philosopher of science and a wheelchair user, is described in the course catalog (2002–2003) as

> a philosophical study of how human diversity interacts with social norms. Topics include health and illness, disability, gender, and sexual orientation. Perspectives from biology and the social sciences are included in a study of how beliefs about normality vary between cultures, change through time, and affect human relations.

The course is not included in a special disability program, nor is it part of a cluster of course offerings designed to provide a closer examination of disability informed by a disability studies. Like many of the new disability studies courses that dot the academic landscape, this course stands alone in a traditional academic department.

Where efforts are under way to develop disability studies programs, course offerings are plentiful and more diverse. Community Planning and Public Policy for Disability, offered through the Department of Environmental Design at the University of California, Berkeley, explores what society and local communities can do to address the needs of citizens with disabilities specific to policies, programs, and local planning. Although the content is shaped by cultural awareness and more progressive interpretations of disability, the course has as its foci the economics of disability and the politics of producing change, with special attention to transportation, housing, public facilities, independent living, employment, and income policies, with content that reflects the perspectives of disabled and nondisabled members of society. Although the disability studies concentration to be offered at the undergraduate level in American studies at the University of California, Berkeley has yet to be finalized, a wide range of interdisciplinary courses already exist. Because Berkeley shares a long history of involvement with the disabled community, many courses were offered well in advance of the recent efforts to create an undergraduate minor in disability studies.

INFLUENCES ON PEDAGOGY AND CURRICULUM DEVELOPMENT

In the example of disability studies, two significant influences on pedagogy and curriculum design are (1) the perspective on disability offered and (2) the context in which the course is offered. When the perspective on disability is informed by cultural criticism and theory, it is useful to consider its relationship to women's studies, African American studies, and queer studies, particularly as each emerged in the era of civil rights movements. However, arguing against the impulse to add disability to the "roster of the disenfranchised," Lennard J. Davis (2002) contends that because the category of disability is porous, it poses a significant challenge to identities that seem fixed. Thus, increasingly disability studies scholarship has moved away from particular claims to status as "another other," opting instead to unsettle fixed identity categories through a more complicated critique informed by disability studies.

GOALS AND OBJECTIVES FOR DISABILITY STUDIES CURRICULA

In its most simple statement of purpose, the goal for a disability studies curriculum is to unpack inadequate representations of disabled people wherever they exist. At the center of many new courses in academe are efforts to disrupt pity, fear, loathing, and overly romanticized and uninterrogated inspirational depictions of disability. Course descriptions are peppered with terms such as *excavate, examine, explore, investigate, interrogate, probe, appropriate,* and so on. Moreover, when the content is organized according to the strictures of cultural studies as a "strategic practice," risk taking and discomfort are likely to follow, according to the critical theorist, Lawrence Grossberg—in short, to radicalize rather than romanticize the content. Demands for authenticity remain a critical feature of the evolution of disability studies curricula. As a consequence, it is not uncommon to find disclosure as a unique feature of the pedagogy of disability studies in academe—with both sides weighing in on the issue. An early framing of the disclosure issue appeared in the *Chronicle of Higher Education* in 1999, when Leonard Cassuto posed the question, "Whose Field Is It, Anyway? Disability Studies in the Academy." The essay sparked a healthy debate among scholars relative to the issue of disability insider/outsider status and who is qualified to speak about disability. It was a timely exchange that provided the occasion to map disability studies as a field and, more subtly, to foreshadow a few of the ruptures in academic traditions likely to follow. Among the most challenging disruptions within the academy at the practice level include those relative to hiring and promotion, instruction, publication, student services, and physical plant design and construction.

In less than three years, issues of pedagogy and curriculum development have become increasingly more complicated and turbulent. The recent publication of *Disability Studies, Enabling the Humanities* provided the occasion for Georgina Kleege and Brenda Brueggemann to consider their own classroom context and their teaching of disability content as professors with visible disabilities. Kleege voiced resentment over the assumption that her own personal experience "augments" her teaching and, more pointedly, that there is pedagogic power in exposing her disability to nondisabled students. Her refusal turned on the unintended effects of naive or well-intentioned approaches that cast her as the "goodwill ambassador sharing the quaint beliefs and customs of my alien world." It is also through her candid exchange with a student depicted in this essay that Kleege articulates the development "over time" of her own disability identity. The impulse to incite activism within a disabled community was revealed to be a latent issue—an insight that only insiders can substantively debate—and one with important implications for K–12 curriculum development. In a variation on us/them positioning still erupting in academe, Brueggemann turns the issue on its head to reveal that the "sword cuts both ways." Initially exasperated by students in her freshman composition class and their resistance to get "in" her disability content, Brueggemann recounts her own resistance to get "in" their abilities. Acknowledging the pedagogic tensions and reflecting upon them, both Kleege and Brueggemann informed their own practices and raised new points to debate as a field.

Arguing against the tradition of silence on the issue of pedagogy among cultural studies theorists, Henry A. Giroux (1995) cited academic elitism, the rewards of disciplinary policing, reluctance to cross academic borders, careerism, and competitiveness as the some of the barriers to probing the relationship between pedagogy and cultural studies. Composition studies, Giroux contends, is one of the few fields in the humanities to seriously contend with pedagogy. However, it is clear that many disability studies scholars have broadened the debate of what is political at the heart of pedagogy and curriculum development. Particular claims to postdisciplinary knowledge is not the ultimate goal for disability studies, at this juncture; there remains too much to be learned from the lives of real people articulating and renarrating lived experience *within* rather than outside history.

DISABILITY STUDIES AND THE PEDAGOGY OF INCLUSIVITY

As academic courses continue to develop and programs gain in popularity, sustained success turns on the pedagogy of inclusivity as the catalyst to sustain explorations into disability studies; to encourage enactment of policies that affect enrollment, hiring, access, and course offerings; and to foster the continuous examination of what counts as knowledge. At the present, those institutions that embrace a pedagogy of inclusivity herald disability studies as more than academic antics in pursuit of another other; rather, these institutions recognize the importance of reimagining the ways disability affects all our lives. In contrast, institutions that practice a pedagogy of exclusivity endorse traditions whereby elitism, entitlement, exclusion, and privilege prevail. Knowledge is more likely inherited rather than interpreted, leaving little appreciation for reflection on the recent ideological shifts that inform disability studies. That is not to say that disability studies courses would not, on occasion, appear in such institutions; novelty or fad-driven courses advance the economic interests of all institutions. But it is to remind us that there are real and measurable political implications for offering disability studies in the first place. Disability studies will be greatly undermined as a viable academic pursuit if institutions fail to simultaneously engage rigorous self-examination of existing policies relative to access and the inclusion of disabled people in the academy regardless of their status as faculty, student, staff, or visitor. A pedagogy of inclusivity would pursue fair representation of disability not only in the curriculum but throughout the university: indeed, no minor undertaking.

DISABILITY STUDIES IN THE CONTEXT OF K–12 EDUCATION

In K–12 educational settings, where disabling constructions are manufactured and conveyed through pedagogy and practice institutionally endorsed by local, state, and federal mandates, the context is thick with a pedagogy that pathologizes difference. Despite the growing legitimization of disability studies in higher education, many teachers are unfamiliar with the field and its implications for K–12 education. Were this encyclopedia entry written 10 years into the future, it would include samples drawn from K–12 school-based curriculum projects in which disabled youth spliced together lived experience, dreams, desires, and reflections on their subject positions in schools. The goal would be nothing short of locating students' experience *within* rather than outside history and, as a consequence, substantively reshaping the extant curriculum.

Given that education, health, and human services are the primary service providers for the disabled community and in schools, an important concern for professionals might be to address why the most recent wave of disability studies has emerged from within the humanities and outside the professions. Or, how can this new wave of disability studies inform and shape the education and training of future educators and school-based professionals? More to the point, how might this scholarship influence disabled students in K–12 educational settings to locate themselves in the curriculum in ways that have yet to emerge? Given that the professions have a high stake in preserving status quo assumptions about disability as pathology, it is highly unlikely that such questions will be considered in the absence of rigorous self-engagement with interdisciplinary disability studies and collaborative planning initiatives. The National Endowment for the Humanities (NEH) has taken the lead to provide funding for such initiatives discussed below.

Emerging K–12 Initiatives

Recognizing the value of cross-disciplinary and interdisciplinary scholarship, the NEH has previously sponsored focus grants and summer institutes for higher education faculty and for secondary educators that focused on disability studies. Although these are quite recent initiatives, it is clear at this stage that efforts to import coursework from academe into K–12 contexts will prove challenging unless the disjuncture between these two competing contexts is explored toward ends that promote reciprocal gains. *A Collaborative Inquiry on Understanding Disability in Secondary and Post-Secondary Settings* (2000) attempted to identify intersecting interests toward the realization of reciprocal goals, but what became apparent was how much a difference disability can make depending on one's context. K–12 teachers work in contexts in which disability is more than a theoretical concern, and although many are unaware of disability studies scholarship, their instructional context continues to include greater numbers of disabled students. This distinction served to complicate the project of articulating shared goals as most universities are situated at the exact opposite extreme and enroll far fewer disabled students—and, for the most part, only those likely to succeed.

"Integrating Disability Studies into Secondary Education," a five-week summer institute for secondary teachers, was cosponsored in 2003 by the University of Illinois, Chicago and the National Endowment for the Humanities. Both general and special educators were treated to a rigorous course of study that stood quite a field from the usual technicist fare that drives in-service "training" for teachers. Exposure to new ways to imagine the lives of their disabled students, informed by a broad survey of humanities content and interactions with disabled artists and performers, led many of the participants to confront, for the first time, the obvious contradictions in K–12 education as it currently exists. For these teachers, five weeks of interactions with wholly new content that, without malice, served to underscore the inadequate representation of disability in their teaching and daily practice was just a beginning. Once these educators returned to their schools, the hard work began as they continued to deconstruct and critique disability in the schooling context. Again, what became apparent was that pedagogy and curriculum development relative to disability studies in the instance of K–12 settings are quite distinct from that in postsecondary settings. Working in isolation to reassemble new images of disabled people and their own students to reflect newly acquired political understanding of disability proved a formidable challenge. Embedded in relationships with content, processes, and policies over which they exert little authority, K–12 educators face an incredible responsibility when attempting to dissolve the boundaries between schooling and popular culture, inherited social scripts, and the limits of their own professional knowledge base. Only through persistence and a long view of the change process can K–12 educators advance disability studies in their everyday practice. Educators' attempts will be greatly enhanced if postsecondary faculty maintain outreach to K–12 contexts as a necessary component of academic disability studies.

—Linda Ware

See also Disability Studies; Education and Disability; Mainstreaming; Special Education.

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PEDIATRIC REHABILITATION

The term *pediatric* refers to medical aspects of children and *rehabilitation* to the medical field of helping people with disabilities acquire greater function. Both are terms of professionalization, in which a field of training, research, and patient care has been assembled by its practitioners and recognized by society at large. As a consequence, this entry refers primarily to the profession, which cares for children with disabilities using medical techniques, following a primarily first world, modern model. In other cultures and at other times, care for children with disabilities has been provided.

In a formal sense, pediatric rehabilitation is comparatively young. It falls against the backdrop of the development of pediatrics from the mid-nineteenth century and the development of rehabilitation largely over the last two-thirds of the twentieth century.

Western medical systems have identified the unique aspects of pediatric conditions of disability from their inception. Certainly, case examples of children with disabilities and the adults they became exist from at least ancient Egypt. Hippocrates, Galen, Soranus, and other ancient authors identified certain conditions of a disabling nature in children and offered interventions appropriate to the time. In the Middle Ages, hydrocephalus, or swelling of the head, in newborn infants was recognized and treated by surgeons. With the earliest texts devoted exclusively to children's medical disorders, disabling conditions were identified and explained, and cures were suggested from Thomas Phaire's *The Boke of Chyldren* (1544) onward. However, it was not until the aggregation of children's care in a coherent way, at the beginning of the nineteenth century, that Western medicine began to identify and react to challenges peculiar to children with disabilities in an articulated fashion.

For much of its history, pediatric rehabilitation was closely related to institutions of chronic, "inpatient" care. In Paris, for example, the Hôpital des Enfants Malades, founded in 1802, was the first hospital dedicated to sick children, using the medical model. In this way, it was distinct from other institutions, which cared for abandoned, poor, or orphaned children. Within its walls, children with acute conditions were gradually separated from those with chronic conditions. Among the latter, those with conditions such as spinal tuberculosis, paralyses, Huntington's chorea, and skeletal anomalies gradually received medical care intended if not to cure then to improve the quality of the child's functional life.

Clearly, part and parcel of the institutionalization process was segregation, social control, and stigmatization. Children with chronic conditions, deemed amenable to intervention, were taken off the streets and away from begging for charity. In this sense, state-sponsored charity for children supplanted spontaneous, private intervention. But the impact on the children, including separation from able-bodied peers, enforced perception of difference; usually, isolation from family was nearly complete. From within the field of pediatric rehabilitation, these effects have been historically downplayed in comparison to the described benefits of concentrated resources, efficiency, and opportunities for learning. Collecting such children together in inpatient and outpatient settings fostered the growth of expertise in their medicalized conditions and care. Thus, pediatrics, pediatric orthopedics, pediatric rheumatology, pediatric neurology, pediatric neurosurgery, pediatric psychiatry, pediatric rehabilitation, pediatric occupational and physical therapy, and other specialties were born and grew.

In the United Kingdom, as in France, figures such as William John Little identified conditions such as cerebral palsy with more or less clinical coherence. This process of medicalizing conditions—identifying a constellation of signs and symptoms and then tracking the natural history of those signs and symptoms from origin to conclusion under a medical rubric—allowed physicians to gain control of knowledge about the children with these conditions. Similarly, conditions from meningomyeloceles to traumatic brain injuries to learning disabilities have been identified, catalogued, and allocated medical resources for intervention and research.

The multidisciplinary growth of the care of children with disabilities is exemplified by figures who wrote pioneering works on their conditions. As well as English surgeon William John Little, in Germany, orthopedist Jacob von Heine (1800–1879) worked with children with paralyses and poliomyelitis, writing on their conditions in 1860; in Vienna, psychiatrist Sigmund Freud (1856–1939) worked with children with cerebral palsy (1897) prior to developing psychoanalysis; and in the United States, the seminal figure in internal medicine, William Osler (1849–1919), wrote an observational study on children with cerebral palsy (1889) and later became the fourth president of the American Pediatric Society. Beyond the frame of medicine proper, other parts of society in other countries followed the French government in allocating central resources to the care of children.

In the United States during the 1920s and early 1930s, the White House advanced elements of a children's agenda; the presidents both convoked symposia for policy creation and created a "Children's Charter" (1928) to begin to identify the needs of children with disabilities, under the auspices of physicians interested in their care. Following his own bout with poliomyelitis, Franklin D. Roosevelt helped create the private philanthropy, the National Foundation for Infantile Paralysis (NFIP), later to become the March of Dimes. From its inception in 1938, the NFIP helped fund both care and research into pediatric rehabilitation. The impact of sequential epidemics of polio continued to bring the care of children with chronic conditions to the attention of reformers, government agents and agencies, and health care practitioners.

In 1947, physical medicine and rehabilitation (PM&R) as a field was formally recognized with its own certification board. Dr. George C. Deaver, commonly identified as the first pediatric physiatrist, influenced training, certification, and philanthropy to aid in the care of children with disabilities from his professorship at New York University and the (Rusk) Institute of Rehabilitation. In 1946, he organized the Advisory Council to the National Easter Seal Society. In these early stages, Deaver was joined by specialists from child neurology (such as Bronson Crothers), neurosurgery, orthopedics, and pediatrics to form the American Academy for Cerebral Palsy (later the American Association for Cerebral Palsy and Developmental Medicine) in 1947. Deaver and others subsequently fostered fellowships in pediatric rehabilitation in the 1950s. In these early years, training was often received as much from the therapists working with the children directly as from the senior physicians "directing" their care.

With further disparate developments in funding, research, and care models, the fields of pediatrics and PM&R began to establish joint residencies in the 1970s on an ad hoc basis. Similarly, PM&R programs created one-year fellowships for those trained primarily in adult PM&R to specialize in the care of children. By the 1980s, numbers of physicians identifying themselves as primarily pediatric rehabilitation specialists reached sufficient levels to form a Pediatric Rehabilitation Special Interest Group (SIG) in the American Academy of Physical Medicine & Rehabilitation (AAPM&R).

Over the past 30 years, pediatric rehabilitation has become a more formalized endeavor. Today, in the

United States, for example, one can enter pediatric PM&R from more general training in PM&R (largely adult) or a dual background in pediatrics and PM&R. Professional political movements over the past 20 years have resulted in a subspecialty examination process begun in 2004 under the aegis of the American Board of PM&R and with the acceptance of the American Board of Pediatrics. Other countries vary from this model, sometimes markedly.

From the point of view of the trappings of professionalization, pediatric rehabilitation is a comparative newcomer to the world of medicine. The first journal confining itself to the topic is in its eight-volume *Pediatric Rehabilitation.* No formal and independent organizations exist solely to sponsor pediatric rehabilitation, although there are professional organizations devoted to individual conditions, such as the American Academy of Cerebral Palsy, or sections of umbrella organizations that address pediatric issues, such as the Pediatric SIG of the AAPM&R.

Providers of pediatric rehabilitation include physical, occupational, and speech language therapists, nurses, social workers, play therapists, teachers, physicians, and others. In many of these fields, some formal training in pediatric rehabilitation is provided, but "specialization" occurs with experience and clinical setting. For physicians, that specialization previously occurred with similar on-the-job training and inclination. However, increasing recognition of the specific nature of such work has promoted certification in many fields. As in all matters with economic consequences, supply and demand in the marketplace change the value of certification. In the United States, while there are fewer children overall with rehabilitation needs compared to adults, there are far fewer specifically trained providers. Those with partial training are still very much in demand.

While there is a core of conditions generally treated by pediatric rehabilitation professionals, concentrating on physical disabilities, practitioners often apply rehabilitation concepts to almost any condition, which might consequently be improved. Conditions traditionally falling under the purview of pediatric rehabilitation include cerebral palsy, neural tube defects (e.g., spina bifida or meningomyeolocele), traumatic brain injuries, amputations, burns, congenital conditions, strokes, neuromuscular disorders, cancers, and a variety of others; in addition, many pediatric conditions, including those related to sports, are treated in outpatient clinics by rehabilitation personnel. There is much room for growth, quite apart from patient numbers.

As in many specialties, pediatric rehabilitation, as a concept, may be effectively applied to many conditions not now generally using it. Thus, standard treatments do not apply full rehabilitation models to children recovering from cardiac surgery as they would in adults. Newborns with complex conditions are only rarely specifically targeted for coordinated rehabilitative care beyond the intensive care unit. But expectations and market forces are gradually changing these limits. Similarly, rehabilitation as a field grew out of therapeutic associations often viewed as "marginal" in the late nineteenth century. As a medical specialty today, it often is amenable to alternative forms of treatment. This is particularly true as conditions treated by rehabilitation practitioners rarely have "cures."

Pediatric rehabilitation uses tools—including rehabilitation; physical, occupational, and speech-language therapies; gait analysis; casting; bracing; orthoses and protheses; electrodiagnosis; physical modalities; pharmaceuticals; and injections—to assess and improve the overall function of children. While the tools are similar to those of rehabilitation physicians for adults, the perspective is often different. In part, this is because of the neurodevelopmentally moving target of the child. Unlike adults, whose physical, mental, and sensory development has plateaued in a gross sense, children are still actively, often aggressively, changing in those respects. Thus, an adult with a low-level cervical spinal cord injury would learn to operate a wheelchair, transfer himself or herself, and so on. For a child, depending on his or her age, this might at first be difficult, but then increasingly possible, and then be complicated by growth and the shifting proportions of the child's body parts. Pediatric rehabilitation providers have to take account of such changes.

In addition, that children are still being educated by society—in a formal school setting—requires that pediatric rehabilitation providers interact with teachers in a fashion that their adult counterparts usually do not have to do. In one sense, this is a salutary symbiosis, as the educational program can be changed to take account of static or evolving impairments. On the other hand, it adds a layer of complexity onto a rehabilitative plan.

Families also play a huge role in pediatric rehabilitation. While parents can sometimes need as much support as the child, they are usually extremely strong advocates and caregivers. In current clinical models, the pediatric rehabilitation specialists are supportive partners to the child and family rather than directors of care. Siblings, like their parents, also need attention, which can be hampered by the physical and emotional demands of a child with a disability.

Research into exclusively pediatric rehabilitation conditions and settings is only slowly growing. Health services research, for example, has been struggling to identify care delivery mechanisms designed specifically for this sector despite exclusion by adult modeling. Clinical research also has met challenges. Since the numbers of children involved are fewer than adults and the reimbursement for their care, at least in the United States, is less consistent, research has sometimes lagged. As is true for its adult cognate, pediatric rehabilitation has also struggled to identify means to measure outcomes of children treated with rehabilitation techniques. A further challenge is the relative infrequence of such pediatric conditions. Low numbers make it difficult to generate statistical proof of treatment efficacy. Nevertheless, taking advantage of related basic sciences, pediatric rehabilitation internationally continues to doff its empirical roots and to seek out theoretical underpinnings for functional intervention and evaluations of outcomes. In this goal, pediatric rehabilitation is following the paths of previous specialties from ophthalmology to adult rehabilitation.

—Walton O. Schalick III

See also Bronson Crothers; Cerebral Palsy; Childhood, Youth, and Adolescence; Physical Medicine and Rehabilitation.

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PEER SUPPORT

Peer support involves a process of giving and receiving help among individuals who are in similar situations. A peer can be defined as a person of equal standing with another—someone who is equal to another person in some important respect such as age, social class, or experience. A peer can also be defined as a friend or companion. Peer support can vary greatly from one circumstance to another, but central to peer support is the ability to understand someone else's situation because of some shared experience. Through this common understanding, peers are able to share stories, exchange information, and often, once the relationship has become solid enough, challenge each other when they are in conflict. Peer support stresses experiential and not professional knowledge. The very value of peers is that they do not have professional training or use professional jargon: They speak from their experience and from a similar status.

The relationship between peer support and disability involves discussing the history of peer support;

how peer support occurs across types, structure, and settings; and the benefits and conditions necessary for peer support to be effective.

HISTORY OF PEER SUPPORT

The concept of peer support in the United States can be traced back to the establishment of Alcoholics Anonymous in 1935, which was formed under the assumption that persons who experienced and overcame alcoholism would be most effective in assisting others who were trying to do the same. The concept of peer support inherently allows individuals to be seen as resources. Specific to the area of disability, peer support offers an alternative to traditional ways of viewing disability as a deficit or problem in need of treatment. Because of societal discrimination, disability can often be an isolating social status. The availability of peer support can provide an antidote to stigma through affirming the very characteristic for which individuals with disabilities have often been disrespected. Furthermore, peer support can be an empowering experience for those who have faced discrimination and marginalization. Such a relationship can provide a positive and/or critical alternative way of looking at the world. For these reasons, peer support has emerged as a central guiding force in many disability-related organizations and services. Peer support relationships involve people with disabilities or family members or caretakers of people with disabilities.

Peer support has grown most visibly through the formation of a number of disability-related organizations across the United States. For example, peer support has been the foundation of the self-help movement and, more specifically, organizations such as Recovery Incorporated, a nonprofit peer-based organization that began facilitating weekly support group meetings for people with mental illness in 1937. As another example, United Cerebral Palsy was created as an organization in 1949 when two families with children with cerebral palsy came together to create a network to allow families to stay together and improve the lives of children with disabilities. Support groups have been a core service of this organization as they strive to help families share resources.

In the United States, the revolutionary thought of the 1960s continued to foster ideas related to peer support, as a rise in service delivery by paraprofessionals and nonprofessionals increased interest in the concept of peers supporting each other. An excellent example of this is the Center for Independent Living (CIL) movement. Led by Ed Roberts in Berkeley, California, a group of students with disabilities organized to pressure the University of California at Berkeley to become more accessible and to provide more supports for students with disabilities. In 1972, the Berkeley Center for Independent Living was founded as a community-based organization, with peer support as one of its central values. Today, more than 400 CILs exist around the United States, and peer support remains a core service for most local chapters.

During the 1980s, peer support continued to make its mark, as seen through the development of the Mood Disorders Association, a nonprofit, peer-based organization that was started in 1982 by and for mental health consumers. As another example, Americans Disabled for Accessible Public Transit (ADAPT) was founded in 1983 to promote advocacy in the disability community through civil disobedience to achieve the goal of public accessibility. Many other large organizations for people with physical disabilities, such as the National Spinal Cord Injury Association and chapters of the Paralyzed Veterans of America, have made peer support one of their major activities.

Peer support has been a strong component of independent living organizations around the globe. For example, independent living organizations in Sweden and Canada have used peer support as a mechanism for bringing people with disabilities closer to independence. Similar to the United States, international peer support developed strongly in the 1960s and 1970s. For example, in 1962 in the United Kingdom, a group of parents of children with disabilities formed the Society for Autistic Children, which later became the National Autistic Society, and includes a telephone support service for parents of children with autism. In Australia, peer support was part of a larger community health movement during the early 1970s. During this time, under the Whitlam administration, local community health projects were directly accountable to the communities they served. There was community involvement at every level of service development and delivery. This involvement opened channels of communication among service providers, bureaucrats, and consumers in areas such as disability and mental illness. Founded in the 1970s, GROW is one example of such organizations that flourished and presently runs peer-led groups for those with mental illness in many countries. More recently, peer support has reached other nations such as Thailand, where, in 2000, people with disabilities were trained as peer counselors. Thai individuals with disabilities have continued with training that focuses on how to establish and maintain an independent living center.

TYPES OF PEER SUPPORT

Peer support can take multiple forms, including peer support provided on an individual basis and that provided in a group setting. Individual peer support can include peer education, peer counseling, and peer-mentoring relationships. These relationships may involve sharing similar experiences and offering advice based on these experiences. As an example, individuals with newly acquired spinal cord injuries may serve as mentors to new patients, so that both can share emotional experiences as well as information regarding resources they have attained since their injuries.

In contrast to individual approaches, peer support groups are often composed of people with disabilities who have common difficulties. Created around common core issues, these groups then meet regularly to discuss their problems and strategies to deal with them. To provide an example, one peer support group among people with psychiatric disabilities announced that their group had two goals: serving as a source of friendships for participants and seeing that interpersonal skills learned via the group process would generalize to other relationships beyond the group.

STRUCTURE OF PEER SUPPORT

Across these forms of peer support, the structure of peer support relationships can also vary. Relationships can range from formal to informal and can occur across or within diverse programs. Regular contact between the supporter and supported can occur face-to-face and may involve educational or recreational activities. Contact can also be less frequent and may involve a simple phone call whereby the supporter is simply "checking in." Last, support can be shared over the Internet in the form of listservs, chat rooms, and other online communities. Online support can be a particularly valuable resource for people with disabilities who face barriers regarding physical accessibility, transportation, and personal attendant care (for example, those who live in rural communities). One peer-mentor program had a variety of mentors "on-call" for consumers to contact as needed. In contrast, one peer support group was more formally organized, as the group included two meetings each week. One meeting was structured by the group. It included both time for each member to talk and also a facilitated discussion around some issue. The second weekly meeting was a recreational activity.

SETTINGS OF PEER SUPPORT

Peer support in its many forms and with its many structures can also be incorporated in a number of environments, including educational settings, employment settings, rehabilitation hospitals, independent living centers, health promotion centers, and supported living/supported housing settings. For example, one peer-mentor program, set up with individuals with violently acquired spinal cord injuries, is based in the rehabilitation setting. This program consists of, among other things, recreational activities, including wheelchair basketball, camping, and sailing. As another example, one supported housing program for individuals with HIV involved a series of groups. These groups were developed to focus on specific needs, such as cooking, emotional and addiction recovery support, information sharing about opportunistic infections, treatment protocols, and medication and alternative holistic therapies. Needs were identified in the group setting, and all community members were asked to contribute to solving them.

BENEFITS OF PEER SUPPORT

The little research that has been conducted to evaluate peer support programs has found positive results. Broadly, peer support seems to benefit the people being supported, those doing the supporting, and the broader community. In terms of individuals being supported, a number of psychological effects have been demonstrated. First, peer support in general seems to promote a sense of empowerment among the group of people with disabilities. When people are faced with a stressful situation, especially when they acquire a new disability, they prefer the company of those facing the same stressful event. Peer support helps people feel validated when they are able to share emotional reactions with others having similar experiences. Furthermore, people are given the opportunity to learn from the peer providing support. They are given the chance to develop skills that have proven effective for someone else in their life situation. They can also learn to advocate for themselves and may experience enhanced feelings of self-worth because someone similar cares about and understands their situation.

Peer support may also help the peer doing the supporting. In general, research conducted across a variety of populations has found that helping others can help you. Specific to disability, peer supporters can experience a heightened sense of self-worth as they are able to share their valuable knowledge and presumably help someone else in the process. They may also feel and explicitly acknowledge a strength of their disability (perhaps for the first time), as it has given them the tools to assist someone else through a difficult time. Furthermore, peer supporters often feel great satisfaction knowing they are helping someone else. This experience has also been cited as a catalyst toward career development.

Finally, the broader community can benefit from peer support in a number of ways. First, peer support can demonstrate to the community a positive contribution that peers with disabilities can provide. Furthermore, it seems to be a mechanism for building capacity for change. When people are sensitive to and aware of common needs and common rights, they have the opportunity to make appropriate social change; they can work together to develop appropriate solutions to complicated social issues and problems. For example, advocacy groups can be built based on common interests and can evolve from peer support relationships and groups. Advocacy groups facilitate change in certain areas.

As an example of the variety of benefits that peer support can yield, one peer support program among persons with psychiatric disabilities reported that participants maintained their independent or semi-independent living and increased their use of community resources. The participants also experienced greater social support networks and social and leadership skills. Furthermore, their likelihood of hospitalization decreased, and they reported high satisfaction with the program.

Benefits include that peer support is more cost-effective than that provided by professionals. Peer support also allows more people to receive assistance more frequently: Assistance becomes a part of individuals' natural networks rather than something they receive only when going to see a professional in an office.

Though advantageous in many situations, effective peer supporters require adequate support themselves to avoid burnout. Often, a strength of peer support is that peers have not been formally trained as clinicians or practitioners and therefore speak to their peers from their own experience. This strength also presents a limitation in that they need to be supported in dealing with others' problems, as this can be an overwhelming burden. Support can be provided to peer supporters in a number of ways, from structured contact with professionals to more informal contact with other peer supporters.

It is imperative that peer relationships, whether individual or group based, are comfortable for all involved and that they make individuals feel that it is acceptable to talk about their problems or sources of stress. A supportive environment is key to an effective peer support relationship.

Given the hundreds of millions of people with disabilities in the world and the limited number of professionals, peer support is a vital resource for people with disabilities. Peer support helps people with disabilities cope with everyday concerns, enabling them to validate their strengths and to move forward to improve their lives. As this review as shown, peer support can take many forms, yield many benefits, and lead to the development of advocacy efforts.

—Erin Hayes and
Brigida Hernandez

See also Advocacy; Empowerment and Emancipation; Leadership.

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National Self-Help Clearinghouse, www.selfhelpweb.org/what.html

PEOPLE FIRST®

People First® is an international self-advocacy organization with chapters all over the world. People First® groups are run by and for people with intellectual disabilities to work on civil and human rights issues. People First® groups are always led by people with intellectual disabilities. They have four guiding principles:

1 Speaking for ourselves
2. Solving problems—making decisions
3. Knowing our rights and responsibilities
4. Contributing to our community

Most People First® groups elect officers to run their meetings and have facilitators or advisers who assist group members. Facilitators help the group without taking control. People First® groups work on a wide variety of issues, including closing institutions, housing, employment, voting, and sexuality and social relationships. People First® groups fight prejudice and discrimination against people with disabilities. They also combat overprotection by parents and professionals. Those who participate in People First® find that their lives are enriched. They have more friends and colleagues to socialize with and help them to solve problems and meet individual goals.

PEOPLE FIRST® HISTORY

In 1968, a meeting was held in Sweden at a parents' organization for children with developmental disabilities. The organization had a motto—"we speak for them," meaning the parents spoke for their children. However, people with disabilities who attended the meeting wanted to speak for themselves. They started their own self-advocacy group. Similar groups quickly spread to England and Canada.

In November 1973, individuals with disabilities living at the Fairview Hospital and Training Center in Salem, Oregon, attended a conference in British Columbia, Canada. The conference was organized and run the British Columbia ARC. The conference was for people with disabilities, but it was run by professionals. The group from Oregon wanted to start a self-advocacy group by having a similar conference, but they wanted it to be organized and run by people with disabilities. They wanted support from professionals only when it was requested. During a meeting on January 8, 1974, they discussed how to name their group. Everyone disliked being called by negative labels such as "retarded," so they decided to call themselves "People First."

In October 1974, the first People First® Convention was held in Oregon. It was attended by 560 people.

Within five years, Oregon People First® had 1,000 members. People First® groups also began in Nebraska, Kansas, California, and Washington state. Self-advocates from 42 other states were seeking help in starting their own groups. The first international self-advocacy conference was held in Tacoma, Washington, in 1984. International conferences have since been held in London, England (1988); Toronto, Canada (1993); Anchorage, Alaska (1998); and Northampton, England (2001).

CONCLUSION

As of 2004, there are People First® and self-advocacy groups in 43 countries with an estimated 17,000 members. It has been estimated that there are more than 800 self-advocacy chapters in the United States with a national organization called Self Advocates Becoming Empowered (SABE). Although not all self-advocacy groups choose to call themselves People First®, this group continues to be a dynamic and visible arm of the international self-advocacy movement.

—Pamela Block and
Tia Nelis

See also Advocacy; Citizenship and Civil Rights; Empowerment and Emancipation.

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People First California, www.peoplefirstca.org/history.htm#Beginning

People First Oregon, www.open.org/~people1/about_us_history.htm

PERL, OTTO (1882–1951)

Author and cofounder of the Self-Help Alliance of the Physically Handicapped

Otto Perl was a German author and cofounder of 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, which was also called the "Otto Perl Alliance." He was born on October 19, 1882, the son of a small farmer, in the state of Saxony. With nine siblings, he grew up in rather simple rural circumstances.

From the age of 13, he suffered from a stiffening of joints. In 1898, he began an odyssey through German so-called invalid institutions and cripple homes. In 1919, he became part of a small circle of founders of the Self-Help Alliance for the Physically Handicapped in Berlin. From 1922 until 1924, he was acting deputy of this first organization to represent the interests of people with birth defects and physical disabilities in Germany. After completing his studies at the gymnasium in 1919, he studied philosophy and economics in Berlin. In 1926, he lived in his own room for the first time in his life, in an institute in Nürnberg, and published his book, *Krüppeltum und Gesellschaft im Wandel der Zeit* (*Crippledom and Society in Changing Times*). He fought against institutionalization and demanded the right for self-determination. However, he limited his demand for education and job training to the "mentally normal" but physically handicapped person, in contrast to the "mentally handicapped," and already in 1926, he showed a thinking that alarmingly coincided with the Nazi ideology for selective care.

In 1946, a year after the end of the National Socialist regime, he described himself as a victim of Nazi encroachments, yet in 1935, he had demanded the separation of the "mentally sound" and the "mentally degenerate" and unmistakably applauded the National Socialists for their measures to control hereditary biological problems. Otto Perl died on October 17, 1951, at the Kaiser-Friedrich-Siechenhaus (Kaiser-Friedrich-Institute for the Invalids) in Wittenberg.

—*Petra Fuchs*

See also Deinstitutionalization.

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PERSONAL ASSISTANCE AND DIRECT PAYMENT

Personal assistance services are the most critical services for individuals with disabilities and are often considered to be one of the individualized supports essential for community life. Personal assistance is defined as one person assisting another with the tasks that individuals would normally do for themselves if they did not have disabilities (Litvak, Zukas, and Brown 1991). Personal assistance services are founded upon principles of universal access; information access, including for children and youth; community access; empowerment; and opportunities for full lives (Racino and Litvak 1999). In the United States alone, personal assistance services affect the lives of more than 9.6 million citizens with disabilities.

The 1991 Resolution on Personal Assistance Services, passed at the International Personal Assistance Symposium, upholds the basic human and civil rights to full and equal participation in society called for in the Americans with Disabilities Act (1990) and the United Nations Universal Declaration on Human Rights. Personal assistance services "shall enable users to exercise their rights and to participate in every aspect of sociocultural life including, but not limited to home, school, work, cultural and spiritual activities, leisure, travel and political life" (Litvak and Kennedy 1991). The right to these services is part of what it means to be without discrimination based on color, race, creed, gender, religious background, income and social class, cultural or ethnic origin, geography, or sexual orientation (World Institute on Disability 1991).

Personal assistance services (PAS) are consumer-directed services (Heumann and Racino 1992; Flanagan and Green 1997), and their growth has indicated a need for development based on the individual and for models that take into account unserved or underserved groups or populations. These groups may include people who need technological assistance and those with mental retardation and physical disabilities, brain injuries, psychiatric disabilities, and other cognitive disabilities (Racino 1993, 1995a, 1995b), in addition to youth and those who belong to cultural and ethnic minorities (Egley 1994). Adaptations may vary substantially by disability field, in part due to the organization and funding of services in countries such as the United States. Leaders internationally in PAS by field include Boston University's Center for Psychiatric Rehabilitation and Judi Chamberlin, as well as consumers such as Lori Stewart, one of the independent living leaders who is a psychiatric survivor. Personal perspectives were shared internationally through the 1991 symposium (Weissman, Kennedy, and Litvak 1991).

Critical aspects of personal assistance services are that it must be available up to 24 hours a day, 7 days per week, to people of all ages, and with access to governmental payments (independent of marital status and not as a disincentive to employment). In addition, selection of personal assistants must be the choice of the service user and include family members (World Institute on Disability 1991). Agency models of assistance, while supported, are more expensive and offer far less user control of services. More than 30 specific services have been surveyed in the United States, including personal, household, cognitive, transportation, and short-term (respite, emergency) services (Egley 1994), and they have been reviewed in the context of specific population groups (e.g., on issues such as involuntary care). Models of assistance include work site support (e.g., supported employment and worker-directed PAS) and have been approached through the individual life course theory (Kasnitz 1993), among others (e.g., Beach Center on Families, University of Kansas, lifespan theory, consumer empowerment theory).

Personal assistance services have been studied and investigated over the past decade, including through a congressionally funded U.S. Center on Personal Assistance Services, based at the World Institute on Disability. Original nationwide work in the field was conducted by Simi Litvak, Hale Zukas, and Judith Heumann (1987) in the report *Attending to America,* based on the independent living paradigm developed by Gerald DeJong, a supporter of personal assistance in long-term care (DeJong, Batavia, and McKnew 1992). The centers also developed from their international roots (e.g., Judith Snow and circles of support [Canada]) with national support, such as the Consortium of Citizens with Disabilities (e.g., Marty Ford of the Arc), state-level field models in severe disabilities (O'Brien 1992), the aging and university communities (Heumann and Racino 1992), and local/ state independent leaders throughout the United States.

New models of youth personal assistance services include peer-to-peer support; self-determination; career development; in-school support; youth lifestyles, including dating; and social relationship facilitation, if desired. Program models of PAS for independent living have been identified as varying based on the degree of consumer choice, often involving variations of state administration in relationship to the service user (Egley 1994). Among other findings (e.g., costs of PAS), "available data have indicated that different models do tend to serve different population groups, but offer no evidence that models and populations are closely or inherently linked" (Egley 1994:18). Major systems concerns in the United States revolve around systems coordination, eligibility, access, service limitations, assessment, workforce, liability, service quality, and long-term services coordination.

Through the past decades, PAS leaders have reviewed the development of the diverse fields (e.g., community integration, supported housing and living) and led national policy at the level of their relationships with organizations such as the National Council on Disability. Margaret Nosek, at ILRU-Texas at the Baylor College of Medicine, has assessed independent living programs on the basis of program age, consumer control, and budget; framed PAS in the community integration context (Nosek and Howland 1993); and supported U.S. and worldwide PAS development at the public policy levels (e.g., Nosek 1991). Leaders such as Ed Roberts have provided the inspiration for the continued development from the independent living movement's early roots.

Direct payments to service users have been the theme of funding in the field of independent living (Brown 1993), while other fields have pursued cash subsidies as part of service packages (Bradley, Knoll, and Agosta 1992 [family support services]) and explored the options of direct payments (Ridley and Jones 2003 [mental health]). In addition, major efforts nationwide in the United States have been placed on modifying public sources of funding for Medicaid, especially for community services (Doty, Kasper, and Litvak 1996; Racino 2000a, 2000b). In the field of mental retardation and developmental disabilities, individualized funding tied to the person has been the major focus in reform for the past several decades (see also Racino 2000a, 2000b; Lord and Hutchinson 2003). In the United Kingdom, direct payments to people with disabilities to purchase their own support services were attributed to importation from the United States and Canada (Maglajlic, Brandon, and Given 2000).

Debates by the late 1990s moved on the services front to privatization in the context of supporting the individual person (vouchers, grants, and service choice; Glover 1999) and less so to the family-user-government relationships. By 2000, the first international conference on individualized funding and self-determination was held in Seattle, Washington, and the Internet hosted sites worldwide on the topic (e.g., European Network on Independent Living, Centre on Human Policy, Syracuse University, Instituto Universitario de Integración en la Comunidad in Spain, the Australian Society Association for the Study of Intellectual Disabilities, Community Living Society of Canada, and Hester Adrian Research Centre in the United Kingdom).

International models of personal assistance services, which were also presented in 1991 at the International PAS Symposium, include housing and personal assistance services in Sweden (Tucker and Kleinman 1990), especially the Stockholm Cooperative Model for Independent Living (Ratzka 1991). Service brokerage with a component of individualized funding began in Canada (Salisbury, Dickey, and Crawford 1987), which has strong proponents for individualized funding and support approaches and links easily with the United States and United Kingdom (Centre for Research and Education in Human Services 1993). Independent living has been pursued in diverse parts of the world, from Japan and South Africa to Norway and New Zealand, and these roots are critical for the future development of PAS.

Today, the support and empowerment paradigm has influenced the development of PAS, including "model variation" based on community membership, person-centered and support approaches, the continued expansion to and from other population groups (e.g., HIV-AIDS), systems reform of state-federal-local financing, and diverse contexts such as those of abuse and rights abridgements. Personal assistance services, with its roots in the independent living movement, has reached new generations and holds a promise beyond its beginnings for personal and community futures in the years yet to come.

—Julie Ann Racino

See also Advocacy; Assistive Technology; Decision Making; Empowerment and Emancipation.

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PERSONAL CARE ATTENDANTS

Personal care attendants (PCAs), also referred to as personal assistants, are individuals who provide help to people who have difficulty performing, or are completely unable to perform, daily living activities by themselves due to a disabling condition or injury. Until recently, the use of PCAs was associated with only the most severely physically disabled population (e.g., people with paraplegia or quadriplegia). However, PCAs are increasingly employed to assist other populations who require extensive supervision or help with daily living activities, such as people with cognitive impairment and frail elderly individuals who are at risk for nursing home placement.

While historically, the majority of PCAs were untrained independent direct care providers, a rising demand for workers who provide assistance services has led to the development of training programs by community colleges and other organizations that certify paraprofessionals in the health care field. The duration of such programs may be from several weeks to several months. In many programs, the titles *PCA* and *certified nursing assistant* (CNA) are synonymous. Like CNAs, PCAs are hired by home health agencies and nursing homes, although many certified PCAs retain independent status.

PCAs are central to the "personal assistance service (PAS)" model of providing help to people with disabilities in the home setting, a mainstay of the independent living movement. The PAS model is in contrast to the home health agency-based model of home care delivery historically associated with the aging service system.

The PAS and agency-based models represent different and incompatible philosophies of service delivery. Proponents of PAS view home health agency-based workers to be part of the medical model of service delivery, in which health care providers define, direct, and deliver services to the individual. Agency supervisors hire, train, pay, and, if necessary, fire the home health aide or homemaker who is the direct provider of care. Under the medical model, the service recipient assumes the passive role of patient, with little input into the nature of services provided and little control over the direct provider of care. Activists and supporters of the independent living movement argue that the medical model entails the sacrifice of personal control as a condition of service receipt. Thus, this model is perceived to foster dependency, which is antithetical to the concepts of empowerment and independence—major goals of the independent living movement.

In contrast, control resides with the service recipient, termed *consumer* or *client,* in the PAS model of service delivery. Under this consumer-centered model, the person with disability interviews, hires, trains, manages, and, if necessary, fires the direct provider of services, generally a PCA. While the title "personal care attendant" is still widely used, members of the independent living movement and its broader counterpart, the disability rights movement, perceive the word *care* to hold connotations that are more appropriate to a medical model approach. *Personal assistant,* on the other hand, conveys a broader role that encompasses assisting consumers to meet work-related and social needs.

The duties of the PCA, or personal assistant, in the PAS model are defined by the consumer in accordance with his or her needs. Payment is either out of pocket or from third-party payers to the consumer who, in turn, pays the assistant, thus reinforcing that accountability is to the consumer in a clearly defined employer-employee relationship.

In general, two features of the PAS model increase the likelihood that service recipients will have their needs met over the more traditional agency-based model. First, the job of the PCA is defined by the consumer, not an agency, and redefined according to the consumer's changing needs. Control over job description such that the highly specific needs of the individual are met empowers the person with disability to participate in life's activities to a far greater extent than the more limited agency-based model, in which tasks performed by the PCA are fixed and typically confined to the client's home.

A second beneficial feature of the PAS model is the additional amount of coverage allowed by the organizational structure of the program. The elimination of administrative overhead associated with agency-directed services results in cost savings that can then be used to purchase additional hours of PCA service delivery.

The majority of third-party funding for PCAs is through states' Medicaid personal care optional benefit. Currently, only 28 states have this option available, although recent emphasis on community care for people with disabilities has heightened interest in expanding the Medicaid personal care option. An obstacle to expansion of this option is concern regarding the feasibility and desirability of the PAS model for elderly persons with disabilities. Advocates argue that the principles of autonomy, control, and independence are appropriate for older as well as younger individuals who need help with tasks essential to everyday life. Furthermore, an alliance of the two constituencies could greatly enhance opportunities for political action in securing the expansion of long-term community-based services in a manner that maximizes the potential for community rather than institutional living, as well as participation in the mainstream of community life.

For some elderly people who need extensive help, PCAs are a feasible and not prohibitively expensive alternative to nursing home placement. However, there is no doubt that some elderly people lack enthusiasm for the personal assistance model, generally because of discomfort with assuming the role of employer or supervisor. In response to this discomfort, many independent living centers offer training to people with disabilities on how to manage their PCA.

Other concerns that have served to impede widespread use of PCAs are fears of client safety, exploitation, and even abuse. Such fears stem from the fact that independent PCAs often lack the training that agency-based workers are required to receive as a term of their employment. In addition, attendants are often hired in response to newspaper ads placed by clients and consequently are not subject to background checks. Despite these potential drawbacks, several large-scale studies comparing the personal assistance model to the agency-based model have found no difference in the instances of abuse, exploitation, or adverse consequences associated with lack of training reported by consumers of the two models of service delivery. In fact, several studies conducted to date have concluded that clients of PAS are more satisfied with care arrangements than are clients of agency-based services.

Another unique feature of the PAS model of care, as offered under the Medicaid personal care option by a number of states, is that family members of the person who requires help are eligible to serve as PCAs. Studies have shown that people with disabilities who employ family members as their personal assistants are most satisfied with the quality of the job performed. This finding has allayed fears among Medicaid program administrators that family members will take advantage of a personal care benefit, by receiving payment for a service they would have performed anyway. Research has shown, however, that payment to family members enables them to stay out of the workforce, assisting their loved ones in performing daily tasks while still earning much-needed income.

Other labor issues associated with the PCA position include low pay and few or no benefits. However, a survey of Medicaid PAS programs conducted by the World Institute on Disability in the 1980s revealed substantial variation in wages and benefits offered to attendants, with independent PCAs in some states earning more than agency-based workers in other states.

With the aging of the population and increase in life expectancy for people with disabilities, it is likely that the demand for PCA services will increase in the near future, particularly by frail elderly people who desire to "age in place" despite disability. As this profession evolves, it is likely that associated wages and benefits will improve, as will its stature in the health care field. An adequate supply of PCAs will be essential to fuel current trends toward the development of home-based alternatives to nursing home care.

—Susan M. Allen

See also Caregiving; Personal Assistance and Direct Payment.

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PHANTOM LIMB PAIN

The term *phantom limb* has been used since the 1870s largely to describe the experience of pain and other sensations from a limb that has been removed, although it has also been applied to sensations seemingly coming from dead tissue. American Civil War surgeon and physiologist Silas Weir Mitchell coined the term after working with amputees in Philadelphia but was not the first person to write about the phenomenon. Early descriptions of phantom limbs appear in the works of Ambroise Paré (mid-1500s), René Descartes (mid-1600s), Charles Bell (early 1800s), and many others. The historical literature even reveals a self-description of a phantom limb by William Porterfield, a highly regarded Scottish physician who described his illusory sensations in 1759.

Different people living at different times had different motives for writing about this disorder. For Paré, a Renaissance barber-surgeon, the important thing was not to be fooled by "false" sensations. His fear was that sensations from dead tissue might dissuade well-meaning surgeons from performing life-saving amputations on riddled, gangrenous limbs. For Descartes, the great French philosopher, phantoms were used to argue that sensory information can be grossly misinterpreted and that the human soul receives information from the brain. Bell, in contrast, used phantom sensations of limbs in various positions to support a sixth sense, his muscle or proprioceptive sense. From his studies of sensation and movement, he became convinced that the brain not only sends messages to the muscles but also must receive feedback from those muscles to manipulate the limbs effectively.

As for Silas Weir Mitchell, he was both a surgeon and a humanist. He viewed phantoms an all-too-common horror of war that demanded compassion from the public and considerably greater understanding by the medical community. He even presented a fictional case involving a wounded medical officer in a popular magazine, hoping that "George Dedlow's" plight would move people to take the mental consequences of amputation more seriously.

Much was learned about phantom phenomena even before the twentieth century, including the fact that phantoms can follow amputations of more than just limbs. Descriptions of phantom breasts and even penises can be found in the early literature. So can recognition of the fact that phantoms can be brought on by loud noises, changes in the weather, emotional turmoil, and physical (including electrical) stimulation of the nerve trunk. Perceived changes in the size and position of a missing part have also been studied, as has the time-since-amputation factor.

The literature on phantom limbs now encompasses hundreds of papers and many books. These writings describe a multitude of treatments that have been tried, often with only temporary success. They include nerve resection, cauterization, narcotics, anesthetics, nerve blocks, acupuncture, and more radical amputations. Like Paré, Descartes, Bell, and Mitchell, people today are still trying to understand the relative contributions of signals from remaining nerve stumps, the roles of associative learning and memory, and the actions of the creative brain in this perplexing disorder. The hope is that, with more knowledge, there will be more effective treatments.

—Stanley Finger

See also Amputation; Pain.

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PHYSICAL ACTIVITY

An important aspect in improving the health of people with disabilities is to encourage higher levels of physical activity. Not only is physical activity important from the standpoint of promoting a higher quality of life by reducing secondary conditions and maintaining functional independence, but it is also essential in terms of reducing health care expenditures. Several reports have noted that a sedentary lifestyle can precipitate functional decline in people with disabilities and that physical activity must be a targeted health priority to prevent a progressive loss in health and function.

TERMINOLOGY IN PHYSICAL ACTIVITY

Physical activity involves all forms of bodily movement produced by contraction of skeletal muscle that substantially increases energy expenditure. Subcategories of physical activity include leisure-time physical activity (LTPA), which is a broad descriptor of the activities one participates in during free time, based on personal interests and needs. A structured form of physical activity is generally referred to as *exercise*, which is different from other forms of physical activity by its well-planned, structured, and consistent body movements and repetitions. Other kinds of physical activity include work-related activity or household activity. Gardening, cleaning, and working in physically demanding jobs (e.g., construction, janitorial) are all considered forms of physical activity. Among people who have a disability or are injured, therapy or rehabilitative exercise could also be considered a form of physical activity.

Physical Fitness. Physical fitness is defined as a set of attributes that people have or achieve that relates to the ability to perform physical activity. Components of physical fitness include cardiorespiratory endurance, muscular strength and endurance, flexibility, body composition (ratio of lean muscle mass to body fat), balance, and respiratory function. Certain individuals with disabilities will require a greater amount of each component depending on the various secondary conditions that may be associated with their disability. For example, persons with post–polio syndrome may require respiratory exercises to maintain the strength of the pulmonary musculature. Individuals with multiple sclerosis often have difficulty with gait and balance and would benefit from an exercise training program that targeted these areas.

Exercise. This is a subset of physical activity that is planned, structured, and consists of repetitive bodily movement that is done to improve or maintain one or more components of physical fitness. Examples of structured exercise that people with disabilities often participate in are chair aerobics, swimming, and handcycling, among others.

Moderate-Intensity Physical Activity. This term is used in the *Healthy People 2010* document to describe any type of physical activity requiring three to six times the energy required at rest. Since the definition has been developed for young individuals without disabilities, it is not clear if a "moderate" level of physical activity would be different for persons with disabilities.

Vigorous Physical Activity. This term is also used in the *Healthy People 2010* document to express any physical activity requiring seven times the energy required at rest. Similar to the definition for moderate intensity physical activity, this definition has been established for younger populations without disability.

Many activities that people with disabilities perform require a higher level of energy expenditure (i.e., transfers, walking with crutches or pushing a wheelchair, carrying various items). It is possible that moderate or vigorous physical activity has a different connotation for people with disabilities and does not fall in the same range that describes these activities for the general population. For example, carrying a bag of groceries from the store to the car may be considered a "moderate" activity for the general population but a "vigorous" activity for someone with reduced gait efficiency. More research is needed to evaluate the intensity level of various instrumental activities of daily living and general physical activities in persons with various types of physical, cognitive, and sensory disabilities.

PUBLIC HEALTH INITIATIVE IN PHYSICAL ACTIVITY

As a result of several landmark studies that have shown a graded, inverse relationship between physical activity/fitness and the incidence of morbidity and mortality, public health officials and federal agencies are recommending that all Americans, including persons with disabilities, engage in a minimum of 30 minutes a day of moderate aerobic exercise. The American Heart Association, National Institutes of Health, Centers for Disease Control and Prevention, Surgeon General's Office, and the American College of Sports Medicine have all developed position statements that call for Americans to achieve a higher level of physical activity. One of the historic documents published by the Surgeon General's Office in 1996 was a report titled *The Surgeon General's Report on Physical Activity and Health.* This report emphasized that physical inactivity is a major contributor to heart disease, adult onset diabetes, and colon cancer and that the risk from inactivity is similar to that of smoking. Today, physical activity has been recognized by numerous public health organizations as an important vehicle for improving the health of the U.S. population.

Despite strong endorsements from the Centers for Disease Control and Prevention (CDC), National Institutes of Health, Surgeon General's Office, and American College of Sports Medicine, most Americans are still not obtaining the recommended amount of physical activity that is necessary for maintaining health, and the level of physical inactivity among persons with disabilities is significantly higher than that of the general population. This represents a significant public health issue for people with disabilities.

OVERVIEW OF PHYSICAL ACTIVITY AND DISABILITY

For close to a half century, exercise has been promoted as one of the most powerful health promotion strategies for reducing chronic disease (i.e., heart disease, diabetes) and functional limitations. The first 25 years of research in exercise physiology contained only a handful of studies that investigated the effects of exercise on people with disabilities. Several of these studies were conducted on children with cerebral palsy and other neuromuscular disorders, primarily in Sweden and other Scandinavian countries. It was only until the mid-1980s that a growing number of researchers began to investigate the effects of exercise on people with disabilities in both children and adults.

The research literature on physical activity, exercise, and disability continues to expand. Exercise-related studies are being conducted to determine the effects of various interventions using cardiorespiratory, strength, flexibility, and balance training to enhance overall health and function. While there are numerous short-term studies demonstrating the positive effects of exercise on improving various health outcomes in people with disabilities, longitudinal studies are still lacking.

Low Physical Activity Participation among People with Disabilities

Federal officials and members of the public health community are growing increasingly concerned that as persons with disabilities age, they will have increasing difficulty performing activities of daily living (ADL) (i.e., dressing, showering) and instrumental activities of daily living (IADL) (i.e., ambulation, doing laundry, grocery shopping) at a much earlier rate than the general population. Persons with physical disabilities are often faced with various environmental challenges (i.e., navigating ramps and curb cuts, performing transfers) as a result of their impairment (i.e., paralysis) and/or associated secondary conditions (i.e., spasticity, weakness, pain, fatigue). The high incidence of physical inactivity observed in persons with disabilities, combined with the natural aging process, presents a greater risk of premature physical decline and accentuates the importance of physical activity in maintaining health and function.

Despite calls for higher levels of physical activity from major federal and private agencies, the vast majority of persons with disabilities are not obtaining the recommended 30 minutes a day of physical activity necessary for conferring health benefits and preventing or mitigating secondary conditions. Several reports have noted that people with disabilities have a disproportionately higher incidence of physical inactivity compared to people without disabilities. The *Healthy People 2010* document reported the prevalence of physical inactivity among people with disabilities to be substantially higher than in people without disabilities, 56 percent versus 36 percent. And in data collected at the National Center on Physical Activity and Disability (NCPAD), very low levels of physical activity were reported among various subgroups of disability. As noted in Figure 1, individuals with stroke, type 2 diabetes, and arthritis were significantly below the recommended 30 minutes a day of moderate exercise recommended by the CDC and other federal agencies.

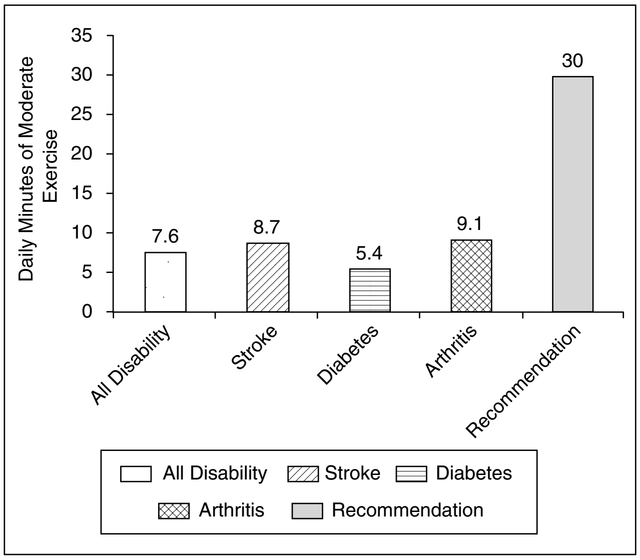

Figure 1 Daily Physical Activity Reported by People with Disabilities

Source: Data from the National Center on Physical Activity and Disability (www.ncpad.org).

Physical Activity and Reduction of Secondary Conditions

Numerous laboratory and field-based studies have quantified the many health and fitness benefits associated with physical activity. Among studies with disabled populations, benefits of endurance and strength training include reduced fatigue, reduced pain, improved fitness, and general well-being. Implicit in these reports is the notion that the health and fitness benefits associated with physical activity most likely follow a dose-response relationship. Most experts agree that any amount of physical activity is beneficial and that even minimal amounts of physical activity are better than no physical activity at all, and increasing amounts of physical activity accrue greater health benefits provided it is done safely. Vigorous physical activity performed in excess amounts (usually greater than one hour) increases the risk of injury. Physical activity must be conducted in a manner that allows maximum benefits at the lowest possible risk. Given the progressive nature of certain disabilities (i.e., multiple sclerosis) or physiological changes that occur after injury (i.e., spinal cord injury), greater attention must be provided by exercise specialists to ensure that the program is safe and effective in enhancing overall health. Shoulder injuries are common in chair users and have prompted researchers to develop alternative ways to exercise that will reduce the stress on joints and muscles that are used for ambulation.

Physical Activity, Functional Status, and Disability

Given the empirical evidence linking physical activity with functional status and overall health, as well as the fact that impaired health and functioning can impede participation in physical activity, one can postulate a downward cyclical pattern in both health and functioning that results from prolonged physical inactivity. The onset of disability often results in greater effort required to engage in physical activity, thereby causing persons with disabilities to remain sedentary. Physical inactivity over prolonged periods results in the development of secondary disabling conditions and further functional loss, which in turn results in greater effort to participate in physical activities.

The relationship between physical functioning and physical activity is a reciprocal one; physical functioning provides the individual with the capability to engage in physical activities, whereas physical activity helps to maintain and, in some cases, improve physical functioning. This reciprocal relationship, coupled with the high prevalence of physical inactivity among persons with disabilities, has profound implications for rehabilitation practice, especially in evaluating intermediate and long-term outcomes of clinical practice. For rehabilitation to play a role in the long-term maintenance and enhancement of physical functioning among persons with disabilities, monitoring of physical activity by both rehabilitation professionals and individuals with disabilities must be part of the recovery and maintenance process. The development of a standardized tool for assessing physical activity levels of people with physical disabilities can serve the purpose of monitoring physical activity patterns at both the individual (clinical application) and population levels (public health surveillance level).

Barriers to Physical Activity Experienced by People with Disabilities

Despite the plethora of evidence supporting the benefits of regular physical activity for improving health and function, people with disabilities are not engaging in physically active lifestyles at the same level as their peers. This may be due, in part, to the many environmental barriers to physical activity that people with disabilities are often confronted with, including inaccessible equipment and programs, transportation difficulties, limited income, unsafe neighborhoods, and a variety of personal barriers such as chronic health conditions and beliefs that exercise will not benefit their health.

Accessibility of fitness and recreation programs and facilities is a critical issue affecting the participation of persons with disabilities in fitness and leisure activities and ultimately affects their ability to improve their health and quality of life. A common barrier in the disabled population is the lack of attention given in promotional campaigns to the needs of persons with disabilities. Public health messages encouraging people to become more physically active usually recommend walking a minimum of 30 minutes a day most days of the week. Unfortunately, this recommendation is unattainable by many people with disabilities and chronic health conditions who are unable to walk (i.e., spinal cord injury, multiple sclerosis), have difficulty walking (i.e., back pain, obesity, heart condition, arthritis, frailty), live in neighborhoods where it is unsafe to walk, or are not allowed to walk without supervision. Campaigns to increase physical activity must present a more inclusive image by providing people with disabilities greater opportunities to improve their health besides walking. For this to occur, personal and environmental barriers must be eliminated so that access to various types of physical activity can be engaged in by a significant percentage of the disabled population.

Resource on Physical Activity and Disability: NCPAD

Through a grant from the CDC and the National Center on Birth Defects and Developmental Disabilities, the National Center on Physical Activity and Disability (referred to as NCPAD) was established in 1999. This information and resource center offers people with disabilities, caregivers, and professionals the latest information on fitness, recreation, and sports programs for people with disabilities. NCPAD's aim is to collect and synthesize various types of information on physical activity, rehabilitation, and disability and to disseminate this information to fitness and health professionals. With advances in technology, the NCPAD website at http://www.ncpad.org contains various types of readily accessible information on exercise and disability. The center also publishes a monthly electronic newsletter and sends out monthly features via e-mail on new topics and information related to physical activity and disability.

SUMMARY

The evidence concerning the benefits of physical activity is compelling. Among people in the general population, participation in habitual physical activity extends life, prevents multiple chronic conditions, and has beneficial effects on many systems of the body. Physical activity epidemiologists have noted that approximately 250,000 deaths in the United States annually can be attributed to a sedentary lifestyle. It is considered one of the leading preventable causes of death in our society.

It is unfortunate that most, if not all, of the physical activity longitudinal research has been conducted on nondisabled populations. While there is good evidence from short-term clinical studies demonstrating the benefits of physical activity among various subgroups of disabled populations, there is a dearth of longitudinal data on the long-term effects of physical activity in this cohort. Future longitudinal studies must be conducted on various subgroups of individuals with disabilities to determine the magnitude of health benefits that might be accrued from a physically active lifestyle.

—James H. Rimmer

See also Activities of Daily Living; Exercise and Physical Activity; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Recreation; Sports and Disability.

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PHYSICAL MEDICINE AND REHABILITATION

Until the beginning of the twentieth century, people with disabilities were generally scorned, pitied, demeaned, and, in some societies, killed. As recently as the 1950s, they were "imprisoned" without trial in places such as "The Home for the Incurables" and custodial facilities. Even when kept at home, they were often isolated and "hidden" from outsiders. Still, "custodial care" too often is considered first, before placement at home.

There were isolated instances of medical people who showed an interest in "cripples," but they were rare. In general, medical students and others were taught that it would be uninteresting and demeaning, if not futile, to be involved in the care of such people (as well as the elderly and chronically ill).

The main thrust toward the organized care of people with disabilities came because of (1) the great drama of polio, a sudden event (paralyzing and sometimes fatal) affecting a president, Franklin D. Roosevelt, and very frequently children, and (2) World Wars I and II. In both instances, the nation decided that care must be given and that there should be an attempt to reintegrate people with disabilities into the community.

This idea of allowing people with disabilities to participate and contribute in the community was not entirely original at that time. At the beginning of the twentieth century, bureaucracies were intended to facilitate employment of people with disabilities, especially if they had been in the military.

In most wars, relatively few numbers of disabled people had returned home; however, with the discovery of antibiotics and better trauma care, more veterans of World War II survived, and there was a national outcry that these people, these heroes, should not be "discarded."

In military hospitals, some physicians took it upon themselves to develop a system to help these veterans (largely men). It was soon discovered that it would be necessary to deal with issues of functional loss and frequently with overwhelming psychological and sociological issues. Social work, nursing, and other allied health personnel were found to be necessary in carrying out this work as a collaborative effort.

A solo physician could not address these needs alone, so "collaborative medicine" practices were developed to unite the physician with a team of medical consultants as well as nurses, physical therapists, social workers, speech pathologists, occupational therapists, vocational counselors, and various technicians. The approach had to be nonautocratic and non–male chauvinistic.

At the same time, the Veterans Administration (VA) system was developed, and most of its 172 hospitals included this potential for a rehabilitation system.

In the meantime, celebrity status was given to polio, especially because of the effect it had on Franklin D. Roosevelt, and huge amounts of money were raised as a bulwark for a national effort to provide care for this population.

These movements required physicians able to practice physical medicine and rehabilitation (PM&R), so the demand grew.

At about this time, a philanthropic couple in New York, Mary and Albert Lasker, became very interested in health. At some point, Albert Lasker decided that although he and his wife could contribute large sums of money to worthy causes, they could multiply this amount hundreds of times by "lobbying" in Washington, D.C., to get the government more involved in health.

Their main contribution to society was providing the impetus for the formation of the National Institutes of Health. They discovered that in Washington, D.C., there was a small agency headed by Mary Switzer that attended to some aspects of people with disabilities, especially vocation. Switzer was an intelligent, charming, and convincing woman with New England force and directness blended with Irish charm.

The Laskers also discovered an extraordinarily capable and charismatic man, Dr. Howard Rusk, who had built a rehabilitation center in New York at the NYU Bellevue Medical Center on 34th Street. He was an internist but had helped invent the techniques of PM&R and promulgated its principles. He had built the rehabilitation center at Jefferson Barrack Hospital in Missouri during the war. Dr. Rusk and Switzer, united by the Laskers, mesmerized the Congress and generated millions of dollars for Switzer's agency.

Mary Switzer's agency developed a mandate to deal with disability very broadly—educating a whole nation about people with disabilities. At that time, few hospitals or medical schools had shown much interest in people with disabilities, but their interest was piqued when money appeared on the horizon. Not only did Ms. Switzer supply funds for programs to train residents in the specialty of PM&R (physiatrists), but she also offered funding for stipends for medical students to train. Training residents made it possible to send physiatrists where there were few or none, and good and early care could be made available. Even now in the United States, if someone becomes disabled, he or she may go to the person considered the best doctor in town and find that the doctor has never seen a similar case and has no knowledge of rehabilitation. Switzer's impact on medical students started with her mandatory summer fellowship. Eventually, mandatory rehabilitation rotations were added for students in medical school.

Switzer also established regional research and training centers, which became very important, and some eventually evolved into centers for spinal cord injury and stroke. In each of these instances, a grant went to a comprehensive center and gave it status along with the obligation to have links to other states and to spread knowledge about aspects of disability beyond the original centers.

All of this made PM&R much more visible—to the medical and lay communities. Progress has been slow in coming, however, partly because physiatrists have not made an effort to explain who they are, what they do, and what their background and education are. Many physiatrists will not even use the word *physiatrist* but will simply say they care for the disabled. This does little to spread the word about the field of PM&R.

EARLY EFFORTS IN REHABILITATION MEDICINE

The first major thrust toward thinking about bringing people with disabilities into the mainstream of society was accomplished by Jeremiah Milbank, a wealthy 30-year-old New York lawyer who had been interested in helping the "crippled beggars" in the streets of New York. He allied his thinking with ideas from Germany, Canada, and France. Even before World War I, he had joined a few pioneering thinkers who were pushing to create self-sufficiency. They decided to create a rehabilitation facility in New York: the Red Cross Institute for Crippled Soldiers and Sailors. (It opened just after the war began.)

At the same time, the Army Surgeon General was encouraging growth of allied health assistance. Soon before World War I began, the American Occupational Therapy Association was formed. Milbank developed a program to educate the country about the potential of people with disabilities by providing medical/vocational assistance, training professionals, publishing literature, and establishing media contacts.

In about 1920, the state of Ohio created an organization to work with crippled children, and the Shriners opened hospitals for the care of these children.

Simultaneously, care providers saw a growing alliance in care among medical, surgical, and vocational/psychological/sociological health care providers, which set the stage for progression toward the collaborative approach of physiatry. Nonetheless, by 1920, there were few people in the field of rehabilitation.

Physical therapy began to develop and became recognized by physicians as vital to their team. In 1926, Dr. John Stanley Coulter pioneered PM&R in the United States and became assistant professor of physical therapy at Northwestern University Medical School.

In 1928, President Hoover established a "Children's Charter" highlighting the need to attend to the needs of crippled children.

In 1929, Dr. Frank Krusen established a Department of Physical Medicine and Rehabilitation at Temple University. He then joined the Mayo Clinic in 1935, organizing and directing the Mayo Clinic Graduate School of Medicine's first three-year fellowship in physical medicine.

In 1935, Dr. Henry Kessler wrote about the absolute necessity of the development of the rehabilitation movement around a comprehensive medical, sociological, psychological, and vocational model. He built a center in New Jersey and published eloquent reports and papers.

Dr. Kessler objected to the Workmen's Compensation Program, which made it more profitable to neglect the disabled than to restore them to activity and productivity.

In 1936, the American Academy of Physical Medicine & Rehabilitation was founded, and Dr. Krusen was elected as its first president. He wrote definitive texts, and his trainees were the first doctors trained to care for the disabled.

In 1942, Dr. Howard Rusk started the Army/Air Force Convalescent Center at Jefferson Barrack Hospital in Missouri. The plan was that "convalescent time" could be "rehabilitation time." In New York, Dr. Rusk learned how to proceed from the Milbank Institute for the Crippled and Disabled and was able to broaden physical medicine in his burgeoning "convalescent program." In the meantime, Dr. Krusen was a consultant in PM&R to the U.S. Army. He also continued to stress the need of education in PM&R.

In the war years, Bernard Baruch established the Baruch Committee on PM&R. He laid the groundwork for a great expansion in rehabilitation. Mr. Baruch gave grants for educating individuals and established major centers in research and patient care at Columbia, the Medical College of Virginia, and NYU. Concomitantly, the number of occupational therapists and physical therapists continued to grow and receive acceptance as key personnel in military hospitals.

The collaborative approach was even more firmly demonstrated through the founding of spinal cord injury centers at Hines VA (Illinois), the Bronx (New York), and Van Nuys (California). Dr. Paul Magnuson, who became the second medical director of the VA system, was first in charge of education and research and then headed the Dean's Committee System, which linked VA hospitals to academic centers. He later founded the Rehabilitation Institute of Chicago.

In 1947, the denouement in officially recognizing PM&R occurred with the approval of the American Board of Physical Medicine & Rehabilitation by the American Medical Association (AMA). The first three certificates of specialization went to Dr. John Coulter, Dr. Walter Zeiter, and Dr. Frank Krusen.

THE PM&R FIELD TODAY

The vision statement for the Academy of Physical Medicine & Rehabilitation, the major professional organization for physiatrists, is as follows:

> The American Academy of Physical Medicine and Rehabilitation will be the leader in assisting PM&R physicians to acquire the continuing education, practice knowledge, leadership skills, and research information needed to provide quality patient care, and to represent the best interests of patients with, or at risk for, temporary or permanent disabilities.

The distinction of the field of PM&R lies today in its ability to deal with the technical issues involved in diagnosing and treating disabilities/functional loss in ways that can in great breadth affect the quality of life of the individual patient. The training of physiatrists gives them a unique ability to unite in consideration of the basic pathology, the psychology of the patient, the social environment and the effects of existing attitudes allied to the patient, and what might appear to be a "new identity."

They have particular skill in bringing together all the facts at hand and being able to turn to members of the coalition who are best equipped to explain and deal with these matters. It is understood that there must be a sense of equality among members of the team and universal, mutual respect for the talents of all involved. Citizens in the United States are well aware of the need for "coordination" in health care and certainly in the case of people with disabilities; good care cannot be given without such talent available. In all health care, these premises are valid.

> Life is short, the art long, occasion sudden, experience fallible and judgement difficult. Not only must the physician show himself prepared to do what is needed, he must make the patients and attendants and the surrounding circumstances cooperate with him. (Hippocrates, 1st Aphorism)

—Henry B. Betts

See also Decision Making; Professions; Rehabilitation Medicine, International.

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PHYSICAL THERAPY

Physical therapy is a health profession serving persons of any age or health status with compromised physical functioning or the desire to improve their current physical functioning. Typical clients are persons with compromised quality of life as a result of impairments, functional limitations, and disabilities caused by disease or injury. Physical therapists complete an examination of the individual and work with the person to determine goals that are reached primarily through exercise prescription and functional training to improve movement. A key component of patient management is education to promote physical health and to prevent injury and disability caused by abnormal posture and movement. Other problems such as pain may be addressed with treatments, including mobilization of soft tissues and joints, electrotherapy, and other physical agents.

Although the use of exercise as part of a healthy lifestyle is ancient in its origins, modern physical therapy developed in response to the needs of injured soldiers. The first physical therapists in the United States were trained to work with soldiers returning from World War I and were called “reconstruction aides.” Some worked in hospitals close to the battlefields in France to begin early rehabilitation of wounded soldiers. Typical patients were those with amputated limbs, head injuries, and spinal cord injuries. As the field developed in the early part of the twentieth century, physical therapists also attended to the movement needs of those affected by polio epidemics. In this instance, strength was impaired by damage to cells that activate muscles to create movement. For these clients, physical therapists developed programs to strengthen muscles when possible and helped patients learn how to use the remaining musculature to accomplish functional mobility activities.

Physical therapists now practice in a wide variety of settings, including private practices, hospitals, rehabilitation centers, nursing homes, public schools, and home health agencies. In all of these settings, therapists work with the other members of the health care team toward common functional patient goals. Typical clients are individuals with back pain, elderly persons with arthritis or balance problems, injured athletes, infants with developmental disabilities, and persons who have had severe burns, strokes, or spinal cord injuries. For all of these individuals, physical therapists are the experts in examining and treating musculoskeletal and neuromuscular problems that affect how people move and perform physical functions such as standing up, walking, and lifting. Persons whose endurance for movement is affected by heart or lung problems or other illnesses are also helped by exercise and education to build activity tolerance, improve muscle strength, and move efficiently during functional activities. Individuals with limb deficiencies are taught to use prosthetic replacement devices.

Examination of the individual begins with identifying the client’s perceived problems with functional activities and his or her movement goals for reducing disability and improving quality of life. Adults with the types of impairments and functional limitations described above can be taught how to recover or improve movements impaired by disease and injury. On the other hand, infants born with developmental disabilities are helped to learn movements they have never done before, with an emphasis on functional mobility for satisfying participation in family and community activities.

New areas of practice are continually developing. For example, the scope of practice of a growing specialty in women’s health includes concerns of women such as incontinence, pelvic/vaginal pain, prenatal and postpartum musculosketelal pain, osteoporosis, rehabilitation following breast surgery, lymphedema, and education for prevention, wellness, and exercise. All females across the lifespan, from the young athlete to the childbearing woman to the menopausal and elderly woman, can benefit from physical therapy.

In addition to working with individuals and their family members, many physical therapists have agencies or organizations as their clients. In the role of consultant, they perform services such as advising clients on preventing back injury in workers or designing workplace environments to prevent repetitive use injury. Physical therapists also teach in higher education institutions, specialize in areas such as the training of high-performance athletes, consult with public school teachers to educate children with disabilities, and provide consultation to fitness centers on developing workouts for clients who already know they have joint or back problems.

Physical therapists (also called physiotherapists) are at work in countries all over the world. The World Confederation for Physical Therapy is a nonprofit organization consisting of 82 national physical therapy associations. The confederation represents 225,000 physical therapists worldwide. In the United States, the American Physical Therapy Association represents 64,000 physical therapists and physical therapist assistants. The organization’s mission is to further the profession’s role in the prevention, diagnosis, and treatment of movement dysfunction and to enhance the physical health and functional abilities of the public.

The Commission on Accreditation in Physical Therapy Education accredits educational programs for physical therapists who are trained at the master's or doctoral level and for physical therapist assistants who complete a two-year associate's degree program. Physical therapy professional education involves grounding in basic sciences such as anatomy, physiology, and movement science followed by clinical science courses on the musculoskeletal, neuromuscular, cardiopulmonary, and integumentary systems. Education for the profession culminates in clinical fieldwork training involving internships of various lengths up to about a year. Although a graduate-level college degree and state licensure are required for practice in the United States, physical therapy education in many countries takes place in polytechnical institutions.

—Suzann K. Campbell

See also Activities of Daily Living (ADLs); Health Care and Disability; Occupational Therapy Physical Activity.

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PHYSICIAN-ASSISTED SUICIDE

Defining physician-assisted suicide might initially appear a straightforward task, as it is an expression that concatenates three terms, each of whose meanings are clear and uncomplicated. However, even the most basic etymological exploration reveals a concept that sustains an inherent contradiction that is only the beginning of the problematization of what remains likely the single most critical issue in biomedical ethics. Said contradiction lies between the notions of "suicide," the killing of oneself, and "assistance," the implication of another in that killing, which by definition renders the assistant an agent and, at times, depending on the circumstances of that killing, even the sole agent in homicide, which may or may not be regarded as justifiable. In the simplest and most literal terms, then, *assistance* and *suicide* combine as—or at least approximate—an oxymoron, although one whose practice, whether legal or illegal, is far from unknown. Furthermore, moving only slightly beyond the most basic sort of definition, physicians are universally known to be admonished to "do no harm," a responsibility that is necessarily, at the very least, difficult to reconcile with deliberately putting a "patient" to death.

A major complication in defining physician-assisted suicide is that it is frequently conflated and even regarded as being synonymous with euthanasia or "mercy killing." The terms are (obviously) not (entirely) synonymous. The former assumes as an absolute given the agency of a medical doctor. The latter does not, and this has often been borne out in practice. While it is customary to presume that both terms assume the consent and even the explicit request of the person who is killed, there is neither anything inherent in the notion of euthanasia to safeguard that presumption, nor in the case of either term is it possible to arrive at an unproblematic definition of consent given the abject vulnerability of a person whose circumstances lead to an intentional death being contemplated.

In practice, those seeking assistance in suicide typically do so either because their physical impairments are such that they render the act of self-killing impossible and/or they are unable to legally and/or easily procure adequate quantities of toxic substances that would facilitate a relatively painless demise. Generally, "patients'" motivations fall into two, often overlapping, categories: (1) those whose impairments are so significant that they find the activities of daily living impossibly difficult without substantial, though possibly unavailable, assistance and (2) those who find their physical/emotional pain unbearable.

How any society responds to the question of physician-assisted suicide provides an important window into how it prioritizes the value and quality of life of its individual members, one that forces an examination of praxes of family units, health care delivery systems, educational programs, and social service networks. The desire to die is often the ramification of the unavailability of entirely feasible if currently/apparently unavailable enhancements to the quality of life, including disability accommodations, educational and professional opportunities, emotional and logistical support, and palliative medical and/or psychological care. In that context, the provision of and advocacy for the alternative of a quick, easy, and economical death as a solution to life's challenges requires the utmost scrutiny.

Laws regarding physician-assisted suicide are sometimes ambiguous. In the United States, the practice is legal only in the state of Oregon. It is also a lawful practice in the Netherlands, Belgium, and Switzerland and was permitted for nine months in the Northern Territories of Australia, ending in 1997. The practice is legal, though, owing to social opprobrium, practically nonexistent, in Japan. Whether physician-assisted suicide is right or wrong, its availability anywhere implicates medical doctors and biomedical ethicists who condone the practice.

In the United States, physician-assisted suicide achieved its greatest notoriety through the infamous "Dr. Death," Jack Kevorkian, a pathologist who claims to have illegally assisted in dispatching over 130 "patients," many obviously and almost surely treatably depressed, others with conditions such as fibromyalgia, which threaten neither life nor general health and for which palliative treatment is frequently available. Since 1999, Kevorkian has been serving a 10- to 25-year prison sentence for second-degree murder, the result of his participation in an assisted suicide.

—Alex J. Lubet

See also Death; Ethics; Euthanasia; Quality of Life.

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PINEL, PHILIPPE (1745–1826)

One of the founders of modern psychiatry

Philippe Pinel is considered by many to be the father of modern psychiatry. After the French Revolution, he was appointed physician to the infirmaries at the Bicetre Hospital, which at that time housed 4,000 criminals, pensioners, and the sick, including many with syphilis. Pinel focused his attention on the ward housing 200 mentally ill men where he instituted a strict nonviolent, nonmedical management of patients that became known as "moral treatment." Although he gave due credit to his mentor, Jean Baptiste Pussin (1745–1811), who had freed patients from their shackles and invented the straightjacket, it was Pinel who was credited for the improved management of the mentally ill. After he moved to the Salpêtrière Hospital, he worked to assure that the shackles were removed from patients there. Pinel also put an end to the bleeding, purging, and blistering "therapeutic" interventions for the mentally ill. He focused his energies on careful diagnosis developed through close contact, observation, and extensive conversations with patients. He kept careful notes on his patients, which served as the basis of his book, *Traité medico-philosphique sur l'alienation mentale; ou la manie* (1801), translated in English as *Treatise on Insanity* (1806). In 1795, he was appointed to the chair of medical pathology, which he held for 20 years, and was also named chief physician of the Salpêtrière, which he kept until his death.

Pinel created an inoculation clinic at the Salpetriere, where the first vaccination was given in Paris in 1800. In 1798, he published *Nosographie philosophique ou methode de l'analyse appliquée à la médicine,* which was, for the time, an authoritative classification of diseases. He was elected to the French Académie des Sciences in 1804 and to the Académie de Médicine in 1820. His treatise on mental illness has had a long lasting influence on French, English, and American psychiatry. He has been immortalized in paintings, prints, and by a statue situated outside the Salpetriere.

—Claude Wacjman

POETRY

Poetry seeks to explore and validate the lived experience of moving through the world with a disability. Sometimes referred to as crip poetry, disability poetry embodies a disability consciousness; it is informed by and contributes to disability culture.

Like the rest of the disability arts movement, crip poetry rejects the view of disability as a shameful, pitiable, tragic, and individual phenomenon. Fundamental to crip poetry is an understanding of disability as a social construction. This is not a denial of the pain and functional limitations that may come with impairment—in fact, disability poetry is often informed by a heightened awareness of those aspects of impairment. But crip poetry is also sharply aware that a major part of the impact that disabilities have on lives results from the ways those human differences are interpreted culturally and responded to by society, so often with prejudice, marginalization, and discrimination. Lynn Manning's poem "The Magic Wand" explicitly addresses this point when it describes the transformation the persona undergoes, "from black man to blind man," through the simple act of unfolding his white cane.

Disability poetry can be characterized by several characteristics: a challenge to stereotypes and an insistence on self-definition; foregrounding of the perspective of people with disabilities; an emphasis on embodiment, especially atypical embodiment; and alternative techniques and poetics.

One of the major impulses of crip poetry is to resist stereotyping and the limits of the socially imposed "handicapped" identity through a process of self-definition. Disability poetry often explicitly rejects social pressure to pursue a forever-elusive "normality" and instead finds value and strength within disability experience, not *in spite of* impairments but *because of* and *through* them. This can be seen in Cheryl Marie Wade's "I Am Not One of The," in which the persona forcefully rejects the labels that are applied to her.

The speaker of this poem rejects the euphemistic labels applied to her by a world that would prefer to not discuss disability and rather simply stereotype her. Instead, she articulates an identity for herself. She claims a kinship with disabled people through history, including those hidden away, left to die, even executed for their disabilities. Each time she rejects the euphemism, she replaces it with images that confound common expectations for people with disabilities—images of strength, of action, of sexual attraction and pleasure. The poem situates people with disabilities not in the margins but in the center of human experience ("I'm the first cell divided," "I've been forever I'll be here forever"). By the end of the poem, she has claimed negative terminology ("gimp," "cripple," "crazy") for her own, transforming the terms with the final, triumphant assertion: "I'm the Woman With Juice."

Disability has typically been described by nondisabled people. Another characteristic of disability poetry is that not only is it situated within the lived experience of disabled people, but it specifically comes from the perspective of people whose bodies and minds have been deemed anomalous. Whether from wheelchair height or through impaired eyes or ears, crip poetry foregrounds an alternative perspective. Sometimes, that alternative perspective is specifically addressed in the poem, as in "Harvest" by Stephen Kuusisto, when the speaker seeks to "admire the white moon of the morning, / even if my eyes tell me there are two moons."

Embodiment is another characteristic of disability poetry. Crip poetry demonstrates an awareness of and sensitivity to the body, which may not be unique to poetry within a disability aesthetic but is certainly present. This is not to suggest that disability poetry is simply participating in a larger poetics of embodiment, which centers the body as the source of artistic production but also expects bodies to conform to nondisabled expectations. Instead, with its attention to alternative ways of being in the world, crip poetry seeks to redefine what it means to have and be a body in the world. In Mark O'Brien's poem "The Man in the Iron Lung," the speaker describes his dream life in "the body electric," which "inserts itself in the map of my mind." As it "whooshes beautiful lies of invulnerability," it forces its way not just into his lungs but into his sense of who he is. Eli Clare describes a far different anomalous embodiment in “Learning to Speak”: “I practiced the sounds *th, sh, sl* / for years, a pianist playing endless / hours of scales. I had to learn / the muscle of my tongue.”

Because of this emphasis on exploding the limits of acceptable bodies in the world, embodying poems through performance is an important part of disability poetry. Disability is centrally about bodies, how they look and act, and how they are construed, so this embodiment is a crucial strategy. People with disabilities are often told to disregard their flawed, unsatisfactory bodies; paying the attention that poems evoke and reward is a powerful antidote, one that is intensified and multiplied through performance. And, as with other disability arts, events that include the performance of crip poetry are an important site for the continuing development of disability culture.

Alternative poetics can be found in disability poetry as well. Anomalous ways of moving through the world can lead to formal differences in poems; for example, using a respirator to breathe has significant potential to influence rhythms and use of the line. Cerebral palsy had a significant impact on the poetry of Larry Eigner, including the length of his poems—it was difficult for him to put a new piece of paper in his typewriter—and his distinctive use of space on the page. It is important to note that alternative embodiment, cognition, and rationality do not guarantee alternative poetics, but anomalous ways of encountering the world seem likely to influence a disabled writer’s poetry.

—Jim Ferris

See also Art Therapy; Disability Culture; Representations of Disability, History of.

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POLIO

Although forgotten by many, polio was during the past centuries one of the most widespread and devastating diseases, leaving many persons with residual functional limitations. The disease is not completely eradicated, however, with a few new cases in some countries in Asia and Africa during recent years. The major health problem is the late effects of polio with reduced muscle functions and other symptoms leading to increased disability decades after the initial period.

DISEASE AND PREVALENCE

Polio (or poliomyelitis) is a virus-spread disease whose only known host is man. There are three types of polio virus (1, 2, 3), which is spread mainly through fecal-oral infection, usually through the water system. Polio has been accompanying man for a long time, and archaeological dig-outs from Egypt have identified skeletons with changes after polio, from more than 13,000 years B.C., and there are hieroglyphic stones with persons seemingly affected by polio. It has been an endemic disease, but with increased hygiene, epidemics started. Large epidemics occurred in Scandinavia, North America, and Australia in the 1940s and later. The virus has a seasonal variation, with a start in late summer and continuing during fall and declining in midwinter. The typical picture of a polio case starts with an initial infection with slight upper respiratory infection, general malaise with slight fever, fatigue, or gastroenteritis. The disease could stop here (so-called abortive polio), but often within a few days up to a week, the meningitis would start. Fever occurs with headaches and a stiff neck. While the fever is still rising, the paralysis starts to occur, and after a few days, the fever goes down but usually the paralysis stays. The paralysis is characterized by flaccid, asymmetric paresis. The most common form is spinal polio, where the legs often are involved and the breathing muscles are often affected, giving reduced pulmonary function. Cranial polio could affect the facial nerves but also the lower cranial nerves. The so-called bulbar polio results in paralysis of the throat and eventual paralysis of the swallowing process, with the gathering of secretion in the throat and lungs, eventually suffocating the patient. The centers for breathing and circulation in the brainstem could also be affected. Cerebral polio is similar to other types of encephalitis, with a drowsy-person "slow cerebration," but could lead to coma and death. The start of the vaccination era halted this.

The first vaccination was developed by Dr. Jonas Salk, who developed a vaccine that was a mixture of the three virus types, which were killed with formalin. Vaccination trials started, and the vaccine was available in 1955, which ended the epidemics in the Western world. A new vaccine developed by Dr. Albert Sabin (approved for use in 1961), which was made of weakened virus strains and given orally, gained popularity and is now the dominating vaccine in the world.

During 2002, around 500 confirmed cases were reported to the World Health Organization (WHO), and polio was still present as an endemic in Pakistan, Afghanistan, India, Nigeria, Niger, Egypt, and Somalia, with a few cases in Ghana and Lebanon. The number of persons who have had polio and are thereby at risk for late effects of polio is not known, but WHO estimates that there are up to 20,000,000 survivors in the world today. The risk for developing post–polio syndrome is not known, with reports ranging from around 25 percent up to 75 percent. This means that 5,000,000 to 15,000,000 persons might need to be in contact with the health system now and in the next 50 years for problems due to the late effects of polio.

CONSEQUENCES OF POLIO

Polio survivors may experience different types of health problems. Dominating are new or increased muscle weakness, general fatigue, pain in muscles and joints, and, for a smaller group, breathing problems. There may also be reduced tolerance to cold.

The muscular symptoms are connected to the initial loss of nerve cells in the anterior part of the spinal cord. During the recovery, after the initial infection, there is a more or less pronounced reinnervation by terminal sprouting from still-functioning motor units—a motor unit is the nerve cell, with its nerve and nerve branches and the muscle cells (fibers) connected to that nerve cell. In that way, one of the same nerve cells may have innervated several times the normal number of muscle fibers. This process leads to recovery of muscle function, which even could become normal or near normal in a polio-affected muscle. Besides that, the other compensatory mechanisms are increased size of the muscle fibers (hypertrophy), which can be double the normal cross-sectional area in muscles used in daily life. Over time (often 20–30 years after the initial polio infection), these compensatory processes may not maintain the muscle strength. This may be due to several factors, as further loss of nerve cells in the spinal cord (aging and/or overload) and less efficient reinnervation. Still, there is evidence of an ongoing reinnervation also at that age, with motor units that may contain five or even more times the normal number of muscle fibers. There may also be immunological factors involved in the deterioration of function.

Fatigue is a common symptom and can be muscular due to muscular overload or reduced physical fitness due to a low level of activity; it can also be of a central origin, to which damage in the central nervous system by the polio affection may contribute. Pain may be due to overload of muscles or joints and connected to physical activity. Persons with previous affection of respiratory muscles may experience further breathing problems.

These impairments may lead to different levels of activity limitation, especially mobility, as the lower limbs are usually more commonly affected than the upper limbs. This may then lead to limitations in activities in household work, work, leisure time, and so on. The person will suffer an increasing amount of disability. This situation has been named post–polio syndrome and is especially defined by increasing muscle weakness.

HEALTH CARE

This new or increased disability situation requires medical analysis to understand the background factors for that particular person and the possibility to give symptomatic help. Pain relief is important. Physical training may have positive effects on muscle strength and general fitness. Still more important is advice about the proper level of physical activity in daily life to facilitate adaptation to a new life situation. Technical aids are important for some persons, especially mobility aids such as canes, crutches, wheelchairs, or adapted cars. Orthoses may be given or renewed, especially in some cases of reconstructive orthopedic operations. Screening for reduction in breathing function is important since some persons may require assisted ventilation. Some people have been dependent on ventilators since the initial infection; others need night ventilators. There may also be psychological crises connected to the increased disability situation.

Although acute polio occurred quite recently in the Western world, knowledge about care for acute disease has disappeared, and the teaching in medical schools about the late effects is scarce. Therefore, not many health professionals have knowledge about the disease and the effects that might come with time. For polio survivors, this can be a frustrating experience when changes are occurring in their bodies and they seek advice. This can lead to unnecessary contacts with different specialists in the health care system and might prolong the correct diagnosis. Special clinics have therefore been created to handle the late effects of polio.

POLIO SUPPORT

In many countries, there are support groups available for polio survivors. They can serve many purposes: They give emotional support to the polio survivor and next of kin, provide information about the disease, help the polio survivor obtain health professionals who are knowledgeable about the disease, and lobby for more interest in the polio disease. The support groups are also involved in trying to get a more accessible society and provide information about disability rights in the society where they are active. Polio support groups have also been of great value, and the "polio-movement" is considered strong in many Western countries. However, new cases have appeared in several developing countries in the later decades, and it may be expected globally that there will be a large number of polio survivors with medical and disability problems for another half century.

—Gunnar Grimby and
Katharina Stibrant Sunnerhagen

See also Developing World; Disease; Infectious Diseases.

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Post-Polio Health International, www.post-polio.org

POLITICAL ECONOMY

The political economy of disability seems like an arcane topic until we realize that the inexorable growth and aging of the world population, particularly those with physical and mental disabilities, is putting enormous strains on governments, economies, and political systems in the developing and industrial worlds. Who will take care of these people? What systems can be put in place to deal with the problem? Who will pay for this and how? What will the burden be on our children and grandchildren? Disability is an issue that forces people to reassess their values and make painful decisions on how to allocate scare resources.

DEFINITION

Political economy is a perspective used in analyzing how money and politics shape behavior in social institutions such as health and welfare systems. Political economists emphasize that studying the interdependent operation of government and the economy is essential for understanding the survival and growth of a nation and the configuration and operation of its institutions. Political economists are equally concerned about how the demands of citizens influence government and economic institutions such as the National Health Service in the United Kingdom, splintered capitalistic health care systems in the United States, and government-run, public health–oriented systems in Cuba. Interestingly enough, the vast disparities in per capita expenditures across nations do not seem to have similar large effects on health outcomes as measured by mortality, morbidity, and disability. In fact, the most expensive system of all, the United States, leaves more than 60 million citizens totally uninsured or dramatically underinsured and does not produce longer life expectancy than that of many other countries. Differences between these systems can be explained by differences in values and economic and political systems. At the root of the issue lie different decisions on how to identify and manage risk, how to allocate scarce resources to those in need, and whether to believe in some sort of safety net. The tagline always is, What do people need? What do they want? Who is going to pay for this? And how much? The consequences of these decisions are far reaching because they speak to idealism, values, quality of life, and cross-generational responsibilities.

THE STATE

Because of global urbanization and changing values, people less often are living in extended family systems where the family as a unit cares for the weak and vulnerable. Consequently, the elderly and disabled are increasingly being thrown to their own devices and become more a concern for the state. In the microcosm of Cook County, Illinois, for example, more than half of the 4,000 current inmates of the county jail are judged to have mental illnesses, often complicated by the dual diagnosis of alcohol and drug addiction. In this case, the justice system is being used as a "dumping ground" for those with serious mental illnesses because their families are unable or unwilling to care for them, and there is no county or state mechanism for dealing with these people in the existing mental health system. In Africa, AIDS has become a similar unmanageable problem for families and governments with meager resources to prevent the problem or care for those with a prevalent, deadly condition. Where AIDS used to be a condition that killed rather quickly, modern treatments and drug regimens have extended life expectancy but often in a disabled condition. These HIV-positive individuals lose their capacity to work and parent, thus requiring constant care and medical attention. The burden on families is enormous. In those regions where HIV prevalency is at or above 40 percent, entire generations are being decimated, with dire consequences for the oldest and younger generations. These examples are illustrative of an international phenomenon. While responsibility for caring for the vulnerable is being transferred from the family to the state, the political and economic systems of most countries are not prepared to deal with these problems. People are living longer, and the numbers of disabled people are growing. Individuals typically have not saved enough for old age or anticipated disability. Families often do not have the resources or are not willing to pay for the care of their older and disabled members and do not want taxes raised in any form to do so. All of this leads to a crisis in the welfare state of industrial countries and insurmountable pressures on the economies of developing countries. As populations age and the number of young workers paying taxes decreases, something has to give. Savings and taxes must go up or the type, quality, and amount of services decrease.

VALUES

Disability exacerbates the pressures put on social institutions by aging and vulnerable populations; raises difficult ethical issues such as abortion, euthanasia, and physician-assisted suicide; and questions the basic values of a society. Disability symbolizes the debate over quality of life for individuals and their relatives and questions judgments about the lived experience of disabled persons. Is living with a disability an unbearable experience to avoided at all costs? Should individuals or their relatives be able to end their lives? If so, under what conditions, and who is to decide? What values and principles underlie these decisions? These are questions that disquiet individuals, family, and the state. For all of the espousal of family values and respect for elders, adult children are not eager to care for elders in their own homes and are reluctant to pay for expensive assisted care living. The trend in North America and other industrialized, urban countries is for more elders to live by themselves or in institutions, particularly if they are disabled or at the end of life.

Research studies complicate these discussions. There is growing evidence that many individuals with persistent and severe disabilities report a good or excellent quality of life even though external observers might judge otherwise. Many disabled people are as happy and enjoy life as much as those without disabilities. Like anyone else, they have no desire to be discounted, be left alone to fend for themselves, or die. Given the aging populations in the world, the trend is that more people will live longer with disabilities exacerbating the existing problem and placing more strains on families and welfare systems. Faced with these issues, disabled people are becoming better organized and more vocal. They are joining forces with the elderly to exert more political pressure on the state to address their needs. Almost every disability group has an organization that lobbies for their cause, be it Alzheimer's disease, multiple sclerosis, arthritis, asthma, depression, or intellectual disabilities. It is also clear that these people do not want to be made dependent. They want to make or at least actively participate in decisions that affect their quality of life and future.

These issues directly address the values of human life and to whom. Utilitarian philosophers have examined these problems through the lenses of an individual's worth to society and contribution to the common good. Economists have spent considerable time assessing the economic value of human life based on age, sex, education, ability to participate in the labor force, and capacity to pay for and consume goods and services. While both of these approaches are informative in exploring disability in society, the political economy of disability adds to the discussion by analyzing the interrelationship between disabled people and political and economic institutions. This is important because the political and economic institutions and values that undergrid them will determine how disabled people are treated in a society.

Political economic values and institutions vary from state to state. In the United States, considerable emphasis is placed on rugged individualism, capitalism, "free markets," and an "American" form of democracy. As a consequence, American funding for and support of disabled people is generally related to an individual's ability to work and be economically productive. In this sense, men are favored over women and children. American pundits say that American health insurance is wonderful as long as you do not have a serious or persistent health problem. This is really true for disabled people. Health insurance companies and the government try to limit the numbers and types of disabled people they cover. This is euphemistically called "cherry picking." The disability system is disjointed and often profit driven or risk aversive. Since there is no integrated "safety net," disabled people frequently fall between the cracks and have to rely on family and friends, live in an institution, or live alone poor. Investigations after the incredible loss of life among the elderly and disabled in the recent, severe summer heatwaves in Chicago and France indicated that thousands died because they were living alone, no one checked in on them during this dangerous time, they were unable or afraid to go out for help, they did not drink enough water, and they did not have fans or air-conditioning. In France, this occurred during the national vacation time when the vulnerable elderly and disabled were left alone. These problems are intensified because these vulnerable citizens are usually poor, so they cannot purchase assistive care if the family is not present. Disabled people are either poor to begin with or the loss of work and cost of dealing with their health and disability problems deplete their resources. These dynamics illustrate the dilemma that citizens face. Either they must care for their elderly and disabled in the family, or there must be an effective state system to do so.

Absent either solution, these vulnerable populations will suffer and even die as in the case of the Chicago and French heatwaves.

THE MARKETPLACE

On the other hand, because there are large numbers of disabled and dependent elderly people, private insurance money, public funds, and personal resources to pay for health care and rehabilitation goods and services, a large industry has developed to define and respond to this multibillion-dollar annual market. Historically, disabled individuals received benefits if they or their work were important to the national economy: members of the armed forces, merchant seamen, railroad workers, miners, and members of the government. More recently, disability benefits were expanded to a much larger population through social security, social welfare programs, and employer-based private insurance. As a consequence of extended coverage, demand for disability-oriented health care and rehabilitation goods and services grew enormously. A massive health care market niche for rehabilitation was created.

In the past, families, local communities, and charitable organizations cared for disabled people. Now, disability has become part of the capitalistic, free-market system where health care and rehabilitation goods and services have become commodities for sale, frequently at a profit. This increasing commodification and privatization of goods and services enabled remarkable growth in the hospital, medical goods, pharmaceutical, insurance, and rehabilitation industries from the 1980s to the present. Not only are these industries some of the fastest growing in the world's stock markets, but they are also among the most profitable. As health care and rehabilitation goods and services became privatized, industry focused on forming companies to serve a need and to make a profit. At times, it is unclear which goal predominates. Certainly, the size of corporations has grown through mergers and acquisitions, expansion of the market through advertising, and development of new products. Concurrent with the privatization of health and rehabilitation care has been the corporate abuses of the past 10 years. Executives of large health care companies have been accused and convicted of accounting irregularities, fraud, questionable marketing practices, and overpricing. The corporate jet, multimillion-dollar salaries, stock options, and golden retirement "parachutes" have become staples in the health care corporate world. HealthSouth is an example of such a multi-billion-dollar company.

While the corporatization of health and rehabilitation care has resulted in remarkable advances in health care and rehabilitation, it has driven up the cost of care to unprecedented heights, creating an expanding chasm between those who can afford these goods and services and those who cannot. These forces raise fundamental questions about capitalism and democracy. What should be expected for all citizens as a minimum standard? Should there be a social safety net? Should health care and rehabilitation be for profit industries in the private sector funded by government and private insurance? How will access for all and equity be effected? The critical issue concerns who will protect the vulnerable populations of any nation.

FUNDING AND RESPONSIBILITY

While the issues are becoming clearer, their solution is not. The problems of an aging population and increases in the numbers of disabled citizens are apparent. How to structure a system that deals with these issues and pays for them is not. It is clear that the very wealthy can afford to pay for their own care. What to do about those who cannot pay for this care out of pocket affects every nation in the world. The existing models are no system (e.g., Sudan, Cambodia), national health insurance (e.g., Canada, United Kingdom, France, Sweden), mixed systems (e.g., Switzerland and Japan), and a strong public health and primary health care system with family support for the elderly (e.g., Cuba). Of those countries with some sort of system to deal with the elderly and disabled, each has attractions. The most attractive in terms of national policy are those that provide universal coverage at some minimum level. This is clearly the most equitable solution, but the problem is funding. Who will pay for it?

The funding issues immediately raise questions of responsibility. Whose responsibility is the care of the elderly and disabled, and how should it be financed? While this is a contentious issue in many societies and raises unavoidable cross-generational tensions, there are but a limited number of solutions. Resolution of the problem will probably involve a combination of strategies. Expectations will have to be lowered. People will not receive services that they and/or the nation cannot afford. Expectations of what constitutes a materially "good life" will have to diminished—hence current attention being given to "simplifying life" and spirituality. Taxes to support an adequate welfare system will need to be increased. The age of retirement will need to be increased as populations age into their 80s and 90s. Social security and retirement systems were designed during a time when life expectancy was in the early to mid-60s. These systems cannot sustain early retirement and life expectancies projected for an additional 30 years. Immigration will continue to be a "hot button" issue. As populations age, more young people will be needed to work, pay taxes, and provide the goods and services required to sustain the elderly and disabled population. Since birth rates are unlikely to increase dramatically, permitting the immigration of healthy, skilled young workers is the likely outcome. This, in turn, will make societies more multicultural and intensify tensions between race/ethnic groups.

Rationing of health and rehabilitation care is inevitable. Today, rationing occurs through the use of health maintenance organizations (HMOs), managed care organizations, queuing in National Health Insurance systems, and copayments for diagnostic and surgical procedures and for drugs. As costs of these goods and services continue to increase, more intense rationing will occur. The heated debate that will ensue will be over universal health coverage, inequities in the access to care and the rationing system, what constitutes minimum standard care for all, and how much care is enough. The economics of the situation will dictate limits on demand.

INFRASTRUCTURE AND STEWARDSHIP

Here the expressed the rights, needs, desires, and demands of the individual collide with the greater good of the community and all the citizens of the state. Sometimes, these perceived needs and demands are in concert; other times, they are not. In ethical terms, should the needs and wants of the individual supersede those of the larger community? The debate is tinged by value systems. In the United States, great emphasis is placed on the rights of the individual, whereas in European and Asian societies, more relative importance is given to the primacy of the community. Hence, the discussion will be framed differently in different countries.

These issues of demand for and allocation of scarce resources in society further lead to discussions of infrastructure and stewardship. The quality of life of elderly and disabled people is contingent on their access to care, ease of use, appropriateness of treatment, and cost of care (particularly pharmaceuticals). The present U.S. and national health care systems of most countries are not constituted to meet the increases in demand of elderly and disabled people. Consequently, they must be restructured. More physicians and health care workers knowledgeable with geriatrics, physically accessible facilities, transportation to and from places of care, home care services, redesigned accessible living quarters, and affordable drugs and assistive devices are needed. These adjustments need not cost more money, but they do require a reallocation of resources. For example, new buildings, homes, apartments, and health clinics can be constructed with a universal design in mind. Social support systems for these populations who can often be isolated need to be encouraged through more family involvement, community activities, friendship networks, and community-based home visiting programs.

Finally, the disabled and aging populations of the world suggest the problem of stewardship. If citizens want to leave the world a better place for having been there, they will have to rethink how they treat their physical and social environments and the people they leave behind. There are many communitarians and community leaders who are calling for a renewed emphasis on respect for our physical and social environments and other people. This requires a rethinking of how we use precious resources and deal with our families and neighbors. All citizens of the world have an obligation to be trustworthy stewards of their own worlds and social lives.

—Gary L. Albrecht

See also Economic Analysis of Disability; Health Management Systems; Managed Care; Social Support; Values.

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POLITICAL PARTICIPATION

Grassroots political activism by people with disabilities formed the basis of the disability rights movement in the United States, leading to the passage of the Americans with Disabilities Act and other important laws. Despite these policy gains, however, recent research indicates that people with disabilities remain underrepresented in the political process, raising concerns that their needs and interests are often neglected and ignored by politicians and elected officials. The lower levels of political involvement can be largely explained by economic and social disparities faced by people with disabilities, which often create barriers that make political participation more difficult but can spur some people to become disability activists. While there has been only limited research in this area, several studies shed light both on overall political participation among people with disabilities and on disability activism.

OVERALL POLITICAL PARTICIPATION

Overall levels of political participation among people with disabilities are significantly lower than among nondisabled individuals in the United States. In addition to being less likely to vote (for further information, see the Voting entry in this encyclopedia), people with disabilities are also less likely to work with others on community problems; write or speak to public officials; attend political meetings; contribute money to political causes, parties, or campaigns; write letters to newspapers; participate in political protests or demonstrations; or otherwise work to change government laws or policies. The following comparisons come from nationally representative surveys conducted in the United States in 1998 and 2000 (see Table 1).

Table 1 Comparison of U.S. Political Participation by People with and without Disabilities

	People with Disabilities	*People without Disabilities*
Number of political activities in the past year (0–9 scale)	1.86	2.33
Political activities (in percentages)		
Voted	61.9	70.9
Written or spoken to elected representative or public official	31.2	41.4
Worked with others on community problem	22.1	29.0
Contributed money to organization trying to influence government policy or laws	16.9	24.3
Attended political meeting	13.1	16.6
Contributed money to political party or candidate	13.2	17.4
Written letter to newspaper	8.2	8.9
Otherwise worked with groups or on one's own to change government laws or policies	15.3	19.4
Participated in protest or march	4.0	5.5

Women with disabilities have slightly but not significantly lower levels of overall political participation than do men with disabilities, reflecting economic and social disparities due to gender as well as disability. Nonetheless, they are about as likely as men with disabilities to vote, write letters to newspapers, and work with others on a community problem and are actually more likely to take part in political protests or marches.

Many people with disabilities face considerable barriers, such as the lack of accessible transportation, stigma, and discrimination, that discourage them from taking part in political activities. At the same time, however, such obstacles motivate others to become and remain politically active, particularly on disability rights issues. The factors affecting political participation in general can be divided into three categories: resources, recruitment, and psychological engagement. Resources include money, education, time, and civic skills that facilitate participation—for example, the ability to speak in public or write an effective letter to a public official. Recruitment networks expose people to requests for participation, and psychological engagement includes interest in political issues, feelings of political efficacy, and other psychological factors.

People with disabilities tend to have fewer resources, including lower average levels of income, education, and civic skills, which help account for their lower levels of political participation. They are also less likely to have vehicles they can drive, which curtails their ability to engage in many types of political activity outside the home.

People with disabilities are also less likely to be recruited for political activities, reflecting their generally greater social isolation. This is due in part to transportation constraints and to the fact that people with disabilities are more likely to live alone and are less likely to have jobs, socialize with friends or family, attend religious services, or regularly attend groups where recruitment can occur.

Less than half of people with disabilities are employed, and these low employment levels contribute to their low levels of political participation. Employment provides not just income and recruitment opportunities that increase participation but also opportunities for developing civic skills through activities such as leading meetings, giving presentations, or participating in decisions at work. There is, in fact, no political participation gap between employed people with and without disabilities, and the particularly low participation level of women with disabilities is partly explained by their especially low employment levels.

Regarding psychological factors, there is mixed evidence on whether people with disabilities express the same general level of interest in political issues as people without disabilities. People with disabilities are more likely to express interest in public health care issues and to identify with the Democratic Party but have a similar average score on a liberal to conservative scale. When asked how disability has affected their political views, about half of people with disabilities say that it has had no effect. Among those who say it has affected their views, about half say it has increased their interest in disability-related issues, while smaller percentages say it has made political participation more difficult, has made them more cynical and antigovernment, or has made their political views more liberal.

The psychological impact of living with a disability can be especially strong in the first few years after onset, as individuals undergo a major life transition and learn to cope with disability-related problems and their new status. This can be exacerbated by the often greater demands on time, energy, and financial resources during this period and helps explain why political participation is particularly low in the first few years after disability onset.

Feelings of political efficacy are another important psychological factor that helps explain the lower political participation levels among people with disabilities. Compared to people without disabilities, they report lower average levels of both internal political efficacy (the belief that one is competent to participate in politics) and external political efficacy (the belief that the political system is responsive to people such as oneself). The lower levels of internal efficacy are largely explained by lower levels of education and employment, but the lower levels of external efficacy are not explained by other factors and appear to be directly related to the experience of living with a disability. Individuals with disabilities are also much more likely to report that people with disabilities do not receive equal treatment from public officials or have equal influence in politics. Combined with their low external efficacy levels, these responses indicate that people with disabilities tend to feel that the political system is not responsive to their interests. Such perceptions may result from internalized "social constructions" of disability, which are popular images of disability that are shaped by public policies that send negative messages (for example, by stereotyping people with disabilities as dependent and needy).

Low levels of political efficacy can be part of psychological responses to the experience of living with a disability. Among the variety of responses that individuals can have to disability, Renee Anspach (1979) and other writers have described how some people with disabilities have a negative self-concept and respond to stigma, discrimination, and other disability-related problems by developing an attitude of fatalism and helplessness. This discourages political involvement and can lead people to withdraw from society.

Other psychological reactions to disability do not discourage political participation. Some people react to the experience of living with a disability through "normalization"—trying to emphasize their similarity to people without disabilities while ignoring or minimizing stigma, discrimination, and other disability-related difficulties. Such people accept society's devaluation of people with disabilities and try to maintain a positive self-concept by de-emphasizing their disabilities. An extreme form of this response is characterized by "role distance," where people with disabilities try to separate themselves as much as possible from others who have disabilities and only associate with nondisabled people. Those who normalize may engage in standard political activities such as voting but avoid political activities directly related to disability issues.

DISABILITY ACTIVISM

While the experience of living with a disability leads some people to retreat from society or practice normalization, it motivates others to become politically active in an effort to end discrimination and improve conditions for people with disabilities. The percentage of people with disabilities who said they took some sort of action on a disability-related issue in the course of a year is shown below (based on U.S. national surveys in 1998 and 2000):

Political activity on a disability issue (as part of one or more of the political activities listed earlier)	10.1 percent
Took action against private organization on a disability issue (e.g., talking to business owners, filing lawsuits)	8.6 percent
Either of above	14.8 percent

(Note: This does not equal the sum of the two previous activities because overlap has been eliminated.)

Four basic perceptions appear to be linked to disability rights activism. First, there must be recognition of the importance of disability-related problems. This is undermined by normalization where people minimize or rationalize such problems. Second, in contrast to people with a fatalistic response, activists believe that many disability-related problems are not an inherent part of living with a disability and can be eradicated. They also perceive that their problems are widely shared and have a strong sense of identification with others who have disabilities. Finally, activists perceive that many disability-related problems require political, rather than purely individual, solutions. They emphasize changing policies, practices, and laws, rather than relying on self-help strategies such as developing a "positive attitude" or learning how to put nondisabled people at ease.

People who become politically active on disability issues are more likely to meet regularly with disability groups. Such groups can provide members with role models, education on disability issues, recruitment networks for political activities, and a supportive environment for the development of a sense of identification with others who have disabilities. It is important to note, however, that not all politically active people who work on disability issues work through groups. Some people are politically active on their own, engaged in private struggles to change laws or policies as a result of discrimination or other negative experiences they have had.

Disability activists are more likely than other people with disabilities to say that they have directly experienced disability discrimination. This partly reflects a broader definition of discrimination. For example, activists tend to define discrimination not just in terms of intentional behavior but also in terms of policies or practices that have discriminatory effects, such as architectural standards that create inaccessible buildings. Disability activists also express greater life satisfaction and a greater sense of control over their lives and have higher levels of internal and external political efficacy than other people with disabilities. At the same time, they are less likely to believe that people with disabilities get equal respect from public officials, which helps motivate their activism.

The most committed activists have lived with their disabilities for a longer period of time on average, consistent with findings on the psychological impact of disability onset. While some people describe becoming activists after being galvanized by a particular experience (for example, an act of discrimination or denial of needed services), others describe going through a slow process in which they gradually learn to come to terms with living with a disability, fully accept themselves, and identify with others who have disabilities. Early in this process, they may go through stages of fatalism, role distance, and/or normalization but then learn to develop broader views of disability and discrimination, as well as an appreciation for the value of political action.

Those who have become leaders in the disability rights movement, in particular, have learned to reject the medical definition of disability in favor of a sociopolitical definition that views environmental and attitudinal barriers as helping create disability. Some people originally join disability groups for nonpolitical reasons (for example, for recreation or needed services) but become politically active after being exposed to new issues and meeting politically active people who serve as role models. The gradual politicization of many activists suggests that there are no apparent prerequisites for who can become active in disability rights politics and that circumstances—the types of groups, information, and opportunities that are available—often play a large role in politicization.

In conclusion, overall political participation is lower among people with disabilities than among the general population. This disparity is accounted for by factors such as lower resource levels, fewer recruitment opportunities, and lower political efficacy levels. The barriers that discourage many people with disabilities from fully participating in political life, however, also motivate others to become politically active on disability issues. While some people view their disability-related problems only as personal matters, many others perceive political dimensions in the problems they face. Disability groups can play a particularly important role in this respect by providing role models, building group identification, and increasing exposure to political information and opportunities for participation. Overall political participation among people with disabilities can also be encouraged by policies that decrease social isolation and increase resource levels—for example, by creating better educational and employment opportunities. Greater political and civic participation among people with disabilities will help them achieve equality, ensure that their voices are heard, and strengthen our democratic institutions.

—Lisa Schur

See also Activism; Participation; Voting.

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POLITICS OF DISABILITY: INTERNATIONAL

The politics of disability refers to the ongoing debates over how disability definitions and programs shape what constitutes disability, who is identified as being disabled, and what resources a society will allocate to disabled people. Disability politics have come to the forefront as increasing demands are made on state welfare systems and as nations experience serious problems in coping with their aging and disabled populations.

This entry conceptualizes the politics of disability internationally and in a social and cultural context. First, at the fundamental level, the very existence of disability as a category of knowledge should be clarified. This is important in an international context because the social and cultural context in which disability is framed has political consequences. Several authors report that the distinction between disabled and nondisabled people is not known in certain social and cultural contexts and hence of no political consequence. Second, in the study on the politics of disability, one would want to know how a person gets categorized as disabled (i.e., the process by which one is assigned and confirmed a label of disability and through which one acts as a disabled individual in a cultural and social context). Third, given the social existence of disability, the next level of analysis is to explain how the very distinction between disabled and nondisabled people, through processes of socialization and social exclusion, is maintained. This is a question of control and/or tolerance for change. Fourth, the politics of disability consists of the development of an ideology of thought, as found in the formulation of the social model of disability, and the building of coalitions to overcome the historical distinctions between disabled and nondisabled people. In processes of identity formation, cultural development in the so-called culture of disability, and social movement, power is used to redefine disability and the relations between disabled and nondisabled people. From a disability studies perspective, the question here is about the contours of a disability model that pertains to different cultures.

The questions above are directed with the goal of recontextualizing a Western perspective on disability. The intellectual benefit is to clarify meanings of disability in other cultures as well as providing directions of studying and practicing the politics of disability internationally.

THE POLITICS OF THE VERY EXISTENCE OF DISABILITY

The very existence of disability cannot be understood without taking into consideration the particular ways in which Western society has separated people with certain characteristics from the overall group, through defining a certain status as human beings, with rights and entitlements, and the right of society to take certain decisions. *Disability* as a linguistic term is a composite; it comprises people with a large variety of unrelated characteristics, yet through processes of separation and practices of defining society's responsibility to those who have been separated from the rest. This is, however, not a universal process. For example, Holzer (1999) observed that in Juchitán, Mexico, the distinction between disabled and nondisabled is not known. Such ethnographic examples may, however, make clear how the distinction *is* made in other cultural contexts.

The category of disability has taken form over the centuries. In the English language, the term *cripple* first took on connotations of designating *all* people with identifiable disabilities. But it is undoubtedly the notion of "handicap" that is perhaps best known for being able to apply a particular ideology to a group of people with varying types of disabilities, namely, the ideology of equal chances. This ideology was first developed in the United States, in the context of building a modern, industrial society. The term *handicap* appeared in public discourse around the turn of the century (e.g., in the *New York Times* in 1905). From the United States, the ideology of equality (through many different transformations known as integration or, more recently, as inclusion) reached most, if not all, societies in the world. The ideology of *handicap* reached Europe in the 1950s. However, it appears in legal texts much later (e.g., in Belgium in 1967). In France, the year 1975 constitutes the essential moment of putting in place the politics of *handicap.* From that moment on, *handicap* serves as a unified field of intervention that figures among other social politics. While *handicap* is no longer in favor in the United States and has largely been replaced by the term *disability,* at least in professional and legal language, the term *handicap* survived in many other countries. Because of the many shifts in language, the use of terminology in a text has become an object of careful explanation for many writers, as a matter of political consciousness.

THE PROCESS OF ACQUIRING PEOPLE BY A LABEL

Social scientists have studied the process by which people are enlisted by a label and the consequences of this enlistment for society. Perhaps the most early and well-known studies are in the area of mental retardation. According to one definition of mental retardation, the number of people who could be identified as mentally retarded could be as many as 16 percent of the U.S. population. The identification of people as mentally retarded evidently has direct consequences for the provision of services and the spending of public funds. Labeling people as mentally retarded added also to the stigmatization of people. This was the case with a disproportionate number of ethnic minorities identified as mentally retarded. This issue put into perspective the cultural inadequacies of tests and, more generally, the politics of testing.

The politics of testing in Jordan is put into perspective by what is being tested and what is left out. According to Turmusani (2003), the only national survey ever conducted in Jordan (in 1979) used a definition of disability based on the concept of visibility of impairment, meaning that persons with nonvisible or hidden impairments would not be perceived as disabled. The consequences are both positive and negative since they would not be discriminated against but also not be entitled to services. The political consequence at the national level would, however, be that disability would remain low on the public agenda.

In *The Disabled State,* Stone (1984) describes how the medical profession achieves and exerts power as the gatekeeper in the process of entitling a person with a particular label, thus giving way to a certain treatment by society. In many cases, the relation between society and disabled people is here defined in terms of employment as a contribution to society. Nonemployment can result from not being able to work, which can in turn be the result from a contribution to society. The distinction between "deserving" and "nondeserving" plays an important role in the determination of entitlements.

In a broader framework of the relationships between society as a governing body and disabled people, one can speak of a political economy of disability, which aim it is to explain the occurrence and the magnitude of the existence of disability. In such a perspective, societies are producing disability and disabled people. Disability in this perspective is the very outcome of historical, economic, and political processes that regulate.

At the more intermediate level, Barral et al. (2000) ask what social form do various organizations take that operate in the field of disability. What are the structural or psychological characteristics of the politics in which they are engaged, the status that is given to individuals who are active within these organizations and in the movements that intend to represent disabled people? By investigating the laws in different countries, one can glean at the ways in which "the national obligation" takes place. In France, this takes the form of a mission of prevention, follow-up, and rehabilitation to which private initiative and public action can be associated. On the other hand, it becomes necessary for the French state to install a way of controlling private initiative so that disabled individuals are given a republican guarantee.

THE DISABILITY MOVEMENT

The politics of disability transcends all times and societies. Indeed, the very existence or nonexistence of the category of disability is the result of a negotiation process among individuals in society, a political process with social consequences. However, in recent decades, a disability social movement has arisen in the aftermath of human and civil rights consciousness throughout the world. This development was both spurred by the aftermath of World War II and the development of the United Nations, as well as by the civil rights movements in the United States. In the early developments of the disability movement, Scotch (1984, 1988) researched how disabled people could define themselves as a minority and how a disability movement could emerge in view of its own historical past. In many countries, the movements have accomplished the passing of civil rights legislation, such as the Americans with Disabilities Act in 1990. In particular in the United States, the independent living movement became a strong advocacy and practically oriented means to implement the ideas of the disability movement. The prominence of disability advocacy and the passing of antidiscrimination legislation evolved differently according to the social and cultural contexts. In the United States, it is clearly connected with the civil rights movement and the prominence of individual development. In most of Europe, the development of a disability movement was less strongly developed, in part as a result of strong social security systems. Lee (2002) argues, mainly in reference to Great Britain, that the disability movement has been rather unsuccessful in reaching out to the disabled population as a whole. Moreover, the movement has been dominated and fueled by a very particular constituency, notably those with strong physical and sensory impairments, who are both relatively active and relatively young. On the other hand, the social disability movements in Southern African countries became strongly developed in conjunction with the struggle against apartheid. In still other countries, the (lack of) prominence of the disability movement could be clearly connected to military and government regimes (for examples on Asian countries, see Charlton 1998). The disability movement was supported by some slogans that intended to express the required attitude changes (e.g., “ability, not inability,” “no pity,” and “nothing about us without us”), expressing wide disparities in the political demands. Following Oliver (1990) and Lee (2002), it can be supported that the disability movement ought to be characterized as a new social movement. It is indeed internationalist, aims at empowerment and consciousness raising, offers a critical evaluation of society, lies at the periphery of the conventional political system, and can be seen to focus on the quality of life of a particular section of society.

The academic and theoretical framework in support of the social movement of disabled people and the emergence of what became known as “disability studies” has been the “social model of disability.” This model was first launched primarily by sociologists and political scientists, some of whom had themselves disabilities and engaged as both advocates and academics. This model was usually defined in opposition to either an individual or medical model of disability. In terms of knowledge, an overall focus on the social construction of disability became central. In Britain, the social model of disability has been supported by Marxist ideas that explained the material conditions and the oppression faced by disabled people. In the United States, the social model became more readily interpreted in the analysis of ecologies (i.e., adaptations between people and their environments) and grew into increasing attention to the discriminatory impact of systems and of language use. This also grew into considerable attention to representations of disability in media, history, literature, and visual arts.

During the 2003 European Year of Disabled People, the key emphasis was on the ways disabled and nondisabled people could work together and on the issues of physical, social, and informational accessibility. Such a European perspective therefore frames disabled people as a political entity to be taken into account and also pushes attention to the politics of the environment as the source of disability. In particular, as a follow-up to the International Year, the European Union maintains its goals of achieving equal treatment in employment and adds goals such as reinforcing mainstreaming of disability issues in relevant policies and accessibility for all.

The proliferation of difference in postmodern times has led many groups to claim their own identities and social movements. For disabled people, this has consequences as such proliferation leads at first glance to “forgetting” the difference. Lee (2002) argues that as the environment becomes the focus, it is suggested that differences can simply melt away. This is a politically dangerous idea since it minimizes the necessary social care and accommodations that disabled people require. The difference of disability is equally challenged by the intersection with other groups, such as women, elderly people, and ethnic minorities. In many cases, coalitions with other groups appear to have political implications (for an example, see Iris 2003).

A future disability model that pertains to different social and cultural contexts and to the impact of globalization will have to respond to the fact that various forms of modern society are found throughout the world. In such modern societies, disability is understood with different degrees of emphasis on religious, biomedical, and social-political components. Such a future model could be called “cultural” in the ways it can integrate existing dichotomies that dominate the current understanding of disability. A cultural model would equally emphasize certain universal characteristics of the world today (such as the importance of information and the media) and of disability (such as its challenge of existing cultural orders and therefore its potentially transforming impact on society). Last, a cultural model would be sensitive to our modes of communication as these are affected by historical and cultural developments in the use of spoken and written language, visual imagery, technologies, and aesthetics. Research on the politics of disability that is steered by such a cultural model of disability would continue to emphasize how new modern societies create orders by overcoming old categories and developing new ones that once again produce disability.

—*Patrick Devlieger*

See also Activism; Developing World; Politics of Disability: International.

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POLITICS OF DISABILITY: POLICIES AND PROTEST

DISABILITY AND POLITICAL ACTION

People with disabilities frequently occupy marginalized social, economic, and political positions in contemporary societies, positions that are only likely to change through effective political action. In recent decades, people with disabilities have increasingly sought to participate collectively in decisions about public policy, both specifically about disability issues and more generally about issues related to participation in governance and the distribution of power. While people with disabilities are almost universally constrained by stigma and limited resources, their political status varies considerably across societies, according to how disability is socially constructed.

In the medical model of disability, which has been predominant in Western culture since the nineteenth century, disability is considered an individualized attribute dispersed across the general population rather than a commonly held position and thus is perceived as not naturally forming the basis for collective political activity. Many disability issues are nominally apolitical, as disability is viewed as inextricably linked to impairment and more a matter for professional treatment than for political action.

Within this construct, whether one has a disability has important consequences, and gatekeeping, the definition of who is and is not considered to have a disability, is considered to be a scientific interpretation linked to impairment and thus is typically managed by medical and rehabilitative professionals. People with disabilities themselves often are not considered to have an appropriate role in public debates over who is entitled to claim public benefits or other entitlements attached to the disabled status.

However, there are considerable political implications within the medical model of disability. Within this conception of disability, the primary question within the politics of disability is reallocative—to what extent public resources should be devoted to medical and rehabilitative services for treatment and to benefits accorded to maintain people with disabilities, who are judged incapable of self-sufficiency. Since disabled people are also considered to be incapable of self-advocacy within this context, such disability politics are typically engaged in by nondisabled advocates rather than by people with disabilities themselves. Thus, in many historical accounts of disability policy debates, people with disabilities are rarely characterized as major political actors, either individually or as an organized interest group. (A prominent exception is the case of disabled veterans, who typically self-identify primarily as veterans who have earned the right to social assistance through their service, rather than as people with disabilities who have needs related to their impairments.)

Taking the lead, rather, are organizations *for* rather than *of* people with disabilities—often charitable organizations or professional service providers led by nondisabled individuals. Political initiatives of this variety frequently emphasize the incapacity associated with disability, as well as the moral blamelessness of "deserving" disabled people, unable to help themselves, whose conditions have been acquired through no fault of their own. Such political discourse frequently features tales of woe about people, particularly children, whose lives will be ruined by their impairments unless help is given.

Many public officials are reluctant to appear insensitive to appeals by those perceived as helpless and blameless, and such political appeals have often been quite successful. At issue in such political discourse is often the moral entitlement of those who are "afflicted," which is based on their impairment being based on random victimization rather than their own choices and behavior. Thus, political debates over disability benefits frequently involve questions of moral entitlement. With the gatekeeping role usually taken by medical professionals, efforts have been made to medicalize a number of conditions to entitle those who have them to a flow of benefits and services earmarked for the "deserving" poor. Questions of personal responsibility may arise, with debates over public funding benefiting people with chronic conditions widely considered to be morally questionable, such as HIV/AIDS, psychiatric disorders, addiction to alcohol or illegal drugs, or learning disabilities.

Nonmedical models of disabilities are associated with quite different political forms, issues, and dynamics. A sociopolitical model of disability conceptualizes disability as a social and political construction that is the result of interaction between physical or mental impairment and the social environment. Technology, architecture, and spatial organization all reflect concepts of what is "normal" and how "normal" people function, as do cultural attitudes and institutional processes. These social characteristics help to define who is “disabled” and who is “normal,” as well as what constitutes an appropriate social response to those who have a disability.

The politics of disability takes far different forms within the sociopolitical model than would be expected in the medical model. Political issues are not simply reallocative, although disputes over resources are found here, too, but may also include conflict over what social roles can appropriately be played by individuals who have disabilities and how the state should support or restrict those roles through its policies. A sociopolitical model of disability would lead one to expect political conflict over issues such as the appropriate role for people with disabilities in education, employment, public services such as transportation, economic development, and participation in civic life. Organizations composed of people with disabilities are prominent in such political activities, groups whose membership and leadership are individuals who themselves have disabilities.

By characterizing the social isolation and enforced dependency of people with disabilities as the result of social choices rather than as inevitable results of impairment, the sociopolitical model suggests analogies between the social status of people with disabilities and other marginalized groups such as racial and ethnic minorities, women, or gays and lesbians. Within this political framework, disability politics can encompass disputes over civil rights (in the American context) or human rights (in the European context and in non-Western societies around the world). Similarly, politics encompasses conflicts over the role of disabled people collectively in the governance of service systems and other institutions addressing the disability community and the role of individuals with disabilities in shaping and controlling the services they receive.

In recent decades, as the dominance of the medical model has diminished, the sociopolitical model has become more prevalent. In such a sociopolitical model, people with disabilities may be grouped together into common medical, educational rehabilitative, human service, and custodial systems, but the establishment of such systems and the definition of who is to be considered disabled vary across cultures and historical periods. Gatekeeping under a sociopolitical model of disability is not solely the province of medical and rehabilitation professionals but can be contested by many within society, particularly by people with disabilities themselves.

DISABILITY IDENTITY AND POLITICAL REPRESENTATION

Disability politics increasingly involves advocates who have disabilities, although individuals with disabilities do not necessarily share the political perspective held by the majority of people with disabilities within a society. The label of having a disability may be taken or rejected by individuals with impairments as well as by others. In some instances, vanguard groups have celebrated their identity as people with disabilities, promoted disability culture, and embraced a belief in “disability pride.” For others, stigma is perceived as associated with disability. People may be reluctant to self-identify as disabled; they may seek to hide their impairment or to portray its effect on their lives as minimal. Even people with significant impairments that interfere with important life functions may not consider themselves to be in a similar situation as others with the same impairments, let alone with quite different ones, and may be unwilling to be visibly associated with them.

Even when individuals self-identify as disabled, having a disability does not in itself inevitably lead to participation in collective political action with others who have disabilities. Many political constituencies form on the bases of spatial propinquity and/or out of already socially cohesive groups. Because impairments are spread spatially and demographically throughout the general population, people with disabilities may not find themselves in naturally occurring communities of their peers; they typically grow up within families of people who do not share the experience of disability and must seek out others like themselves. Thus, while some disability advocates commonly refer to the “disability community,” those who actively identify with this community may include only a portion of the substantial number of people with disabilities in any society.

One issue that often arises within disability politics is that of who may legitimately represent the broader disability community, which is diverse in terms of impairments, demographics, socioeconomic status, and cultural perspective. This dilemma is reduced when diverse people with disabilities representing a variety of constituencies are engaged in politics, rather than a few token individuals purporting to represent a single disability community. At the high end of representation, for example, a total of approximately 47,000 Ugandans with disabilities serve in the country's governing bodies, including 40,000 who have been elected at the village level.

This strong national presence of persons with disabilities is unique, but increased political participation by people with disabilities has occurred in many nations around the world, often in accordance with growing democratization and concerns about representation of diverse minority interests. In the Soviet Union, along with a number of other political organizations founded in the wake of the Helsinki Accords in the late 1970s, the Action Group to Defend the Rights of the Disabled in the USSR was founded in 1978 to advocate for legal rights for Soviets with disabilities. In the Philippines, a national political party was recently established to represent the interests of disabled persons.

Many individuals with disabilities have challenged the legitimacy of political representation by anyone but those who themselves have disabilities. These advocates question whose interests actually are advanced by nondisabled service providers and contend that only people with disabilities should speak on their own behalf. Such issues of representation have been applied to parents or other family members of disabled individuals; some contend that parents should be viewed as a part of the "disability community" and allowed to represent that community in political forums, while others strongly disagree. These questions become even more complex when applied to individuals with severe cognitive or psychiatric impairments who may have difficulty articulating their own interests in political discourse. However, whenever disability is created as a social category, particularly through public policy and the provision of health and social services, those defined as having a disability have the potential to become a distinct political interest group that may become capable of mobilization and political action.

There are numerous examples of people with disabilities engaged in protests or forming organizations on their own behalf. In the past four decades, political activity by individuals with disabilities and organizations of disabled people has particularly increased, and much of that activity has been directed toward the goals of equal access, community integration, and independent living. Among the explanations that have been offered for this increase are emerging medical and assistive technologies that have supported independence for many people with disabilities, changing ideologies of treatment that have encouraged noninstitutional service strategies, and the models of other minority movements in the 1960s and 1970s that advocated for inclusion and social change.

LEGAL ADVOCACY

Some efforts to redefine the social position of people have occurred through legal advocacy in the courts, particularly in the United States. Enabled by the distinctive American constitutional and legal framework and building on the civil rights advocacy that fought racial segregation through federal lawsuits in the post–World War II era, a number of class action suits were successfully pursued in the late 1960s and 1970s on behalf of children denied public school education because of their disabilities, people with disabilities receiving inappropriate treatment in residential institutions, and others denied fair treatment because of their disabilities. These lawsuits were often the product of advocacy groups representing parents of children with disabilities working in partnership with public interest law centers.

Key judicial rulings have helped to establish legal protections for disabled people and foster the growing disability rights movement in the United States. In the American disability policy context, with its emphasis on civil rights, legal advocacy has been a crucial component in ensuring that broader public policies are applied appropriately to individual cases. Legal organizations such as the Disability Rights Education and Defense Fund and the Bazelon Center for Mental Health Law have been valuable resources in the protection of individuals with disabilities. Yet in the absence of more broadly based political advocacy, litigation-based political strategies tend to be episodic and non-self-enforcing and may have a limited capacity to effect institutional change. Such advocacy is most effective when it is part of a wider political mobilization of people with disabilities on their own behalf, a process that requires both social solidarity and collective action.

ELECTORAL POLITICS

Participation in electoral politics is a potentially important avenue for people with disabilities to secure their political voice, yet Americans who have disabilities are much less likely to register and vote than are nondisabled individuals. For example, in the 1994 election, 56 percent of people with disabilities were registered to vote, as compared to 71 percent of nondisabled individuals; only 33 percent of people with disabilities reported voting, as compared to 54 percent of nondisabled individuals.

While there has been little research on possible explanations for this pattern, one factor may be accessibility of the polling place, where individuals with disabilities may encounter a variety of architectural barriers. Another issue is the receptivity and responsiveness of election officials. At times, election officials may become sufficiently frustrated with meeting accessibility needs, so they urge the disabled voter to vote absentee, although some individuals with disabilities view absentee voting as an inferior form of participation. People with mental retardation, blindness, or deafness are sometimes subjected to challenges or have to encounter election officials who are uninformed about their accommodation needs or who resist taking the necessary steps to make the voting process or polling place accessible.

In addition to these physical and attitudinal barriers, policy barriers may affect participation. In the United States, 44 states disenfranchise some individuals with cognitive and emotional impairments, and England's Representation of the People Act 1983 disenfranchises people who have been involuntarily admitted to mental hospitals. Similarly, the constitution of Albania prohibits voting by individuals who have been adjudicated incompetent.

PEOPLE WITH DISABILITIES AS POLITICAL CANDIDATES AND ELECTED OFFICIALS

Persons with disabilities hold or have held elected offices in several countries, and this may help to shape the electorate's response to people with disabilities and the problem of disability. These include Joshua Malinga of Zimbabwe, who was mayor of Bulawayo; Joseph Sinyo of Kenya, a member of the national parliament; Kalle Konkkola, who has served on the city council of Helsinki, Finland; Midori Hirano, of Japan, who was elected in 1998 to the Kumamoto Prefecture; a Philippines congressman, Ernesto Herrera; and several individuals with disabilities who have served or are serving in the national parliament of South Africa.

Informal observations of U.S. politics indicate that disability is often an issue in campaigns, particularly contests for the presidency. In the 1996 American campaign, for example, the Republican Party candidate, Senator Robert Dole, was a World War II veteran who had lost the use of his arm from an injury sustained in combat, whose disability was labeled a badge of honor. The Democratic Party candidate, Bill Clinton, is not disabled, but the Democratic national convention featured an address by Christopher Reeve, an actor who had become quadriplegic after a riding accident. Reeve, a controversial figure in the U.S. disability community, issued a plea for funding for research to cure paralysis. In neither of these instances was civil rights for people with disabilities a major focus of the campaign message, although in both parties' campaigns, disability rights was a minor emphasis.

Because they tend to be less affluent than nondisabled individuals, people with disabilities around the world are less likely to have the wherewithal to contribute money, time, or other resources to political candidates. To the extent that these circumstances make their voice less likely to be heard in the electoral process, people with disabilities will be disadvantaged in democratic governance.

LOBBYING AND PRESSURE GROUPS

In addition to participation as elected officials or through political parties, disabled people in many nations have formed organizations whose purpose is to represent the disability community and influence governmental bodies responsible for the enactment and implementation of public policy. While there is a long history of political activity by and on behalf of people with disabilities, disability politics has become far more widespread in the post–World War II era, particularly in the last three decades of the twentieth century, building on the example of similar movements for self-determination and inclusion by other politically marginalized social groups around the world.

In recent decades, a number of umbrella organizations have been formed to coordinate political activity and speak with one voice on behalf of the disability community. In Great Britain, for example, the British Council of Disabled Peoples (BCODP) formed in 1981 to represent 80 organizations and approximately 200,000 Britons with disabilities. In the United States, the American Coalition of Citizens with Disabilities was organized in 1975, with 19 constituent groups. In Canada, the Coalition of Citizens with Disabilities (CCD) was founded in 1976 with affiliates from most Canadian provinces. In Denmark, De Samvirkende Invalideorganisationer (DSI) has been active for decades in promoting the integration into Danish society of Danes with disabilities.

Parallel to the formation of these national coalitions has been the creation of cross-national coalitions. Some international groups have organized around specific disabilities, such as the African Union of the Blind, founded in 1987, whose activities have been supported by the Norwegian Association of the Blind and Partially Sighted. In 1981, Disabled Peoples' International (DPI) was formed, an international cross-disability coalition of more than 110 organizations, including many from developing nations in Latin America, Africa, and Asia. DPI has been particularly active in advocating for disability rights in international governmental and particularly nongovernmental activities, as well as in supporting the development of organizations of people with disabilities around the world. Pelka (1997:103) quotes Joshua Malinga, a former DPI chairperson from Zimbabwe, who remembered the 1980 organizational meeting of DPI in Singapore: "It was at this meeting that most of us from Africa first understood what was meant by a 'disability rights movement.' We had never thought about disabled rights as a cause, to the disabled community as a community. . . . It was a shift from looking at disability as a health issue, to looking at it as a human rights issue."

Perhaps the most established political role for disability advocates has been in the United States, where a number of organizations maintain active lobbying roles in Washington and many state capitals. Representatives of disability organizations in the United States played an extensive and significant role in disability policy development in the 1970s and 1980s. In Scandinavian nations, disability policies have been shaped by disabled representatives of community-based disability organizations. Organizations of people with disabilities in many other countries, including Canada, Singapore, England, Ireland, and the Netherlands, have participated in the reformulation of outdated disability policies.

Most American disability policies since the mid-1970s, including the landmark Americans with Disabilities Act, have been drafted with the active participation of representatives of organizations of disabled people, and in the 1990s, many appointed government officials responsible for making and enforcing government disability policies were recruited to their posts from organizations of people with disabilities. In a number of instances, the prior connections among government appointees from the disability movement have meant that the long-standing absence of communication and cooperation among competing public bureaucracies has been overcome.

While access to positions of power and influence has had many important benefits for the disability community, it has often created dilemmas for those holding them, who must balance their loyalties to their constituencies with the practical considerations of public policy making. Nevertheless, since so many aspects of life for people with disabilities are shaped by public policy, institutionalized participation in policy debates within government appears to have incorporated the experience of disability into many policy decisions. Where regular participation does not occur, however, disability advocates may need to turn to more contentious nonelectoral political action to represent their own interests.

PROTEST POLITICS

Disability protestors have been willing to confront public officials, block traffic, occupy public places and government offices, or be arrested for their causes. In 1972, for example, members of the cross-disability group Disabled in Action blocked traffic in the New York financial district. In 1981 in Canada, coordinated national protests were organized by the Council of Canadians with Disabilities to advocate for a Human Rights Amendment to protect the civil rights of Canadians with disabilities.

Through much of the 1980s, members of ADAPT (originally Americans Disabled for Accessible Public Transit) chained themselves to buses and disrupted meetings of the American Public Transit Association to protest inaccessible public transportation. Following the enactment of the Americans with Disabilities Act, ADAPT changed its name to Americans Disabled for Attendant Programs and has conducted numerous protests against the unnecessary institutionalization of people with disabilities in nursing homes. In 1988, deaf students at Gallaudet University in Washington, D.C., forced the closure of their campus for a week, demanding that a deaf person be hired as university president. British organizations of people with disabilities have engaged in similar disruptive tactics; Gooding (1994:160) cites a 1993 *New Statesman* report of a national register maintained by the Direct Action Network of more than a thousand disability activists willing to take part in civil disobedience.

Typically, protests involve not just short-term objectives but also a sense of shared purpose based in a vision of an alternative to existing social arrangements. The goal of an inclusive, barrier-free society may motivate disability activists beyond the specifics of an exclusionary policy or demeaning practice. It is such a vision that will increasingly serve as the basis for disability politics.

—Richard Scotch and Kay Schriner

See also Activism; ADAPT; Advocacy; Disability Pride; Lobbying; Politics of Disability: International; Voting.

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POOR LAWS (UNITED KINGDOM)

The English poor laws consist of the parliamentary legislation, as well as subsequent practice, related to the public relief and control of the impoverished, including the disabled poor. The period from 1531 to 1834 is known as that of the *old* poor law, with an emphasis on parochial, predominately noninstitutional, provision (outdoor relief). From 1834 to 1929, the *new* poor law involved national supervision and extensive use of workhouses.

Responding to concerns about the social order and influenced by Christian humanism, the sixteenth-century elites passed legislation initially to punish vagrants but later to identify and relieve needy paupers. In 1572, England became the only country in Europe to permit parish authorities to regularly levy poor rates (compulsory property taxes). In 1598 and 1601, further legislation *required* parishes to levy rates, to punish vagrants, to provide outdoor relief (usually a pension) for those disabled to work, and to provide work for the able-bodied. Further legislation included a 1662 act establishing settlement laws limiting migration and providing a way for paupers to establish a right to relief in their "home" parish (usually where they were born), with the right to appeal to local justices of the peace.

In the seventeenth century, the system spread in practice throughout the country, and pension numbers and levels grew substantially. Disability to work was the test in practice, with the elderly, those disabled on the job, the feebleminded, and war widows given priority. Medical care was provided. Institutions were increasingly established (almshouses, workhouses). From 1593 to 1679, thousands of disabled veterans were relieved via a statutory, county-based pension system administered by county justices and paid for by taxes (after 1679, the central government took over this responsibility).

From 1700, workhouses increasingly included infirmaries that provided medical care. It has been argued that the sick and disabled had more control over their lives and bodies on out-pension (noninstitutional) than in-house (institutional). Others argue that the infirmaries provided much-needed medical attention for those with disabling conditions such as syphilis. "Out relief" continued, with relief manipulated by employers to top up and consequentially depress wages.

The costs of the poor law came under increasing scrutiny, with many assuming the poor were unwilling to work. In 1834, a new poor law was enacted that created a uniform national system, with parishes joining together in unions running workhouses controlled by Boards of Governors. Outdoor relief was significantly curtailed. The disabled had to be prepared to enter the workhouse to be relieved. Conditions within some of the workhouses were appalling.

In 1929, the Local Government Act officially abolished the Boards of Governors and workhouses, although many related aspects of the poor laws continued to be implemented for some time.

Throughout the history of the poor laws, the actions of the disabled poor themselves were an important factor in the growth of the system, as well as changes in practice, particularly at the local level. The disabled increasingly felt entitled to relief and negotiated as best they could to that end.

—Geoffrey L. Hudson

See also Poverty; Veterans.

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POPE, ALEXANDER (1688–1744)

Eighteenth-century English poet

Alexander Pope, eighteenth-century England's most celebrated poet and his generation's most frequently portrayed celebrity, dominated the emergent literary marketplace as the first self-supporting, nonplaywriting professional author while fascinating his audience as a spectacle of deformity. Characterizing the career of a wit as "a warfare upon earth" and complaining in his *Epistle to Arbuthnot* of "this long disease, my life," this master of the heroic couplet endured a war between an exceptional mind and a body lambasted as "at once resemblance and disgrace" of humanity's "noble race." Barely four and a half feet tall when grown—in Voltaire's words, "protuberant before and behind" (speculation as to the cause of his deformity has ranged from tuberculosis of the spine contracted from a wet nurse, to trampling by a cow, to excessive study)—and socially disenfranchised for his Catholicism, Pope transformed his marginality into a vehicle for self-reflection, self-representation, self-possession, and self-legitimation. His life's work was the ultimate couplet of deformity and poetic form. Mocked early on as "the ladies' plaything" for a best-selling translation of Homer appealing to a nonaristocratic and female audience (a serious attempt at post-Miltonic epic refracted in his mock-heroic mirror *The Rape of the Lock*), at his career's close, the Tory satirist cast himself as a hyper-masculine epic hero embodying moral integrity in an age of beautiful hypocrisy. Radically conservative in his final nostalgic critique of British economic and imperial progress, innovative in his exploitation of the literary marketplace, Pope embodied, negotiated, and redefined the ambiguities of his age. When the curtain falls at the end of *The Dunciad* and "universal Darkness buries all," Pope's couplet art concludes triumphantly by envisioning art's destruction.

—*Helen Deutsch*

See also Poetry.

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POSSESSION

See Witchcraft

POSTCOLONIALISM

Only recently have scholars in both disability studies and postcolonial studies attempted to explore the intersections between these two areas of scholarship. Disability studies' scholars have ventured into global contexts to explore the intersection of disability and culture in comparative perspective and/or have explored the impact of globalization on disabled people internationally. However, they have only very rarely situated these same discussions within the political space of postcoloniality—a space that postcolonial scholars would argue provides a very different analysis of the global.

Postcolonialism, in its broadest representation, foregrounds the effects of imperialism and exploitation as a result of the colonization of specific cultures and societies, but this representation has itself been widely contested. While on one hand, the term *post* in *postcolonialism* clearly highlights a historical dimension to the discussion (i.e., "after" colonialism), this position has been contested by other postcolonial scholars who argue that colonialism has become transhistorical because the effects of imperialism and exploitation continue to affect the former colonies via the neoliberal policies of globalization. Other postcolonial scholars have broadened this focus to include discursive analyses of postcolonial culture that foreground contradictions, ambiguities, ambivalences, and ruptures. In this case, the *post* in *postcolonial* foregrounds a more nuanced discourse that supports "going beyond" materialist analyses of contemporary culture to foreground radical possibilities of movement, fluidity, and mobility that produce hybrid (postcolonial) subjects.

It is in engaging Otherness that scholars in both postcolonial studies and disability studies find common ground, especially in their deconstructive analyses of how representation, hegemony, and normativity produce both the postcolonial and the disabled Other. For example, postcolonial studies scholars have described how the colonized body has been constituted as the abject Other when situated in opposition to the "civilized, civilizing, [and] normal" body of the colonizer. Similarly, disability studies scholars have also demonstrated how the Western paradigm of knowledge has produced specific ideological representations of the "normate" through a series of exclusions that constitute the disabled Other as outside the purview of rights-bearing humanity.

These ideological representations of the colonized and disabled Other often draw on the presumed interrelationships between physiognomic factors and social/geographical environments. For example, even though John Langdon Down (Jackson 1999) recognized differences between those he termed "mongoloid idiots" and the "real Mongols," he still saw what he claimed were unmistakable similarities and considered these combined physical and mental features of this ethnic group as pathognomonic of a distinct and prevalent class or type of idiocy. Even though this was refuted in later years, the racial assumptions inherent in his study continue to persist such that, on one hand, "mental defectives" became metaphorically as well as literally "a race apart," and at the same time, the racialized Other was seen as "mentally defective" and in dire need of civilization via colonialism. As a result, just as it was imperative that attempts be made to tame the savage racialized Other in the colonies, the minds and bodies of the "idiot," the "imbecile," and the "feebleminded" were also to be subdued and domesticated in the segregated internal colonies of state institutions.

The oppressive interrelationship between disability and colonialism was epitomized in the freak show, a popular form of entertainment that had its heyday in the United States from 1840 until about 1940. Of particular interest to this discussion are those "freaks" who were exhibited as the exotic mode. This was a mode of presentation that accentuated the culturally strange, the primitive, the bestial, and the exotic. Promoters of the shows claimed that their exhibits came from mysterious parts of the world—darkest Africa, the wilds of Borneo, a Turkish harem, and an ancient Aztec kingdom. Many of these exhibits were non-Western people with demonstrable physical differences who were exhibited in the exotic mode by emphasizing their anomalies as well as their "strange ways," and though they were nondisabled, they were exhibited alongside native-born Americans with disabilities. One of the most famous examples of such an exhibit was the "Hottentot Venus," whose enlarged labia and buttocks were accentuated to foreground her savage sensuousness and mark her as measurably different from the European woman. Moreover, in another blatant distortion of presentation that brought together both disability and colonialism, native-born Americans with disabilities were misrepresented as savage foreigners (e.g., Ohio-raised dwarfs as the "Wild Men from Borneo"; African Americans with microcephalus from Alabama as members of the Ituri—a head-binding African tribe). While such exhibits at the freak shows were arguably presented as entertainment, at the same time, they also provided a quasi-scientific basis for the justification of both slavery and colonialism by depicting the nonwhite world as childlike, barbaric, and dangerous and therefore in desperate need of the civilizing influence of the West.

A critique of Western science and its devastating effects on both the disabled and the colonized Other is yet another commonality shared by both postcolonial and disability studies scholars. According to postcolonial scholars, Western medicine, armed with an enormous battery of tests and discursive practices that focused specifically on the physical and mental constitution of the colonized body, extended its reach beyond mere scientific interest to explore and use its knowledge to further the authority, legitimacy, and control of the colonial state. Describing a similar history of the asylum on Robben Island, South Africa, postcolonial scholarship describes how the racial superiority of the white settler over the African native was codified in the science of ethnopsychiatry. Unlike the European "madman," whose insanity was seen as physiological, the African "madman's" insanity was attributed to his racially determined incapacity to cope with the stresses of urbanization and civilization and was therefore provided physical rather than psychological therapy, with the therapeutic purpose of introducing the African to civilization. Such examples demonstrate how Western science used specific ableist and racist discourses to justify European control of its colonies even in the face of Enlightenment ideals of universal humanity.

With this oppressive context as their historical backdrop, postcolonial subjects have attempted to distance themselves from what they perceive as a stigmatizing context of disability and, in doing so, have failed to realize the emancipatory possibilities of forging a political alliance with disabled people. In fact, postcolonial scholars, for the most part, almost never recognize disability as a political construct and, as a result, seldom include disability in their analyses of difference. When disability does appear in their analyses, it is often used as a metaphor to describe the colonized condition.

For example, postcolonial analyses have explained how, under the censorship of Japanese colonialism, Korean writers often drew on the trope of disability to create characters who lacked freedom in bodily function and movement. Casting their literary work in metaphorical terms as the textual body impaired by the violence of colonialism, these writers overturned traditional views of disabled people as abject citizens by recasting them along with the colonized (disabled) nation-state as a bearer of rights. The silencing of these writers by colonial censors also represented a shared critical relationship with disability such that just as the physically disabled were constituted as objects of colonial hygiene and social control, these intellectuals were also constituted as objects of thought control and censorship. In this way, Korean writers produced literature that was encoded with anticolonial and anticapitalist messages of protest by using disability as the discursive means to articulate various positions of their colonial destiny, ranging from internal critique and self-criticism to objection of their unfree colonial situation.

The radical potential of disability in postcolonial literature is also echoed by various postcolonial literary critics. According to these analyses, because the postcolonial subject is forced to enter into a multiple symbolic order (e.g., colonial, native, and postcolonial/neocolonial contexts), he or she is forced to go through (as per Lacanian psychoanalytic theory) multiple castrations to achieve wholeness and, as a result, experiences symbolic deformity—entering into a condition, sometimes problematically described as "disability." At the same time, some scholars also realize the radical possibilities for the "disabled" postcolonial subject in this context as it enters into a combat over meaning by using one cultural/symbolic system against another. This space where disability and postcoloniality intersect has been described as the "third dimension," where the Self can no longer be contained within the simplistic binary of Self/Other, thereby producing an identity that is both ambivalent and muted. Located now at the point of slippage between identity categories, the disabled postcolonial subject appears as the "evil eye"—the figure that resists the image of totality that is critical in the myths used by both the colonizer and the colonized. However, some scholars have been quick to point out that postcolonial authors often fail to capitalize on this radical potential of disability in their novels and have instead characterized the disabled body as a docile body against which nationalist tensions can be arbitrated and against which a rationalist ideology can pull "a collection of disparate peoples into a self-identified nation" (Lacom 2002:141). In this way, national identity is consolidated so as to maintain the differentiation of the national "us" from aliens within and without. Unfortunately, such efforts fail to serve the interests of both the postcolonial and disabled subjects because they continue to support oppressive representations invested in tragedy and exoticism.

Just as postcolonial scholars have used disability as a metaphor to represent their oppression under colonial rule, disability studies' scholars have also appealed to the metaphor of colonialism to depict and explain the social oppression of disabled people. For example, some scholars describe the harsh and delimiting educational segregation of students with disabilities in U.S. public schools as mimicking the historical trajectory of colonialism. Others point out that just as emerging European states drew on particular notions of normality to support their project of imperialism, these same states looked inward at the human variation among their own people and produced a form of internal colonization that supported a dehumanizing view of disability. In educational contexts, in particular, these oppressive beliefs about disability have resulted in disabled students experiencing a "pedagogy of control" that, according to authors, mirrors the forced labor and absolute confinement that was experienced by those living in the colonies. In addition, scholars have likened the struggles for equal schooling for disabled students as a decolonization effort that has sought to challenge the social hierarchies that have reduced disabled students to the status of defective and dependent citizens.

What is apparent in the previous examples is that the metaphoric representations of both the colonized and disabled Other hold emancipatory possibilities for each other. At the same time, these metaphoric discourses of Otherness sometimes fail to account for and/or describe the actual experiences of disabled postcolonial subjects living in the former colonies that constitute the so-called Third World. Already living in impoverished conditions in nation-states incapable of providing an economic safety net for even their nondisabled citizens, disabled citizens living in postcolonial contexts continue to struggle for survival amid conditions of abject poverty; unemployment; lack of adequate medical care, education, and assistive technology; and the denial of basic human rights.

These conditions have been exacerbated in recent years by the neoliberal policies of the World Bank and the International Monetary Fund, which support economic austerity measures to be implemented by countries that had defaulted in their payment of debts incurred as a result of more than a century of colonial economic exploitation. These austerity measures, called structural adjustments policies (SAPs), are specifically designed to cut public spending in the areas of health, education, and public welfare in an attempt to support sustained economic growth and eventually lead to a reduction in poverty. However, as a result of these policies, there has been a drop of 10 to 25 percent in average incomes, a 25 percent reduction in spending per capita on health, and a 50 percent reduction in spending per capita on education in the poorest countries in the world—material conditions that set the stage for the social construction of disability. In addition, the World Bank uses the concept of the DALY (disability-adjusted life years) to prioritize health interventions by calculating their relative cost-effectiveness measured by the number of DALYs saved through each intervention, where the cost of each intervention is weighed against the person's potential "productivity' (i.e., contribution to economic growth). Here postcolonial disabled citizens who are unable to work are awarded zero value and therefore have little or no entitlement to health services at public expense. In this context, postcolonial conditions are seen to once again support the oppression of disabled citizens.

—Nirmala Erevelles

See also Freak Show; Globalization; Poverty.

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POSTER CHILD

Poster children are persons with disabilities portrayed in the media (e.g., newspaper, television, and publicly displayed posters) to encourage the public to donate money to organizations set up to help persons with disabilities. Most of the general population views disability as a statistical tragedy and often is not familiar with anyone who has a disability. In portrayals of poster children, the emphasis tends to be placed on the difficulties these individuals face, and the language tends to be negative, referring to the persons with disabilities as victims and sufferers who spend their life waiting for a cure. Poster children tend to be children because it is easier to portray children than adults as innocent victims. The vivid portrayal of the "tragedy" of an adorable child with a disability touches the emotional hearts of the viewers by eliciting feelings of pity and guilt, which in turn stimulate individuals to donate money to help these "helpless" individuals.

Throughout the past century, the media have used poster children to collect large sums of money. During the nineteenth century, religion-based charities often took on the responsibility for persons with disabilities. The concept of the poster child was invented at the beginning of the twentieth century, when volunteer organizations were developed that depended on donations. In 1919, Edgar "Daddy" Allen, a businessman from Ohio, founded the Society for Crippled Children, today's Easter Seals, and during the 1920s, Franklin D. Roosevelt inspired the March of Dimes. Today, when 99 percent of families own televisions, telethons have become a popular method for reaching large numbers of potential donors. The telethons portray the struggles of persons with disabilities, most of them cute disabled children, and their families (e.g., Jerry Lewis's Muscular Dystrophy telethon on Labor Day).

Although these organizations are set up to help persons with disabilities, an increasing number of disabled individuals, including former poster children, criticize them. Common criticisms include the following: these organizations have developed into million/billion-dollar enterprises, which have lost sight of their original goals; the organizations exploit poster children; primarily nondisabled individuals run the organizations; and disabled people are not consulted on how the money is used. In fact, many disabled individuals oppose using contributed money for various types of therapy (e.g., surgery and physical therapy), preferring instead that it be used to provide disabled individuals with necessary aids to live full and productive lives and to make built environments more accessible. The organizations tend to deny the various criticisms or insist that the protestors' opinions are not representative of larger groups.

The portrayals of poster children may have a negative impact on disabled children, especially those without disabled adult role models, because the children may learn to view their disability as a defect that needs to be cured. By overemphasizing the struggles in their lives, the children may reject (this part of) themselves. This rejection in turn can lead to insecurity, depression, anxiety, or other types of psychopathology, thus affecting disabled individuals into adulthood. The portrayals can affect children directly, by being poster children or seeing the portrayals, and indirectly, by interacting with members of society who have seen these portrayals and adopted the perspective that disability is a defect.

—Ingrid C. Hofmann

See also Easter Seals; Telethon.

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POSTTRAUMATIC STRESS DISORDER

A person's life can be interrupted by sudden, unexpected, and uncontrollable events involving death, injury, inflicted pain, or threat to self-integrity. Such events are very distressing. With time and appropriate support from others, distress and sorrow subside in most survivors, leaving scars but no open wounds. Some, however, do not recover and develop prolonged and disabling mental conditions. Posttraumatic stress disorder (PTSD) is the prototype of prolonged psychological disturbance that follows a stressful event.

Known since ancient time and masterfully described following World War I, PTSD was formally delineated in a classification of mental disorder in 1980 (*Diagnostic and Statistical Manual of Mental Disorders,* third edition [*DSM-III*]). The definition was further refined in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*). Some PTSD symptoms are directly related to the triggering event. These include reliving the traumatic experience through distressing and intrusive flashbacks, nightmares, heightened sensitivity to reminders of the event, and fearful avoidance of places, situations, or mental representations of the traumatic event. Other PTSD symptoms resemble depression and anxiety: loss of interest in previously pleasurable activities, restriction of one's emotional life, irritation, trouble falling or staying asleep, jumpiness, and constant vigilance.

For PTSD patients, therefore, the traumatic event is ever present and extremely demanding. A war veteran with PTSD may feel that the war "never ends." Combat scenes may continue to intrude into his or her consciousness, and he or she might experience an overpowering need to remain vigilant and defensive (e.g., scan building roofs for potential snipers). Survivors of terrorist attacks will, similarly, feel that another attack is imminent and behave accordingly. Rape survivors with PTSD might find it difficult to freely engage in sexual activity—even with known and beloved partners. As in other anxiety disorders, PTSD patients are well aware of the irrational nature of their fears but are trapped and overpowered by them.

Because many PTSD symptoms evoke the traumatic event, a prevalent theory explains the disorder as an inappropriate acquisition of fear responses during the event. Specifically, it has been argued that those brain areas that mediate fear responses (such as the amygdala) come to control and dominate PTSD patients' emotional and cognitive life. Brain-imaging research has shown that trauma survivors with PTSD tend to activate the brain's alarm system whenever confronted with novelty or challenge.

PTSD does not develop in every survivor. Inherited vulnerability and lifetime exposure to trauma increase the risk of developing PTSD. Adequate support and a nurturing recovery environment in the aftermath of traumatic events help protect survivors from developing the disorder. PTSD symptoms can be alleviated by pharmacological agents from the family of selective serotonin receptor inhibitors (SSRIs) and by psychological treatment (such as cognitive or cognitive-behavioral therapy).

Some writers have challenged the validity of this syndrome, arguing that PTSD is an artifact that reflects skewed social perception of normalcy and pathology. Clinicians are well aware of the suffering of PTSD patients and, while admitting that the definition of PTSD might be imperfect, use this diagnosis and the related research findings in the best interest of their patients.

—Arieh Y. Shalev

See also Mental Illness; Psychiatric Disorders; Stress.

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POVERTY

A family is considered poor when their monthly income is less than the income threshold set by the particular country's census bureau. Poor families do not have adequate income to cover their basic needs, including food and shelter. People living in poverty are more likely to be unemployed, have limited education, and are more likely to lack health care. An increasing number of people with disabilities, including children and adults, live in poverty.

Poverty is both a cause and consequence of disability. Several reports have found a strong correlation between disability and poverty and have described them as being cyclical in nature. First, living in poverty has implications for being at increased risk for developing a disability. Pregnant women living in poverty are less likely to receive prenatal care and are at higher risk for having low-birthweight babies and birth complications that place them and their offspring at a higher risk for experiencing disabilities. Also, people living in poverty are more likely to have either insufficient or unhealthy nutrition and live in conditions that put them at high risk for exposure to malnutrition, hazardous working conditions, and unhygienic living conditions, increasing their likelihood of developing impairments. Second, having a disability can lead to poverty. It is estimated that people with disabilities are three times more likely to live in poverty than the population as a whole. Individuals with disabilities experience additional stressors and expenses related to daily living. These include expensive assistive devices/adaptive equipment for increased functioning, home modifications expenses, health care attendant costs, special services (e.g., interpreters), extra transportation expenses, and health care costs.

Individuals with severe disabilities are more likely to experience difficulty seeking and maintaining employment. They are more likely to receive welfare benefits and less likely to have health insurance. All of these difficulties, combined with the marginalization from community and social activities, increase the likelihood of leading a life of poverty. According to the 2001 census data for the United States, only 48 percent of citizens 25 to 64 years old with severe disabilities have health insurance compared with 80 percent of individuals with nonsevere disabilities and 82 percent of nondisabled Americans.

In the United States, at least half of the adults with disabilities who cannot work because of a chronic disease or disability receive federal cash benefits under Social Security Disability Insurance (SSDI) and Social Security Insurance (SSI), and some may qualify for Medicaid and Medicare. The paperwork and bureaucracy involved in receiving this income are complex. Even if an individual successfully obtains these supplements, the small monthly income is often not sufficient to cover living expenses. In brief, having a disability has three different types of consequences that increase the likelihood of experiencing poverty for the individual and the immediate family. These consequences include (a) the income lost due to incapacity and discrimination; (b) the direct cost of treatment, access, and accommodations; and (c) the indirect costs to family caretakers who are not necessarily directly affected by the disability. Caregivers may have to quit their jobs or accept only part-time jobs so that they can care for the family member with a disability.

Women with disabilities in general are also more likely to live in poverty than men. Disabled women, compared with men with disabilities, are likely to have fewer years of formal education, less likely to have health care and to be employed, and, if employed, likely to be earning less income. A similar outlook has been reported for the elderly with disabilities worldwide. It has been reported that the proportion of the elderly with disabilities living at or below the poverty line, with limited health care, limited income to meet their daily needs, and limited access to attendant care, transportation, and assistive devices, is higher than younger adults with disabilities.

Adults are not the only ones affected by the relationship of poverty and disability. Children living in poverty are particularly at risk for having a disability. For example, in 2003 in the United States, it was estimated that about 28 percent of children with disabilities were living in poor families compared with 16 percent of all children. Poverty affects a child's development and learning, and in turn, the presence or onset of a disability exacerbates poverty. Children living in poverty have a higher incidence of malnourishment and exposure to environmental toxins; furthermore, poverty contributes to other factors such as parental stress and reduced exposure to a healthy and safe learning environment. Children with disabilities living in poverty are more likely to be neglected and malnourished and are more likely to die young than nondisabled children. Antipoverty programs need to closely examine the needs of families with children with disabilities who may experience emotional and material hardships.

Researchers have also highlighted the relationship between race, poverty, and disability in the United States. Minorities with disabilities (including

Hispanics, African Americans, and Native Americans) are more likely to live in poverty than nonminorities with disabilities. Researchers have called this "triple jeopardy" or triple discrimination of race, poverty, and disability that increases social inequalities. Minorities with disabilities are at a higher risk for being discriminated against when looking for jobs compared to Caucasians with disabilities. They are likely to have less formal education, to be less integrated into the fabric of society, and to be more often marginalized from societies' social and economic life than are Caucasians with disabilities.

It has been shown that, worldwide, people with disabilities are poorer as a group than the general population and that people living in poverty are more likely than others to be disabled. Individuals living in developing countries in poor conditions are more likely to experience poor nutrition, dangerous work environments, limited access to vaccination programs, limited preventive health care and maternity care, poor hygiene and sanitation, war and conflict, and natural disasters that can cause disability and impairment.

In communities around the world, people with disabilities are among the poorest and most vulnerable of all groups. Individuals with disabilities are often stigmatized and abused and less likely to have social security and health care. Furthermore, the housing and environmental conditions in which poor people live and work make them and their children more vulnerable to mental and physical impairments.

According to the World Health Organization (WHO), it is hard to obtain an accurate estimate of the number of people with disabilities in the world. Disability rates may vary by the type of country, type of disability, and age group. Nevertheless, the percentage of disabled persons ranges from 0.2 to 20.9 percent of the population in a given country. It is estimated that more than 500 million individuals in the world have a disability, and about 80 percent of these individuals live in developing countries. The fact that developing countries have such a high number of people with disabilities is due, in part, to the large number of people who live in poverty. Many international efforts are under way to address poverty and disability. For instance, the Action on Disability and Development (ADD) and the Chronic Poverty Research Centre (CPRC) attempted to understand the relationship between poverty and disability and are sponsoring a multitude of efforts to address these issues. These efforts have included economic development initiatives to create new and safer jobs, campaigns to eradicate polio and other childhood diseases through appropriate vaccinations, campaigns to prevent malnutrition in small children, and educational campaigns about appropriate handling of hazardous materials.

A worldwide effort is led by WHO to eradicate polio and other preventable childhood diseases with vaccinations. Much of the WHO efforts are also concentrated in Asia and Africa. In addition, the Department for International Development is sponsoring numerous programs through the United Nations in developing countries to improve sanitation and the water supply, as well as decrease exposure to environmental hazards. More research needs to be done to address policy issues and examine the impact of current international efforts. Research endeavors also need to focus on practical strategies for reducing the poverty that people with disabilities face, instead of continuing to gather data to reaffirm the well-known link between poverty and disability. It is important to increase the inclusion of people with disabilities in policy and social change efforts concerning poverty and disability. Inclusive and participatory research is needed to empower people with disabilities during the process of gathering data and information, to assess progress, and to challenge the exclusion and marginalization that help perpetuate the link between poverty and disability.

—Yolanda Suarez-Balcazar and
Sharibeth Cooper

See also Education; Political Economy; Poor Laws (United Kingdom); Race and Ethnicity.

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PREMATURITY

Prematurity, as defined by the World Health Organization, includes infants born at < 37 weeks gestational age (GA). The prematurity rate varies between 5 and 7 percent in Europe and Canada, whereas in the United States, it is 8 to 10 percent in white and 16 to 18 percent in African American women. Despite improvements in obstetric care, the prematurity rate has not declined in the past 40 years. Prematurity remains the leading cause of mortality and morbidity worldwide and accounts for between 60 and 80 percent of deaths among infants without lethal congenital malformations.

Survival of preterm infants is directly related to the degree of immaturity and birthweight. Although only about 1.5 percent of all infants are of very low birthweight (VLBW, < 1500 g), this group accounts for a disproportionately high mortality and morbidity. Neonatal survival improves dramatically with increasing GA; currently, the survival is more than 50 percent at 25 weeks and more than 90 percent at 28 or 29 weeks GA.

Although recent advances in the care of infants have resulted in a significant improvement in survival, they have not been associated with a parallel decrease in the rates of subsequent neurosensory sequelae, which include cerebral palsy, mental retardation, blindness, and deafness. The rates of cerebral palsy for infants < 1500 g birthweight are between 13 and 90 per 1,000 live births, which is nearly 40 times higher than the rate of 2 per 1,000 in the general population. The rates of blindness for infants < 1000 g are between 2 and 8 percent. The current estimate is that 1 in 2 extremely low birthweight (ELBW, < 26–28 weeks GA) survivors will have a neurodevelopmental disability; the most immature infants often have multiple disabilities.

At mid-childhood, additional problems such as behavioral difficulties, inattention, and learning disabilities may emerge. Children who were ELBW have mean IQ and achievement scores that are 9 to 13 points below the normative mean. Nearly half of the ELBW cohorts require special educational assistance and/or repeat a grade. These difficulties have been shown to persist to mid-to-late adolescence. Even children who are normal neurologically and have intellectual scores within the average range do not perform as well as their term birthweight peers. Thus, there is an economic burden for remedial assistance over and above that for term infants. However, by self-report, adolescents born with ELBW placed a high valuation on their health-related quality of life, despite recognition of their disabilities.

In terms of general health, the high prevalence of recurrent illness and hospitalization in early childhood appears to decline as the children born prematurely grow older. However, although there is some catch-up growth, overall, ELBW survivors have lower growth attainment at adolescence and early adulthood. Disturbances in growth in the intrauterine and postnatal period may have long-term implications in terms of metabolic derangements, hypertension, and cardiovascular disease in adulthood.

It is important to emphasize that the morbidities described are more prevalent in the least mature infants. By and large, infants weighing >1500 g at birth or born above 32 weeks gestation do substantially better but may still have minor disabilities. Thus, prematurity is a major public health problem. The high disability rates are often compounded by psychosocial disadvantage.

To date, medical efforts to prevent premature birth have been largely unsuccessful.

—Saroj Saigal

See also Prenatal Testing.

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PRENATAL TESTING

Disability plays a major role in prenatal testing. This entry focuses on the principal diagnostic categories that contribute to risk of disability in prenatal testing and the major technologies that are used to assess prenatal and preconceptual risk of disability; full discussion of the social contributors to prenatal testing is beyond this brief essay. Prospective parents seek prenatal or preconceptual testing to determine specific anatomic or genetic diagnoses with which to assess risk of disability in their fetus or yet to be conceived fetus. Individual parents generally seek to optimize the chances of a "normal" (i.e., nondisabled) child. As access to prenatal information concerning fetal anatomic and genetic characteristics has increased, the gap between accurately predicting fetal anatomy or genetic mutations and predicting childhood disability has widened. This widening gap leaves parents to define the limits of hope for their offspring individually, based on heterogeneous information and experiences. In many industrialized countries, socioeconomically advantaged parents act on these risk assessments in decisions to terminate pregnancies. Some parents who have a specific disability and are faced with a relatively certain fetal diagnosis of the same disability (e.g., achondroplasia) will opt to continue the pregnancy based on their own life experiences. Alternatively, parents faced with a similarly certain but life-limiting disability (e.g., Tay-Sachs disease) may opt for pregnancy termination.

The major diagnostic categories in prenatal testing associated with a significant risk of disability are genetic, anatomic, infectious, and environmental. Genetic diagnoses include cytogenetic abnormalities (too many, too few, or malformed fetal chromosomes, e.g., Down syndrome) and inherited genetic diseases (e.g., cystic fibrosis). Diagnosis of either category of genetic disease requires access to fetal cells or DNA through amniocentesis, cordocentesis, chorionic villus sampling, or embryo biopsy. Anatomic diagnoses are established by antenatal ultrasound and include major birth defects (e.g., congenital heart disease or spina bifida) and prematurity. These diagnoses can also lead to the prediction of childhood disability (e.g., cerebral palsy in premature infants). Fetal infections (e.g., rubella or German measles) can be diagnosed using either maternal or fetal blood samples or amniotic fluid and can lead to the prediction of significant pediatric disability. Finally, fetal exposure to specific teratogens through maternal or paternal environmental exposure discovered through a careful medical history can increase the risk of childhood disability (e.g., fetal alcohol syndrome or birth defects due to paternal exposure to organic solvents). Each of these categories includes many conditions with widely varying outcomes in disability. This biologic heterogeneity in outcome can complicate parental understanding of disability risk.

The two most frequently used diagnostic methods for prenatal testing are antenatal ultrasound and amniocentesis. After ultrasound technology was developed during World War II to detect German submarines, early ultrasonographers in the United States began to visualize the fetus in "black and white pictures of things that looked like the clouds seen in hurricane reports," according to Lewis H. Nelson, president of the American Institute of Ultrasound Medicine. With rapid advancements in technology, accurate anatomic evaluation of individual organs (e.g., hearts or spinal cords) in fetuses as early as 8 weeks gestation has become commonplace. However, antenatal ultrasound has significant false-positive and false-negative rates. In addition, the anatomy of a fetus may not predict the disability of a child. For example, with enlarged chambers in the fetal brain midway through a pregnancy (hydrocephalus), the likelihood of adverse neurodevelopmental outcome (e.g., seizures, inability to read or talk, blindness, or deafness) is significantly increased. But some children with this finding are "normal," and the ultrasound test cannot distinguish those who will have from those who will not have disabilities.

Amniocentesis, or the removal of a sample of amniotic fluid from the womb, was first developed in 1950 by a Uruguayan obstetrician to measure pressure changes in the womb during labor. This procedure transformed obstetrics from an exclusively maternal discipline to a medical specialty that included prenatal testing for fetal chromosomal composition around 16 weeks gestation. Recent advancements now permit fetal chromosomal evaluation at less than 8 weeks gestation (by chorionic villus sampling) or prior to implantation in the womb of an embryo (by embryo biopsy). Diagnosis of disabling chromosomal and genetic conditions in the embryo or fetus prior to the legal definition of viability is feasible (24 completed weeks of gestation in the United States). However, like antenatal ultrasound, the biologic continuum of many genetic diagnoses plus the socioeconomic status of different families may lead to different degrees of disability in children with similar fetal genetic diagnoses. For example, children with trisomy 18 are frequently born with life-limiting birth defects that lead to death within hours to days after birth. However, some of these children survive for years. Parents faced with a fetal diagnosis of trisomy 18 may choose to terminate or carry the pregnancy depending on their perceptions of the disability these children develop. These techniques also provide access to fetal DNA that can be used for molecular diagnosis of specific gene defects. When unambiguous evidence is available correlating a specific gene mutation with disability, parents use this information to make decisions about the management of the pregnancy and the child. However, the ability to predict disability based exclusively on genetic information is limited due to the biologically complex interactions among gene mutations, environmental conditions, and genetic backgrounds (e.g., different ethnicities). For example, in Tay-Sachs disease, the neurodevelopmental progression of the disease is invariable and life limiting. In cystic fibrosis, while the diagnosis is equally precise, the disability outcome may be quite variable, with many affected individuals surviving and being productive well beyond age 30.

Preconceptual testing for predicting risk of disability in future children has also become increasingly commonplace. Using careful review of family histories of both parents and DNA testing for many different gene mutations, preconceptual testing attempts to reduce the risk of conceiving children who will be born with disability or become disabled. For example, if there is a strong family history of spina bifida or anencephaly, folic acid is recommended for prospective mothers prior to conception and for the first three months of the pregnancy. Epidemiologic studies have shown that this inexpensive nutritional supplement can reduce the risk of spina bifida and anencephaly by 75 percent. A more difficult problem with newer DNA technologies is the ability to predict the risk of disabling adult diseases (e.g., Alzheimer's disease, Parkinson's disease, or breast cancer) prior to conception. Available genetic testing technologies permit the identification of genetic predisposition, and risk can be reduced with strategies such as the selection of a genetically determined low-risk sperm or egg donor. In some conditions, pharmacologic, behavioral, or monitoring strategies can also be used to reduce the risk of disability.

Prenatal and preconceptual testing leaves parents with a conundrum that they must resolve based not only on test results but also on personal values, prior experiences, and, ultimately, hope. Parents use the input of medical providers, religious advisers, family members, financial consultants, the media, the Internet, and cultural expectations differently and selectively. Frequently, mothers and fathers differ in their perception of disability based on prenatal testing, and this difference will lead to conflict concerning consideration of pregnancy termination. Some parents will choose to rely on hope that their child will be less disabled than predicted, on hope that technology advancement will offer their child new strategies to reduce the impact of disability, or on faith that their child's disability will be a leavening factor in their lives. Other parents will choose to terminate a pregnancy rather than subject a child to multiple painful medical interventions without reasonable hope of the ability to overcome disability. While technology offers impressive anatomic and genetic precision for fetal evaluation, the biologic continuum of disability outcome associated with specific fetal anatomic and genetic findings, parental perceptions of disability risk, and the timing during pregnancy of the diagnosis all contribute to decisions that may alter significantly the population-based frequency of specific disabling conditions.

Prenatal and preconceptual testing provides a battery of powerful medical tools to predict risk of disability. Prenatal testing also provides an area for disability research to improve the capability of prenatal testing to predict disability, to identify strategies to understand mechanisms of disability, and to improve outcomes of specific disabilities. Such research is critical to ensure that parents optimize their children's futures rather than choose their future children. Prenatal testing must be viewed as information for parents that will help them decide wisely about their pregnancies, not simply make wise decisions prompted by medical providers. Given the significant contributions of genetic, environmental, anatomic, and infectious causes to risk and severity of disability and the substantial amount of prenatal testing provided to parents, the opportunity for improved understanding of disability has never been greater.

—F. Sessions Cole

See also Cystic Fibrosis; Down Syndrome; Prematurity.

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PRESSURE ULCER/SORE

Pressure ulcer/sore (PU) is a severe soft tissue breakdown most commonly reported in individuals confined to an unaltered body posture such as sitting in a wheelchair due to mobility impairment or staying in bed due to illness. Unrelieved pressure squeezes tiny blood vessels, which supply the skin with nutrients and oxygen. When skin is starved for too long, the tissue dies and a PU forms. The most frequently affected body locations are where soft tissue is overlying a bony prominence and where body weight is supported, such as the ischia and tailbone for sitting posture and the hip bone, back of the head, shoulder blades, spine, ankles, and heels for supine posture.

Persons with impaired nervous systems are not able to sense the need to change posture for pressure relief. Those in bed may get PU after as little as one to two hours, while those who sit in wheelchairs can get PU in even less time because the force on the skin is greater.

A number of factors predispose an individual to a high risk of PU. External factors include interface pressure, shear and friction, time remaining in a fixed posture, temperature, and humidity. Internal factors (i.e., sensory impairment, vascular disease, previous history of pressure damage, malnutrition, and dehydration) determine the level of loading tolerated by the tissue before damage occurs. In practical situations, these factors interact with each other, making an individual more vulnerable to PU formation. Increasing the time that pressure is applied without relief and the loss of muscle bulk and tone all make the tissues more liable to be damaged by a given level of pressure.

Among the above-mentioned factors, pressure, which is more concentrated over bony prominences, has been considered the single most important etiologic factor in PU formation. High pressure leads to impaired lymphatic circulation and hypoperfusion in the compressed tissue, resulting in an accumulation of toxic intracellular materials and a compromised blood flow, which further lead to tissue hypoxia, acidosis, interstitial hemorrhage, and cellular death. Both duration and intensity of pressure affect the amount of damage. Reestablished tissue perfusion after a long period of high loading will result in ischemic/reperfusion injury, which has been implicated in tissue damage. Studies have shown that muscle is highly susceptible to localized compression, eventually leading to tissue degeneration in the form of a deep PU that progresses toward the skin surface.

If pressure is relieved periodically, higher pressures can be tolerated for longer periods. This forms the basis of pressure relief regimens used in clinical practice, which involve regular turning, pushing up from the support surface, and the use of alternating pressure support systems. Short-term loading generally produces elastic deformation and rapid elastic recovery, whereas long-term loading results in marked creep and requires significant time for complete tissue recovery.

It is suggested that skin inspection be performed regularly and the frequency determined in response to changes in the individual's condition. Patients who are able and willing should be informed and educated about PU risk and prevention strategies.

—Mohsen Makhsous

See also Spinal Cord Injury.

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PREVENTION

Prevention: (noun) 1. action that stops something from happening; e.g., prevention of crime. 2. something that acts to prevent something: an action or measure that makes it impossible or very difficult for somebody to do a certain thing, or for something to happen.

In everyday language, the word *prevention* refers to stopping something bad or unhealthy from happening. *Promoting* or *encouraging* are the antonyms—actions that facilitate or help something to happen. The two ends of the spectrum are generally associated with negative outcomes, on one hand (prevention), and positive outcomes, on the other (promotion).

PUBLIC HEALTH PREVENTION

The traditional public health meaning of prevention refers to efforts to eliminate a negative health condition. For example, infants are immunized early in life to prevent certain childhood diseases. An overwhelming percentage of infants in the United States are now immunized, and this is clearly a public health triumph—one that few would question. Traumatic injuries, another example, are associated with several negative health outcomes, ranging from long-term limitations in activities to death. Public health interventions to prevent injuries include seat belt protection, swimming and diving safety, and bicycle helmet programs. Research has shown that a large percentage of neural tube defects could be prevented if women of childbearing age take 400 micrograms of folic acid each day by a combination of nutrition, food fortification, or vitamin supplementation. Obesity is another significant problem in the U.S. population, resulting most often from a combination of poor diet and lack of physical activity. Major public health programs have been implemented to prevent each of these—childhood illness, traumatic injuries, birth defects, and obesity through population-based programs—through immunizations, automobile safety, folic acid consumption, and appropriate diet and exercise.

"Prevention," as it pertains to disability, is a more complicated topic. Disability, by public health definition, is a negative health outcome to be prevented. Disability prevention is perceived by many in the disability community, therefore, as an attempt to prevent the person with a disability from existing. This interpretation can create an adversarial relationship between public health and the disability community—one that need not be present.

Public health does not inherently disrespect the experience of disability. In the pursuit to improve the health of the public, in the context of the history of public health, it is easy for public health professionals to forget that no accumulation of public health activities will eliminate all conditions that limit people's activities. Public health can, therefore, inadvertently frame messages designed to help prevent behaviors associated with disabling conditions so that they disrespect the human experience of disability—and those living with a disabling condition. Those messages, for example, proclaim the need for safe driving while showing someone in a wheelchair. The explicit connection disrespects the experience of disability and draws an inappropriate connection. Disability, then, is presented as equated with illness. To the extent that public health messages, in an effort to prevent the conditions associated with disability, equate illness with disability, they unwittingly demean people living with a disability.

People with disabilities can also contribute to an adversarial perspective. In their pursuit for inclusion, people with disabilities may believe that public health prevention activities are implicitly (or explicitly) trying to prevent them from being. Seeing the emphasis placed on primary prevention often leads those with disabilities to conclude that all public health activities are focused on trying to keep them from existing. Past experience is not balanced with current reality—the reality that public health emphasis on improving the health of people with disabilities is growing. There is no inherent conflict between primary prevention interventions that try to reduce disabling conditions and maintaining and improving the health of individuals who experience disabilities. Those who experience disabling conditions often have fallen through the primary prevention net—that is, all the public health activities did not prevent them from experiencing the disabling condition. They live with disabilities related to birth defects, developmental disabilities, injuries, chronic illness, or aging.

Primary prevention messages are equally important for people with and without disabling conditions. This is a crucial perspective for public health professionals, as well as individuals with disabilities and their families. Individuals with disabling conditions are just as vulnerable to cancer or heart problems, for example, as the rest of the population. Screening for breast or prostate cancer or cardiovascular problems should be a part of clinical preventive services for all of the population. Cancer research comparing women with and without disabilities show that women with disabilities are diagnosed later and treated less intensively than the general population. Even though they might see medical professionals more often, people with disabilities often do not receive these preventive services as routinely as the general population.

Part of the problem might be that clinical preventive services (e.g., shots, prostate or breast cancer screenings) are usually completed in the offices of family physicians or internists. Many individuals with disabilities use specialists as their primary care physicians. The specialists may be less aware of, familiar with, and sensitive to the need for clinical preventive services.

In addition, there are times when public health messages should be tailored specifically to reach people with disabilities. This is particularly important when people with disabilities could be at particular risk. For example, people with mobility limitations are at greater risk for weight gain than the general population due to their often reduced physical activity and poor nutrition. In fact, national data suggest that people with disabilities report significantly more obesity and less physical activity than the population without disabilities. Few public health messages, however, focus on this at-risk group.

Prevention and the Environment

There is another kind of public health primary prevention activity relevant to people with disability—environmental factors. Dramatic improvements in the health of the public have come about as a result of environmental changes. It is clear, for example, that more improvement in the health of a population occurs because of clean water and hygienic waste removal than because of any other contributors. Improvement of the health of the public has often been intimately tied to such environmental improvements. Changes in environmental conditions have been estimated to account for an overwhelming percentage of decreased mortality during the first half of the twentieth century. That is, environmental improvements have been primarily responsible for the increase in lifespan from 45 years in 1900 to 72 years in the year 2000. Toxic air, water, or food can decrease quality and quantity of life for the population, including those with disabilities. In addition, however, environmental factors such as a lack of curb cuts, negative attitudes of society, and government policies can dramatically affect the health and well-being of people with disabilities.

PUBLIC HEALTH PREVENTION PROGRAMS

Programs to implement primary prevention activities associated with disability were officially begun at the U.S. Center for Disease Control and Prevention (CDC) in 1988. The program focused on disability prevention using the traditional public health model—identify the condition, generate interventions to control or prevent the conditions, identify those at risk for the condition, and intervene. This approach has been used universally by public health agencies to protect the health of the world. Unfortunately, emphasis on primary prevention of conditions associated with disability has been the major focus but is only a small part of public health's responsibility related to disability. Many conditions are not prevented from occurring despite the best public health effort. Children are born with sensory, physical, and cognitive problems. Throughout our lives, we may experience traumatic injuries anytime, and chronic illnesses develop for many individuals as they age. Vernon Houk, a public health physician and CDC leader, speaking to one of the early disability prevention meetings, suggested that "people with disabilities form the only minority group to which anyone may join at any time with no intention to do so." Prevention of conditions associated with disability is one, albeit important, set of public health activities. Public health also has responsibility to people who live with disabilities.

SECONDARY CONDITIONS

The term *secondary conditions* is relatively new to the lexicon of public health and disability studies. While the term has created some confusion—in part because it is new and in part because the definition continues to be refined—the distinctions it creates are essential to the lives of people with disabilities. "A secondary condition is *any* condition to which a person is more susceptible by virtue of having a primary condition" (Lollar 1999). The concept of secondary condition does not reflect its importance but rather its temporal quality—that is, a secondary condition occurs after a primary condition.

There are fundamental distinctions between comorbid conditions and secondary conditions. Often, the science of public health addresses individual conditions in terms of risk, prevention, and intervention, as if those experiences occurred in isolation. That is seldom the case, of course. In some situations, conditions occur as comorbid health conditions—that is, they are unrelated; there is no association. An older person with macular degeneration (an eye disease) might also have arthritis. There is essentially no relationship between these two conditions, although the combined effect may be significant in terms of mobility and quality of life. In other cases, one condition creates risk for another. A person with paralysis, for

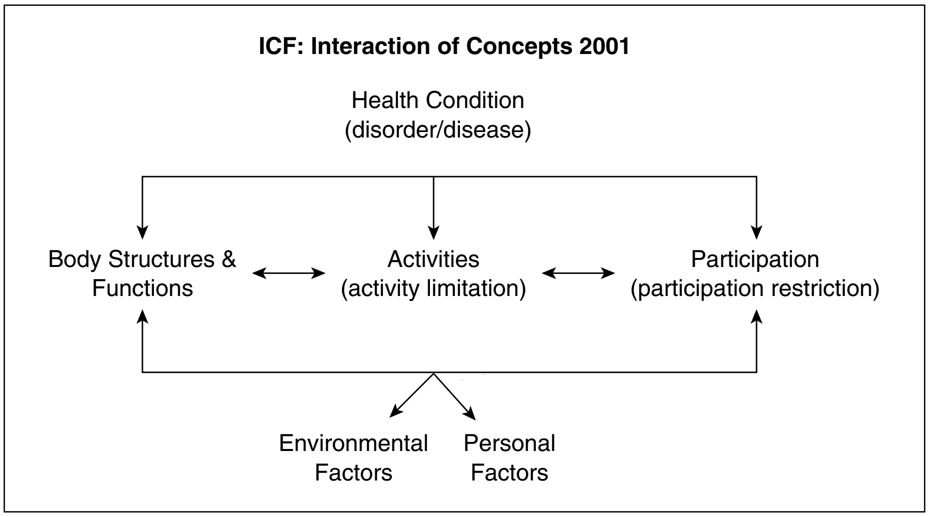

Figure 1 ICF: Interaction of Concepts 2001

example, may be at risk for pressure sores. One follows the other. An important characteristic of a secondary condition is that it can be prevented. Prevention strategies to avoid pressure sores would include shifting weight, repositioning, or having a good seating system. Some secondary conditions are unique to people with disabilities, while some are not. For example, because of a disability and its consequent isolation, a person might become depressed. An individual without disabilities may be depressed as well, though the underlying causes may differ. Common secondary conditions include depression, chronic pain, joint and muscle pain, sleep disturbance, obesity, fatigue, contractures, and lack of conditioning.

The concept of secondary conditions, however, is now regarded as broader than associated impairments to include activity limitations and participation restrictions. Recently, the concept of secondary conditions has expanded: "Secondary conditions can create significant impediments to an individual at the level of *body system* dysfunction, *activity limitations* or *participation restrictions*" (Lollar 1999). This expanded notion of secondary conditions emerges from efforts over the past 25 years to reconceptualize the lived experience of disability. Until recently, the so-called medical model dominated how disability was described. The essential notion was that a problem at the body system level created inherent limitations in function—for example, the ability to pronate or supinate the hand. The medical model relies on an accurate diagnosis that allows problems to be "fixed." However, in disability, people's lives go on—"fixed" or not—and individuals generally demonstrate remarkable capacities to make do with what they have. The ability of individuals to deal with adverse circumstances and go on is mediated by many factors in addition to restoring function. One's financial resources, the kinds of activities one performs, and the supportive nature of the environment, as well as one's own resilience, may have more to do with quality of life and social participation than restoration of function. Thus, in recent years, scholars and advocates in disability have attempted to portray the multidimensional characteristics of disability as a way to understand how people carry out their lives or how they might be more successful in pursuing meaningful activities. This effort is described as a social model of disability.

This more dimensional portrayal of disability embraces the complex relationships of human experience and illustrates the potential impact of secondary conditions. The World Health Organization developed the *International Classification of Functioning, Disability, and Health* (*ICF*) as a companion to the *International Classification of Diseases* (*ICD*). The *ICF* creates a framework to "map" human experience. It is not designed to be used exclusively to model disability. The *ICF* creates a taxonomy to portray the relationship of human experience in related domains—body, person, and society. Health condition describes disease, injury, or disorder at the at the person level. Health conditions may result in changes of body structure and function. These can be described and measured; for example, macular degeneration occurs at the cellular structure of the macula, and its effect can be measured in altered acuity and central loss of visual field. Activities describe the things people do: walking, lifting, reading, driving, and preparing meals. And participation deals with the social roles that people carry out—going to school, working, voting, and having friends and relationships. The multiple arrows of Figure 1 illustrate the multidimensional characteristics of the concepts of the *ICF.*

For example, a disease or injury may create changes in body function and structure that, in turn, may or may not affect the performance of activities, which, in turn, may or may not affect social roles. In this model, the environment plays an important mediating role insofar as the environment can serve as either a barrier or a facilitator. An example helps to make these relationships substantially clearer. A person with macular degeneration (an eye disease) experiences changes in the structure of the macula. These changes can be measured in terms of visual acuity, that is, function. As a result of macular degeneration, then, a person may have difficulty reading print, driving a car, getting around in dimly lit environments, or recognizing faces at a distance. These are all activities. As a consequence of these activity limitations, a person with macular degeneration may be less inclined or less able to go out to dinner with friends. The print on the menu might be too small to read, steps could create hazards for falls, and an individual may not be able to get to the restaurant unless someone picks her or him up. These relationships are not inevitable or predictable. This model suggests multiple places where interventions may reside. For example, medical treatment may mitigate the effects of macular degeneration, low-vision services (technology) may improve function, and rehabilitation services might improve the performance of various activities (say, using a cane to detect steps). Moreover, the environment can have a major influence in reducing the negative outcomes of macular degeneration for the individual. For example, a robust transportation system would likely solve the problem of getting to the restaurant. Better light at the steps might improve safety and mobility, and a large-print menu might ease the difficulty and anxiety of ordering. Also, helpful and patient restaurant staff could make the entire outing more pleasant. In the *ICF,* the concept of environment has to do not so much with the built characteristics of the environment as with the environment as it is defined by social attitudes and public policy.

While the *ICF* allows us to map the course and dimensions of disability, the conceptual framework also helps to understand the role of secondary conditions in a complex system defined by our lives. The definition of a secondary condition emphasizes *any condition* that creates significant impediments to individuals at the level of body system dysfunction, activity limitations, or participation restrictions. Therefore, if we map potential secondary conditions against the *ICF* model, we can see that there may be secondary conditions at the body structure or function level (say, pressure sores or contractures), a secondary condition may occur at the activity level (e.g., personal care might be limited due to a fall), or secondary conditions can occur at the participation level if one is socially isolated or cannot get a job.

Consequently, the prevention of secondary conditions is embedded in more responsive clinical care. For example, physicians should routinely ask about weight, exercise, and pain among patients with disabilities, and broad health promotion activities should include or target people with disabilities in health messages. The prevention of secondary conditions may evolve from improved technology, for example, as wheelchair design and improved seating systems reduce contractures, pain, and skin abrasions. And secondary conditions related to social isolation and social roles (e.g., work) can be mediated by changes in the environment, as the built environment becomes more accessible, transportation systems more robust, and employers more welcoming.

—Donald J. Lollar and John Crews

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

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PRIMARY AND SECONDARY EDUCATION

See Education, Primary and Secondary

PRIVATIZATION

Starting in the late 1970s and continuing today, there has been a worldwide movement by countries to privatize government-owned industries and state-provided services. Starting with Prime Minister Margaret Thatcher, the rightist governments in the United Kingdom and the United States (under President Ronald Reagan); labor governments in Scandinavia, New Zealand, and Australia; socialist governments in Spain and Mexico; and the governments in the countries of the former Soviet bloc have all implemented privatization programs. This unprecedented growth in privatization will likely have profound and long-term impacts on the type, cost, and quality of social and health care services that individuals with physical and mental disabilities receive.

Privatization (or liberalization, as it sometimes is called) has strong political, technical, strategic, and ideological dimensions. It has been proposed as a strategy to meet an almost limitless set of objectives, from shrinking the overall size of government, to raising funds and lowering taxes, to enhancing the technical efficiency of specific public-sector services. For some, privatization is an end in itself; for others, it is the means to other valued outcomes.

The privatization movement raises a number of important fundamental public policy questions that governments and citizens must address. These questions include the following: How large of a role should governments play in their nation's economies? What are the basic realms and responsibilities of governments? What specific tasks should governments perform for their citizens? Which tasks are best performed by the private sector? What role should governments play in regulating functions best implemented by the private sector?

The term *privatization* first appeared in the business and management literature in the early 1970s. Economic and social theorist Peter Drucker is credited with inventing the word. Since it was coined, numerous definitions of privatization have been proposed. Some of them have been very broad and vague, while others have been very narrow and specific. All of the definitions, however, have two common elements: a movement away from the reliance on government agencies to provide goods and services and a movement toward the private sector and market forces.

Privatization can take on a myriad of forms. They include governments: contracting with organizations in the private sector to purchase goods and services; providing grants and subsidies to individuals and organizations to encourage them to provide needed items; charging consumers fees for the use of particular services; encouraging volunteerism so that charities and other organizations assume a larger portion of the social burden; encouraging self-help services by individuals and groups; granting franchises to private organizations to provide particular services within specific geographic areas; issuing vouchers to consumers, authorizing them to purchase specific goods and services from government-approved private-sector companies; totally withdrawing from the provision of existing services; selling assets, such as land holdings, to the private sector to generate revenue or to spur development; and deregulation, the weakening or total elimination of legislative rules and regulations governing certain private-sector industries.

In the United States, most privatization to date has occurred at the local and state levels of government. Much of it has been through increased contracting with private-sector companies to provide such services as trash collection, fire protection, public health laboratory services, and the operation of correctional facilities. Also, several cities and states have established school voucher programs enabling students in public schools to enroll in private charter schools. Recently, however, there have been a number of proposals to partially privatize the nation's Medicare and Social Security programs.

Outside of the United States, privatization has taken place mainly at the national level and primarily through the sale of assets and the withdrawal of services. Many countries have concentrated their privatization efforts in the areas of telecommunications, energy production, and health care and community services. For example, Sweden, the world's traditional exemplar of the welfare state, has privatized much of its health care system, selling many of its formerly state-owned hospitals to private corporations.

Views about privatization's virtues and pitfalls vary widely. In most cases, the views are fundamentally ideological and political in nature. Conservatives in general and businesses in particular tend to advance positive arguments, while liberals in general and labor unions in particular are strongly opposed to any form of privatization.

Proponents of the privatization of health care argue that it enhances individual choice, fosters innovation, and reduces inefficiencies. They state that selling off government-owned hospitals brings much-needed money into state, county, and regional coffers. And privatizing local clinics removes their operating costs from public budgets. Proponents argue that private companies, or groups of physicians, who purchase these medical facilities can run them more efficiently, increase patient access, and provide better quality care. They also indicate that privatization can "free up" scarce government resources to provide services for the poor, to the extent that those individuals who are willing and able to pay for health services seek care outside the public sector.

In sharp contrast, opponents of privatization argue that although some health care programs may have serious problems and need attention, privatization is not a general solution to them. Critics say that privatization erodes the very principles of universality and social equity in the delivery of health care services. It creates an inappropriate "multitiered" health care system where the provision of care is based on the ability to pay, rather than on need. Such a system decreases the access of underprivileged groups to care and ultimately worsens health outcomes. Also, important preventive care and community public health services such as immunizations, which are generally not profitable, tend to be neglected. Critics further point out that privatization interferes with real accountability to consumers. Last, they argue that privatization hurts health care workers because it threatens their job security, pay and benefits, working conditions, and career opportunities.

Despite the large number and types of privatization programs implemented in countries throughout the world, it is notoriously difficult to assess their impacts. There have been few evaluations of the programs in terms of their stated objectives. Even in crude terms such as the number of privatized firms, the proceeds of sales, or the share of gross domestic product coming from the private sector, it is very difficult to get hard data and an overall picture. Many of the privatization programs have been implemented haphazardly and often with little consistency across different regions of counties. Furthermore, because every industry is different and because countries have their own unique cultures and traditions, no two acts of privatization are ever identical.

The effects of privatization on health care services and patient outcomes are also very difficult to assess. In several countries, privatization appears to have adversely affected the health of its citizens. For example, in Russia, after the collapse of communism, many former state-owned hospitals and clinics were privatized. Some of these private for-profit facilities offer the latest medical technology and high-quality health care but, unfortunately, at prices that few Russians can afford. At the same time, state-owned facilities are critically short of money and medicine, equipment and buildings are crumbling, and physicians and nurses earn near-poverty wages. The decline of these facilities has resulted in a rise in Russia's overall mortality rate and a decrease in average life expectancy unparalleled among developed nations in recent peacetime history.

Rural health care in the People's Republic of China is reported to have suffered because of privatization. As China moved toward a free market system, an increasing number of state-owned clinics have contracted out services, and a large number of privately owned for-profit clinics have been established. The for-profit clinics charge their own rates, which many of China's hundreds of millions of poor rural citizens cannot afford. The private clinics have also led to the decline in community public health services. Because it is not profitable, clinic physicians no longer trek to distant villages to vaccinate children or to exhort women to obtain prenatal care.

The health care system of Mozambique also appears to have suffered from privatization. After independence, the Mozambique government established a national primary health care system. The system was so successful that the World Health Organization considered it a model for other African nations. To undertake various development projects, Mozambique borrowed funds from the World Bank, the International Monetary Fund, and other international financial institutions. These institutions pressured the nation to adopt free market policies. Many local private organizations and foreign agencies began providing health care services. As a result, Mozambique now has a two-tiered health system where poor people continue to seek care in an underfunded, understaffed, demoralized government-run system, while a small group of largely urban, rich elites receives services from private for-profit clinics.

In summary, it is not clear how individuals with physical and mental disabilities have fared under these and other privatization programs. It is clear, however, that all privatization efforts must address the special and unique social and health care service needs of those with disabilities. To protect them and other disadvantaged groups, governments must maintain a safety net of services that they alone can provide. Last, although empirical studies do not provide clear evidence on the costs and benefits of privatization, public perceptions and pressures to improve government efficiency and hold down taxes will keep proposed privatization programs on present and future government agendas.

—Ross M. Mullner and
Kyusuk Chung

See also Health Management Systems; Managed Care; Political Economy.

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PROFESSIONS

Professions are a special type of occupation. The sociological study of professions examines the social forms taken when work is organized and controlled by experts. According to Freidson (1970a, 1970b, 2001), work ("the practice of knowledge") is best understood by constructing three ideal types (or conceptualizations) of work: free market, bureaucratic, and professional. Each ideal type represents a different form of control over work: (1) the consumer/buyer (free market), (2) managerial (bureaucratic), and (3) occupational (professions). In turn, each has its own characteristic ideology: the market in consumerism (or what Freidson terms "popularity generalism"), the firm in managerialism ("elite generalism"), and professionalism in "specialization." Freidson also identifies five "critical contingencies for establishing and supporting professionalism": (1) an esoteric body of knowledge requiring "considerable discretion"; (2) control by the occupation over its own division of labor, (3) its own labor market, and (4) its own training program; and (5) "an ideology serving some transcendent value." For Freidson, a major sociological question of our time is the "status of professionalism in advanced industrial society." However, and as noted by Abbott (1988, 2001), the concept "profession" is distinctly Anglophone, with the term having no direct translation in either French or German. Professions trace their early roots to the guild system in England. The general form, as we know today, emerged in the early to mid-1800s in England and the United States, with medicine serving as the prototypical profession. Studies of the historical evolution of medicine as a profession generally point to a period of rapid growth from the mid-1800s into the early 1900s, followed by a period of consolidating professional powers and privileges that lasted until the late 1960s. Beginning in the 1970s, traditional professional groups came under sustained attack by rival occupational groups seeking their place under the professionalism sun, a growing consumer rights movement, increasing encroachment by the state, and the aforementioned arrival of a for-profit marketplace. Social theorists in the 1950s and 1960s envisioned a groundswell of professionalism that would neutralize the evils of political authoritarianism and capitalistic exploitation—a vision that has not materialized.

AN EVOLVING SOCIOLOGICAL INQUIRY

Analysis of professions has undergone its own evolution. Early works such as Carr-Saunders and Wilson (1933) adopted a functionalist approach to social analysis, an analytical framework that reached its zenith in the 1950s and 1960s with the theoretical writings of Talcott Parsons. In 1970, Eliot Freidson published two watershed volumes, *The Profession of Medicine: A Study in the Sociology of Applied Knowledge* and *Professional Dominance: The Social Structure of Medical Care.* Freidson sought to critique the functionalist emphasis and to explain the rise of professional dominance and autonomy—with allopathic medicine serving as Freidson's occupational template.

Works critical of the "professional dominance approach" quickly followed. Notable was work by Margali Larson (1977), Paul Starr (1982), and Andrew Abbott (1988). Alternative theoretical frameworks included "deprofessionalization" (Haug 1973), "proletarianization" (McKinlay and Arches 1985), and "corporatization" (Light and Levine 1988). A vigorous decade-long debate between Freidson and his critics ensued, as insights into the nature of professions were extended to occupational groups other than medicine and to a more nuanced cross-national understanding of professional work (Hafferty and McKinlay 1993). Most recently, Light (2000) has extended his earlier work on corporatization into a more robust theory of "countervailing powers."

THE "REDISCOVERY" OF PROFESSIONALISM BY ORGANIZED MEDICINE

The failure of the Clinton Health Plan in 1994 occurred in the midst of what would be the United States' longest running bull (stock) market, thereby unleashing a deluge of investor dollars into a number of new corporations and corporate sectors—health care being one. What had once been defined almost solely by the pharmaceutical industry quickly came to include new market sectors such as "health care services," "physician practice plans," biotechnology, and, most recently, "genomics"—as purchasers and providers alike quickly staked out territory in a new "medical marketplace" (itself a new way of thinking and talking about medicine). The arrival of "managed care" and the development of varied strategies to alter both physician and patient behaviors were greeted with fear and distrust by organized medicine. Editorials, commentaries, and articles began to appear in authoritative medical journals (e.g., *JAMA, New England Journal of Medicine, BMJ*) about the "inherent conflict" between medicine's "culture of professionalism" and the marketplace's "culture of commercialism" and medicine's loss of public trust. In turn, a number of medical organizations ranging from trade groups (e.g., Association of American Medical Colleges) to specialty societies (American Board of Internal Medicine) to accrediting agencies (American Council of Graduate Medical Education) began to call for a rededication to the principles of professionalism, for a more explicit presence of professionalism in medical education, and for the development of licensure and accreditation standards for professionalism. Similar efforts appeared in England and Canada.

MEDICINE AND THE "NEW PROFESSIONALISM"

This mingling of medicine and Wall Street, along with other social changes, brought about another call to professional arms, this one for a "new professionalism" or for a "reformulation" of old professional ideals. Traditional professional values or organizational forms such as a "autonomy," "monopoly," "hegemony," and "hierarchy" were deemed "lacking" and/or "inappropriate" in a "new medical era." Instead, the physician and patient were being cast as a "partnership of equals."

MEDICINE AND THE SHIFT FROM IMPAIRMENT TO DISABILITY

The evolution of disability as a social form follows a somewhat similar path to that of professions and the sociological analysis of expert work. The growth of medicine as a scientific enterprise was both a cause and a consequence of a broadly based effort to "objectify" disease and to extend the influence of a distinctly biophysiologic account of "normal" and "patho" physiology. Behaviors and/or attributes that had been seen as personal shortcomings and/or moral weaknesses became markers of disease, a process sociologists refer to as "medicalization." This increasing encroachment of medicine over domains of social life was not without detractors (Illich 1976). Nor were they without negative consequences, as advances in medical science seemed to be doggedly shadowed by the rise of treatment side effects, iatrogenic disease, and an appalling rate of fatal medical errors. Organized medicine, operating within an insular cocoon of elitism and arrogance, rebuffed criticisms. Earlier promises to place the patient's welfare ahead of its own (e.g., altruism) slowly morphed into a less stringent promise that medicine would act in the best interests of the patient (paternalism). Organized medicine had become less responsive to the needs and concerns of patients.

A FUNDAMENTAL TENSION BETWEEN PROFESSIONALISM AND DISABILITY

The emergence of "disability" as a unique social form, distinct from that of "impairment," reflects the emergence of a "social" versus a "medical model" of disability. This growing recognition of the barriers faced by people with physical and/or cognitive conditions was not defined solely by pathophysiology or rooted within the individual but could (and did) involve elements of social organization. This recognition, however, with its underlying recognition of a form of expertise rooted within the lived experience of disability, stands in conflict with professionalism—and not just "medicine's version" (grounded in scientific expertise) but sociology's as well (with its focus on "expert work"). Of the two, the conflict between the disability and medical professionalism is more stark. Sociological professionalism, on the other hand, is not so much "antidisability" as it is likely to view disability as part of a broader consumer rights movement than as a countervailing example of expertise grounded in knowledge.

Recent calls for a "patient-centered" medicine rooted in egalitarian notions of a "partnership among equals" have served to heighten this tension between traditional medical authority (e.g., the physician as expert—the patient as the object of that expertise) and the physician-patient relationship as a partnership of authoritative equals. The rise of genomics and the search for the "root causes" of disease also stand to re-excite tensions between the individual-medical and the social-discriminatory models of disability. While individual physicians may profess or "play at" partnering, the prevailing belief system within medicine is that medicine believes itself to be a "culture of no culture" (Taylor 2003) and therefore a domain where knowledge is neither relative nor culturally determined but rather exists as "fact" and therefore outside the relativizing presence of time, place, or social arrangement/forms. This cult of science, with its ideology of "objectivity," is not so much disdainful of the lived experience of patients with disabilities as it is truly uncomprehending about how "subjective experience" can be anything more than a source of distortion and bias. All of this is taking place within an occupational arena (medicine) that itself is currently undergoing a fundamental value shift via the "evidence-based medicine" movement. In this latest iteration of scientific objectivity, "truth" is to be based on "evidence" *rather than* "experience," whether that experience is the clinical type of practitioners or the "lived" expertise of patients.

The identification of disability as residing in social arrangements and structures (as opposed to individuals) also allows medicine to disavow expertise and authority in this later arena and thereby delegate "those problems" to other health care or social service workers, all the while maintaining occupational control over what medicine considers to be the defining issue—physiologic or cognitive impairment. While any such unbundling may invite other types of "experts" into the fray, it does not, necessarily, acknowledge patients as an *alternative and legitimate source of expertise.* As noted above, the sociological definition of professionalism stresses "esoteric knowledge" and "considerable discretion" with respect to its work. This stands at odds with the notion of physician and patient as equal partners or, better still, "equal experts." Patients may constitute competing sources of authority—"the market" for individuals with disabilities (as consumers) and professionalism for physicians—but this does not elevate experience to expertise.

However, as Western industrialized nations face the tsunami of an aging population, so will medicine and sociology face the conjoint social fact that age is more than a biological marker and that lived experience may well come to represent a new type of social authority.

—Frederic W. Hafferty

See also Medicine; Models.

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PROGRESSIVE ERA WOMEN IN SPECIAL EDUCATION

While special education has taken significant advances in recent decades, throughout the world, its history did not begin in the 1960s. Generations earlier, reformers, often women, were beginning to establish the underpinnings of pedagogical and therapeutic approaches to children whose disabilities seemed to require alternative means of education, as well as the bureaucratic and professional cultures that have developed to provide those alternatives. These women worked in various national contexts, from a wide array of motives and backgrounds; they shared an era of innovation and unprecedented opportunity for women's participation in policy making and the development of theory.

The numbers of women activists who took a role in Progressive-era beginnings of special education are impressive and may be explained by several factors. Reformers in the Progressive era were often especially drawn to the problems of children in cities, immigrant children, and other young people in apparent crisis. Through the settlement movement and similar ventures, reform-minded women's groups sought reforms that some term "maternalist" because they imposed middle-class notions of femininity, hygiene, and domestic relations on the working-class objects of their charity. While many of these reforms seem uncontroversial today—child labor regulation, milk safety, kindergartens, urban playgrounds, and parks—others cast grave suspicions on families that could not easily conform to the domestic ideals proposed. And among the latter were measures to identify and segregate children with special educational needs, especially those associated with eugenic "defect."

Meanwhile, newly opened opportunities in medicine, education, government, and law gave some individual women professional credentials and expertise for establishing programs. Women working in the public schools as teachers and administrators saw the need for separate classes and methods for educating "misfit" students; women with medical training working in such positions as health inspectors, home visiting nurses, and clinic doctors saw the children unserved by public schools on account of their disabilities and the ways they might be otherwise educated. As the field of special education was new, it held great potential as a niche where professional women might gain positions of significant authority, without encountering resistant, entrenched networks. In addition, the specialties of pediatric medicine, public health nursing, and eugenics research were unusually accepting of women's expertise, with the added assumption that any endeavor that involved children or health appealed to a "natural" talent inherent in the female sex.

Among the many women whose names appear in the era's history of special education, only a few can be mentioned here. Italian doctor Maria Montessori (1870–1952) is best known today as a pioneer in early childhood education, but she derived many of her theories during her stint as director of the State Orthophrenic School in Rome, where she performed direct teaching with "feebleminded" children as well as developing a teacher training program. In London, Mary Ward (1851–1920) was a novelist from a literary family when she became involved in philanthropy, founding the Passmore Edwards Settlement (now the Mary Ward Centre); among its offerings, beginning in 1898, was an innovative model day school for children with disabilities. A year after the English school opened, Elizabeth Farrell began teaching an ungraded class of boys in the New York City public schools, using a self-developed curriculum that emphasized individualized, practical skill building. Farrell, who would eventually found the Council for Exceptional Children, was part of a cluster of socially active women centered around public health nurse Lillian Wald (1867–1940), who founded the Henry Street Settlement and mentored Lina Rogers (the first public school nurse in the United States) and Margaret Sanger (the birth control activist). Meanwhile in Providence, Rhode Island, two medical doctors, Mary S. Packard and Ellen Stone, conducted a summer camp in 1907 for children with tuberculosis, which would develop into school-year programming in specialized classrooms to serve students with special health needs. These stories must stand for those of many other women in the early twentieth-century history of special education.

—Penny L. Richards

See also Feminism; Maria Montessori; Margaret Sanger; Special Education.

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PROSTHESES

See Mobility Aids

PSYCHIATRIC DISORDERS

Psychiatric disorders are estimated to affect 20 percent of the adult population in America in any given year. Although less well developed for children, epidemiological studies estimate an annual prevalence rate of 20 percent for this population also. With more than 40 million persons affected annually by mental illness in the United States, it is likely that very few individuals have not had contact with a person with a psychiatric disorder. Psychiatric disorders exist along a spectrum from the very mild, with little or no evidence of disability, to the very severe, with profound disruptions in all areas of functioning, leading to severe, disabling consequences.

Based on functional impairment, it is estimated that 9 percent of the adult population has severe mental disorders. Prevalence rates in childhood are not predictive of adult prevalence rates. Many children with psychiatric disorders will recover from their disorders. Many adults with psychiatric disorders have their initial onset as young adults without a prior premorbid psychiatric disorder in childhood. Although prevalence rates in adult and child populations approximate each other, the numbers are not in and of themselves predictive of how psychiatric disorders impair or disable over the life course of an individual within a population as the correlation between symptoms and disability, while positive, remains weak. Some individuals can function well with severe symptoms, and others are genuinely disabled with few symptoms.

It is estimated that approximately 20 million adults in the United States have psychiatric impairment. Of this number, 4.5 million adults have persistent mental disorders that, by virtue of the severity of their symptoms, significantly disrupt or impair their ability to carry out activities of daily living (ADLs). ADLs include maintenance of personal care and hygiene, maintenance of school or job tasks, maintenance of household duties and responsibilities, and maintenance of interpersonal relationships. When these functions are disrupted by a psychiatric disorder, an individual is said to have a psychiatric disability. By understanding and measuring disruptions in ADLs, the extent of the disability can be measured quantitatively and qualitatively.

It is well documented that individuals with psychiatric disabilities manifest limitations in everyday functioning. In interpersonal situations, social cues are misinterpreted, yielding inappropriate responses to social situations. Minor stressors can lead to catastrophic emotional responses. Individuals can experience poor concentration, poor memory, lack of initiative, lack of affective expression, and indifference to socially appropriate expectations. These symptoms place the individual with a mental illness at a disadvantage in a society where cognitive and interpersonal skills are highly valued. In developing and agricultural societies, the World Health Organization (WHO) has shown that individuals can enjoy higher functioning in the presence of more severe psychiatric illness.

The World Health Organization's *International Classification of Impairments, Disabilities and Handicaps* has stated that psychiatric disability is a predictable consequence of having chronic severe mental illness. With disability, there are always quantifiable restrictions and lack or loss of the ability to perform specific roles and tasks.

PSYCHIATRIC DISORDERS

The fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) is the official diagnostic manual used in the United States for diagnosing psychiatric disorders. The content of the DSM-IV is exhaustive and far exceeds what can be covered in this review. It is an excellent reference text, comprehensive in its scope and readily available to anyone seeking a comprehensive text describing diagnostic criteria used to diagnose all psychiatric disorders.

Disorders that occur with the greatest prevalence and are likely to be associated with disability are the anxiety disorders, mood disorders, schizophrenias, and substance abuse disorders. The *DSM-IV* provides a comprehensive listing of diagnostic symptoms for each disorder listed.

As a group, anxiety disorders represent the most common psychiatric disorders. Symptoms include a subjective feeling of nervousness or fear in conjunction with specific physical symptoms. Physical symptoms include heart palpitations, shortness of breath, sweating, muscle tension, sleep disturbance, fatigue, urinary frequency, diarrhea, sensation of having a lump in the throat, and dilated pupils. These symptoms typically manifest themselves when an individual comes into contact with a specific object or situation. Persons with anxiety disorders frequently report avoidance as a means of symptom management. Although not fully understood, it is believed that this category of psychiatric disorders is caused by a dysregulation of the brain chemicals norepinephrine, serotonin, and gamma amino butyric acid (GABA).

Generalized Anxiety Disorder (GAD). Excessive worry and anxiety in addition to some of the physical symptoms listed previously characterize this disorder. The anxiety, worry, or physical symptoms are severe enough to cause impairment or distress in the individual's ability to carry out social or occupational functions.

Panic Disorder. Individuals with this disorder frequently report a sudden feeling of impending disaster or doom. Patients frequently report symptoms that resemble those reported by heart attack victims. These include but are not limited to palpitations, shortness of breath, dizziness, sweating, lump in throat, numbness or tingling in fingers or around the mouth, and chest tightness. Symptoms generally peak within 10 minutes. Chronic symptoms can lead to significant impairment in functioning as the individual attempts to avoid those situations psychologically linked to the panic attacks' occurrence.

Specific Phobias. This group of disorders is characterized by excessive fear of specific objects (simple phobia), situations that expose the person to the possibility of judgment or ridicule (social phobia), or situations where escape may be perceived as difficult by the patient (agoraphobia). This group of disorders constitutes the most common of all psychiatric disorders according to epidemiological catchment area (ECA) data. The avoidance or distress that occurs as a consequence of phobia can be debilitating.

Obsessive-Compulsive Disorder (OCD). This disorder is characterized by persistent and recurrent thoughts, impulses, or images that are experienced as unwanted or intrusive (obsessions). The person attempts to alleviate these thoughts and the associated anxiety by engaging in repetitive nonsensical behavioral rituals (compulsions) such as avoiding stepping on cracks in the sidewalk or excessive hand washing. Obsessions can impair concentration and thus lead to disability. Compulsions likewise can lead to incapacitating disability as the person's time is consumed by the performance of the ritualized behaviors.

Posttraumatic Stress Disorder (PTSD). This disorder typically follows exposure to a traumatic event that is life threatening, leading the person to experience intense fear, helplessness, or threat of losing one's physical integrity. The traumatic event is then reexperienced in a manner that is intrusive, occurring as flashbacks or recurrent dreams. Avoidance of events or places that may trigger memories, increased arousal (decreased need for sleep), or enhanced startle response are additional associated features. In its most severe forms, this disorder causes significant disability.

MOOD DISORDERS

This category of psychiatric disorders includes those disorders that have a disturbance of mood as the primary symptom. The mood may appear as excessively sad, as seen in depression, or as excessively happy, irritable, or grandiose, as seen in mania. When a patient experiences episodes of depression alternating with a single or multiple episodes of mania, the individual is said to have bipolar disorder. Prevalences for major depression and bipolar disorder in the general population are 4.4 percent and 1.2 percent, respectively.

The etiology of mood disorders is hypothesized to be related to a dysregulation of neurochemicals in the brain (norepinephrine and serotonin).

Major Depression. This condition refers to a mood disorder in which the patient experiences sadness, loss of interest, or loss of pleasure daily for a period of two weeks. During this period, the patient might experience crying spells, decreased or increased need for sleep, decreased or increased appetite, agitation, loss of energy, loss of sex drive, and thoughts of death. Untreated, this disorder can lead to significant time away from work and an inability to carry out ADLs, as well as result in suicidal behavior or completed suicides.

Manic Depression or Bipolar Illness. This disorder is characterized by recurrent episodes of depression alternating with mania. The depressive episodes are synonymous with the major depressive episodes described previously. Mania is characterized by persistent elevated expansive or irritable mood lasting at least one week or shorter if hospitalization is required. Other accompanying symptoms include inflated self-esteem, decreased sleep, engagement in high-risk behaviors, increased speech production, and goal-directed behavior. A variant of this disorder (Bipolar I), in which symptoms of mania are decreased in their intensity, is known as Bipolar II mood disorder. Both disorders can lead to significant disability if treatment is not accessed.

Dysthymia. This is a disorder that is experienced by the affected person as a subjective experience of a continuous low-grade form of sad mood lasting a minimum of two years but not meeting threshold criteria for the diagnosis of major depression.

Cyclothymia. This disorder is an attenuated form of bipolar illness. In this disorder, episodes of mania alternate with episodes of subsyndromal depression. Although less severe than Bipolar I, it is associated with significant disruption of social functioning and can lead to disability if undiagnosed and untreated.

SCHIZOPHRENIAS

This group of disorders includes a spectrum of disorders characterized by the presence of “psychotic” symptoms. The term *psychosis* is generally used to indicate a state of impaired reality testing, leading to severe impairment of social, personal, and occupational functioning. Whether schizophrenia is a single disorder or a series of disorders occurring along a continuum is unresolved. This disorder has a prevalence of 1 to 2 percent in the general population. It is characterized by symptoms that are referred to as “positive” and “negative.” Positive symptoms include hallucinations, delusions, and bizarre associations. Negative symptoms include decreased motivation, decreased attention, and social isolation.

Although the cause of the disorder is unclear, it is believed to be due to a disruption of function of a main neurochemical known as dopamine. Dopamine interacting with serotonin, GABA, glutamate, and acetylcholine in such ways as to enhance the effects of dopamine on neuroreceptors appears to play prominent role in the etiology of this group of disorders. Environmental and genetic cofactors appear to play a significant role in determining who gets these disorders. Of all psychiatric disorders, the schizophrenias carry the highest level of morbidity and psychiatric disability as a group.

SUBSTANCE ABUSE DISORDERS

These disorders represent some of the most prevalent and psychiatrically disabling disorders known. Alcohol abuse and dependency affect 15 to 17 percent of the general adult population. Alcohol or another drug of abuse is involved in 50 percent of homicides and 33 percent of suicides recorded in the United States.

Substance abuse or dependency is typically seen as a comorbid condition in all of the major psychiatric diagnostic groups. Schizophrenia, bipolar disorder, and anxiety disorders are all associated with significant levels of comorbid substance abuse or dependency. Substance abuse contributes to the morbidity of psychiatric disorders by precipitating psychiatric disorders directly (e.g., substance-induced mood or anxiety disorders) or by exacerbating a pre-existing disorder in an individual. Failure to diagnose and treat substance abuse in patients results in treatment noncompliance, treatment failure, overutilization of mental health resources due to recidivism, and increased rates of suicide.

Typical substances abused by today's adolescent and adult populations include alcohol, cocaine, marijuana, ecstasy, heroin, and PCP. All have addictive potential, but addiction is not a prerequisite to these substances having a profound impact on the course and outcome of psychiatric disorders.

SUMMARY

When thinking about psychiatric disorders associated with disability, one should keep in mind specific characteristics held in common by all that can lead to functional impairment.

Many psychiatric disorders, when severe (as defined by the presence of psychotic symptoms), have symptoms such as hallucinations, delusions, disordered thoughts, poor concentration, and loss of reality testing. These symptoms can interfere with the patient's ability to make decisions, process information, problem solve, or follow instructions. Occurring singularly or in combination, it is not a stretch to ascertain that impaired functioning can be a consequence.

The life course of a psychiatric disorder may reveal the presence of intermittent or constant symptoms. Psychiatric symptoms can result in a person experiencing low self-esteem, loss of confidence, emotional fragility, and feelings of helplessness and hopelessness. The consequence of these symptoms can be a lack of initiative, lack of motivation, loss of confidence, and lack of pleasure, which can impair one's ability to perform tasks, function in required roles, or carry out the daily activities of living.

Because psychiatric disorders typically have their onset for many in the most productive years of life, many individuals experience interruptions in social and interpersonal development that lead to impaired social functioning, interpersonal dependency, and arrested achievement.

Many individuals with psychiatric disorders are in a double bind. On one hand, they have an illness that can profoundly impair them emotionally, interpersonally, and professionally. On the other hand, the stigma attached to mental illness prevents some individuals from accessing mental health systems where help is available that could reduce the disabling consequences of living with a psychiatric disorder.

It is not unusual for individuals with psychiatric disorders to have lower socioeconomic status, to experience social isolation and rejection, to have lowered expectations from family and friends, to have increased rates of substance abuse, or to have increased levels of homelessness and crime victimization. Clearly, morbidity associated with mental illness is significant and requires the collective efforts of our nation's health care system to find treatment strategies that are accessible, affordable, and tolerable, whether pharmacologically, psychotherapeutically, or psychosocially based.

Psychiatric disorders are treatable, and the cost in both financial and personal terms of not treating them can be monumental. It is estimated that more than $100 billion in direct (associated with treating psychiatric disorder) and indirect costs (associated with loss of productivity and other sequelae of being mentally ill) is spent yearly. Not treating these disorders can lead to major disruptions in interpersonal relationships, diminished socialization, loss of educational opportunity, and failure to maximally participate in society and make significant contributions.

Activities and interventions directed at reducing the potential for disability in at-risk individuals need to focus on those factors that can reduce the effects of psychiatric disorders as they are diagnosed or reduce the long-term effects of the disorders once an illness manifests itself. Thus, activities that focus on prevention by educating at-risk populations to seek mental health services can be effective. Education of the public at large that reduces stereotyping and stigmatization of those with psychiatric disorders can further enhance reduction of potentially disabling symptoms of mental illness by encouraging and promoting early diagnosis and treatment. It is not enough for those with mental illnesses to simply avail themselves to treatment; they must also comply with recommendations made by physicians and other mental health care workers if treatment is to be successful. Reduced morbidity or disability defines success in this case.

Many communities have underdeveloped mental health networks that can lead to reduced availability of mental health services. Inadequate funding, lack of qualified mental health professionals, and absent rehabilitation services can contribute to the disabling effects of mental disorders over time. Improved awareness by citizenry may lead to improved availability as citizens lobby their government officials for increased expenditures for the creation of more mental health service networks.

Even when available, mental health services are often underused. Access issues related to affordability of mental services can create opportunities for disability. For the working poor and minority communities, lack of adequate insurance coverage can prevent individuals from gaining access to treatment, thus contributing to the potential for disability. Stigma associated with having a psychiatric illness may also negatively affect access to psychiatric services.

Providing improved ways of funding services and educating the public on the importance of accessing these services can reduce disability. Addressing mental health availability and access issues through increased funding and education in conjunction with efforts to make mental health services more sensitive to the specific cultural needs of those being serviced will likely improve utilization. Improved utilization of mental health services offers the best possibility for preventing and controlling the disabling effects of psychiatric disorders, thereby improving outcomes for many with these disorders.

—Henry Dove

See also Bipolar Disorder; Depression; Mental Illness; Normality; Schizophrenia; Substance Abuse.

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PSYCHIATRIC SURVIVORS MOVEMENT

The psychiatric survivor movement consists of a loosely affiliated coalition of individuals who have used the psychiatric system and found it extremely lacking. Most members portray their experiences as harmful and disempowering and therefore have adopted the term *survivor* to indicate that fact. Reflecting a diversity that is characteristic of the nature of the movement, various factions may use different terminologies to describe themselves such as “ex-patients,” “ex-psychiatric inmates,” “consumers,” “service users,” and “psychiatrically labeled.”

Because self-definition is a central theme within the survivor/user movement, it is accepted that participants will define themselves as appropriate, as opposed to having a medical authority “diagnose” their condition. Those who use terms such as *survivor* and *inmate* emphasize their militancy by taking up a decidedly antipsychiatric orientation, while those who prefer the term *consumer* may be less critical of psychiatry and more attentive to improving the quality of services. Even given these differences, a sense of the mental health system as broken and in need of repair infuses the whole movement. While the method and degree of repair may be somewhat controversial, the innate value of user input and control is an integral foundational belief for all factions.

A largely North American development of the late 1960s, the psychiatric survivors movement was heavily influenced by this era's emphasis on individual choice and civil rights. Its membership was collectively energized by negative experiences at the hands of the psychiatric system while incarcerated as patients; the survivor movement is rooted in self-advocacy. It is an important principle of the movement that practices that induce discrimination toward those labeled with a mental illness diagnosis must be changed so that a psychiatric diagnosis has no more impact on a patient's choices and rights than a diagnosis of arthritis or heart disease. Challenging their stigmatized status in society, the movement promotes the values of self-help and collective action while rejecting forced treatment of any kind. While it would be incorrect to characterize the survivor/user movement as antipsychiatric, it does negatively critique the dominant medical description of mental illness and demands a more holistic view of mental health disability or, as some survivors might say, "extra-ordinary mental experiences." As one pioneering survivor put it, "Because psychiatric ideology mystifies people's difficulties into 'illness' that only experts are thought capable of treating, we are all rendered a little less human" (Chamberlin 1990).

While there are overlaps in social and developmental histories, the relationship between the psychiatric survivors movement and the disability rights movement is a complex one. Kept separate by a theoretical and medical taxonomy applied to physical and mental impairments as if people were either "apples" or "oranges," interpretations of disability as different types of personal tragedies worked to draw attention away from shared situations and shared needs. In addition, some disabled people may have difficulty viewing psychiatric survivors as disabled because their impairment is not evident and may fluctuate. Alternatively, survivors may not consider themselves disabled because they reject the medicalization of their experiences.

STAGES OF DEVELOPMENT

Driven by their perception that the psychiatric system damaged its users, the psychiatric survivors movement began when clusters of ex-patients spontaneously gathered in small local venues. These early years were exciting but tiring times. Like other disabled people, psychiatric survivors were geographically and socially dispersed, suffering from economic hardships, accessibility issues, and stigmatizing social forces. Many people with psychiatric labels were still in state hospitals or on strong psychiatric medication. Promoting healing through consciousness raising, survivor groups worked to move themselves from the static position of victim/survivor to the active role of providing mutual support and advocacy. Common goals included fighting for patients' rights, eradicating stigma, ending economic and social discrimination, and creating peer-run support services. Out of these seemingly disconnected efforts, coalitions began to form, leading to regional associations in Oregon (Insane Liberation Front, 1970), Northern California (Network Against Psychiatric Assault, 1972), New York (Mental Patients' Liberation Project, 1971), and Massachusetts (Mental Patients Liberation Front, 1971). Early advocates such as Judi Chamberlin, Howie the Harp, Sally Zinman, Leonard Roy Frank, and Su and Dennis Budd staged civil disobedience actions, chaining themselves to the gates of psychiatric facilities and picketing American Psychiatric Association meetings.

Sponsored by a nonpatient professor and the New York City–based Mental Patients' Liberation Project, the first Conference on Human Rights and Psychiatric Oppression was held in 1973 at the University of Detroit. Fifty people from the United States and Canada, many working together for the first time, met to develop philosophical guidelines. True to the movement's core belief in self-advocacy and leadership, by 1976, the conference was limited to only patients and ex-patients.

The Madness Network News first went to press in 1972. Begun in San Francisco as a simple newsletter, it evolved into a newspaper that perpetuated and connected the growing survivor efforts in North America and throughout the world. *The Madness Network*

News existed solely on subscriptions and volunteer efforts yet became the voice of the ex-patients' movement, publishing a wide range of material that included personal experiences, art, and factual reporting. It ceased publication in 1986.

In the late 1970s, the federal government began to support the movement's efforts with small grants. The Community Support Program was developed within the National Institute of Mental Health to increase the involvement of users in the development of psychiatric services. Projects such as the "Alternatives" conference were begun with its assistance. The first national Alternatives conference was held in 1984 and has been held annually ever since. Offering workshops related to self-help and self-determination, the Alternatives conference is a great success, bringing together national and international leaders in the survivor/user movement with an annual attendance often exceeding 1,500.

Many of the early pioneers in the survivor/user movement were angry, promoting the complete abolishment of the psychiatric system. By 1980, some individuals were identifying themselves as "consumers" and had begun organizing self-help advocacy groups and promoting peer-run services. While still sharing many fundamental beliefs, consumer groups differed from earlier militant groups in that they preferred reform over abolishment, believing certain traditional services were necessary. Increasingly, these consumer groups have gained access to mental health policy-making and advisory committees. Many such groups have incorporated and now receive direct funding to provide peer-run services. These have proven to be effective, and the "consumer-driven" model is now generally accepted as key to the provision of mental health community services.

The California Network of Mental Health Clients (CNMHC) is an example of a mental health consumer organization. In 1987, it received funding from California's Protection & Advocacy agency. In 1989, CNMHC produced *The Well-Being Project: Mental Health Clients Speak for Themselves* (Campbell and Schraiber 1989), which included groundbreaking research on mental health services developed and implemented by mental health clients themselves. They went on to produce what some consider the movement's self-help bible, *Reaching Across: Mental Health Clients Helping Each Other* (Zinman, Harp, and Budd 1987). Today, user/survivor groups in California have a strong public position, and members sit on mental health–related planning boards and advisory councils throughout the state.

In more recent times, consumer/survivors have moved into paid jobs as "peer specialists" in their state-funded consumer organizations or as case managers in the mental health system itself. (*Prosumer* is a new term that attempts to capture the liminal position of those providing a service within the mental health system while receiving or having received services.) States may require boards that receive federal or state mental health funds to include consumer/survivors. Many states now have an Office of Consumer Affairs, which is headed by a psychiatrically labeled person. This infusion of survivor/user perspective can be attributed to the pioneering efforts of the psychiatric survivors movement, with its core belief in the importance of self-determination and the essential humanity of psychiatric system users.

The Bazelon Center for Mental Health Law was founded in 1972 by a group of committed lawyers and professionals in mental health and mental retardation who attempted to affect mental health service provision through individual and class action suits. In 1980, a group of these lawyers formed the National Association of Rights Protection and Advocacy (NARPA). One-third of NARPA's board of directors must identify themselves as current or former recipients of mental health care. Dedicated to promoting the preferred options of people who have been labeled mentally disabled, NARPA is committed to the abolishment of all forced treatment.

There are some disadvantages to this infusion of federal funds and the growing coalition with community mental health agencies. Many "consumer" groups have become dependent on state or federal money, while independent organizations have faded as volunteers are drawn to paid positions in publicly funded projects. A split has formed between "consumers" and "survivors," with the more radical groups, which relish their independence, warning against "sleeping with the enemy." While some say the independent psychiatric survivors movement is over, a few radical groups continue to directly challenge the fundamental principles of the psychiatric medical model. In 1988, leaders from several grassroots psychiatric survivor groups formed the Support Coalition International. Now an alliance of nearly 100 groups in 14 countries and known as the MindFreedom Support Coalition, it works to defend the rights of psychiatric survivors and to promote empowering treatment alternatives. The coalition has produced a journal since 1987. Originally known as the *Dendron News,* it advocates the global networking of "free minds."

HISTORICAL AND PHILOSOPHICAL ROOTS

Although the psychiatric survivors movement began in 1970, the earlier efforts and writings of former patients in the late nineteenth and early twentieth centuries challenged society's views on insanity and the use of asylums. A good example is the Alleged Lunatic's Friend Society, formed in England by ex-patients in 1847. Another example would be Mrs. Elizabeth Packard, who began publishing books and pamphlets that detailed her forced commitment in the Jacksonville (Illinois) Insane Asylum in 1868. Though she later founded the Anti-Insane Asylum Society, it never gathered significant public attention or support. At the same time, Elizabeth Stone worked in Massachusetts to change public opinion about mental states and to stop the incarceration of those unjustly labeled as insane.

With rapid and expansive industrialization, and as medical science became more elaborate and readily available, more people were given mental illness diagnoses while asylum populations mushroomed. At the dawn of the twentieth century, there were approximately 126,000 patients in 131 state hospitals, yet by 1940, there were 419,000 patients in 181 state hospitals. By the mid-1950s, New York state alone had 93,000 inpatients (Grob 1994). By 1943, with a U.S. patient-doctor ratio as strained as 277:1, a hospital could become more holding tank than medical treatment center. In 1908, Clifford Beers wrote *A Mind That Found Itself,* chronicling his own incarcerations in public asylums. Speaking out against mistreatment and neglect within the system, Beers founded the National Committee of Mental Hygiene, an organization that persists in its current incarnation as the National Mental Health Association.

Another landmark moment in the history of mental health advocacy occurred in 1961 with Erving Goffman's (1961) publication of *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates.* Goffman emphasized that institutionalization created the role of "mental patient" and challenged the central importance of diagnosis in predicting outcome. Many psychiatric survivor leaders continue to credit Goffman's work as significant in expanding the understanding of how a dependency on long-term institutionalization creates an inherently disempowering system of psychiatric care.

By the 1940s, invasive procedures such as insulin coma therapy, Metrazol convulsive therapy, electroconvulsive therapy (ECT), and prefrontal lobotomy had become popular treatments in psychiatric hospitals. These often damaging treatments created a tide of criticism among users and some professionals. Ken Kesey depicted these modes of treatment in a decidedly negative fashion in his 1962 novel *One Flew Over the Cuckoo's Nest*—a book he claimed to have modeled on his actual experiences as an orderly at the San Mateo Mental Facility. The 1970s movie rendition won five Academy Awards and strongly influenced the general public's view of the psychiatric system while fueling the antipsychiatry and psychiatric survivors movements.

In the 1950s, in response to the excessive and violent intervention plans developed in the field of psychiatric care, a critical analysis of psychiatry also began from within, among a small number of practitioners. This insider critique, most literally, authorized the knowledge base for what is recognized today as "antipsychiatry." Charging that the medical model attended almost exclusively to pathology, antipsychiatry accused the field of leaving its patients powerless and isolated. Antipsychiatry practitioners stressed the value of difference, attempting to reconfigure normalcy and deviance.

In 1965, R. D. Laing, Aaron Esterson, David Cooper, and supporters founded the Philadelphia Association, devoted to the creation of therapeutic communities that valued agency and experience as integral components of psychosis. In his influential

The Politics of Experience (1961), Laing declared that normality entailed intrinsic hidden losses, while madness, if we allowed it to unfold instead of subordinating its power beneath an array of medication and psychiatric technology, harbored potential benefits. As an alternative to medical intervention, he recommended initiation and guidance.

Current participants in the antipsychiatry movement also often reference *The Myth of Mental Illness* by Thomas Szasz. Szasz's popular work, although originally published in 1961, is still controversial and continues to be used as a focal point for the antipsychiatry movement. Remaining active, Szasz consistently proposes that psychiatric patients are not ill but are instead social misfits who receive poor treatment and eventually find themselves placed improperly in asylums.

In sum, a more radical faction of the psychiatric survivors movement eventually affiliated with antipsychiatry—both share critiques of a profession and systematically expose historical violence that occurred under its purview. The more moderate consumer groups reject the complete denouncement of the medical model, feeling some portion of traditional treatment to be helpful. They would emphasize the fact that many who have been diagnosed with mental illness relate experiences of real and terrible suffering that both psychiatry and community treatment ultimately helped to alleviate.

—Pam Wheelock

See also Antipsychiatry Movement; Psychiatric Disorders; Psychiatry.

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Zwang: Journal of International Association Against Psychiatric Assault, www.freedom-of-thought.de/zwang/

PSYCHIATRY

Psychiatry is the field of medicine that is devoted to the scientific study of mental illness and the evidence-based treatment of mental disorders. A physician must complete a four-year course of postgraduate training after college and medical school to qualify as a psychiatrist. Psychiatry is a board-certified medical specialty. The concept of mental disorder currently used in American psychiatry is defined in the fourth edition of the *Diagnostic and Statistical Manual of Mental*

Disorders (*DSM-IV*). It states that a mental disorder is a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress, such as a painful symptom, or a disability, such as an impairment in one or more important areas of functioning or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom. The *DSM-IV* recognizes approximately 386 distinct mental disorders, each of which can be characterized by a set of criteria. Many other conditions may be included in subsequent editions of the *DSM* as their criteria become empirically validated. This current classification of mental disorders can be divided into broad categories that include dementias, cognitive disorders, mood disorders, anxiety disorders, dissociative disorders, personality disorders, eating disorders, sexual disorders, sleep disorders, developmental disorders, attention deficit disorders, and substance use disorders. Physicians who graduate from four-year residency training programs in psychiatry develop a high interrater reliability in assigning a *DSM-IV* diagnosis to a given patient and also in assigning a similar score on the Global Assessment of Function Scale (GAF), which provides a standard measure of symptom severity and degree of functional impairment for a given patient. This scale score, in conjunction with the multiaxial diagnostic system, provides a criterion-based approach to the measurement of progress of any therapy chosen for the treatment of the patient.

Mental disorders can be severely disabling and can be measured in terms of missed employment, accommodated employment, and full disability; approximately 20 percent of the U.S. population will experience some form of psychiatric disorder with related disability. By far, the disorders that account for the greatest impact on employability and workplace accidents are alcohol abuse and dependence, with a lifetime prevalence of 13.8 percent. Phobia, with a lifetime prevalence of 14.3 percent, and generalized anxiety disorder, with a lifetime prevalence of 8.5 percent, are also major factors in the workplace. Major depressive disorder and substance abuse and dependence have a prevalence of about 6.2 percent each. Other mental disorders that significantly account for psychiatric disability are dysthymic disorder, with a lifetime prevalence at 3.3 percent; obsessive-compulsive disorder, at 2.6 percent; antisocial personality, at 2.6 percent; panic disorder, at 1.6 percent; schizophrenia, at 1.5 percent; and bipolar disorder, at about 0.8 percent. A major concern for school-age children is attention deficit hyperactivity disorder, which has a prevalence rate of between 3 and 5 percent. Absences and suspensions from school have been positively affected by the widespread use of psychostimulants such as methylphenidate, which are effective in 70 to 80 percent of children with this disorder.

Historically, modern psychiatry grew out of the need for those who superintended the large asylums and mental hospitals (alienists) to develop common principles of care at the beginning of the nineteenth century. First in Europe, then North America, then spreading throughout the world, associations of asylum directors began to meet on a regular basis to discuss management and treatment issues and gradually assumed the name of psychiatrists (from *psyche* [mind] and *iatros* [physician]). At the beginning of the nineteenth century, psychiatry focused primarily on the social and psychological factors that were thought to underlie mental disorder such as immoral behavior, unrestrained ambition, or political and religious enthusiasm. This trend led to the formulation of moral therapy as the fundamental mode of treatment. During the second half of the nineteenth century, the pendulum shifted toward biological and brain-related causes of mental disorder, with the disease of neurosyphilis serving as the paradigm mental disorder. The two Nobel prizes specifically given for the treatment of mental disorders were awarded for fever therapy for neurosyphilis, developed by Wagner von-Jauregg, and psychosurgery for intractable psychosis, developed by Egaz Moniz during this era.

By the early twentieth century, the pendulum had shifted back in the direction of psychological causes of mental disorders with the success of the Austrian psychiatrist Sigmund Freud's psychoanalytic theories. This trend, also attributable to French psychiatrist Pierre Janet, culminated in the latter half of the twentieth century with an appreciation of the role of psychologically traumatic experiences, stemming from child abuse, adult trauma, and wartime experiences, as causes of mental disorder and led eventually to the addition of the category of posttraumatic stress disorder to the psychiatric nomenclature. However, with the advent of the psychopharmacology era in the 1950s, as well as the development of chlorpromazine as the first specifically antipsychotic medication and imipramine as the first specifically antidepressant medication, the pendulum began to swing back in the direction of brain-related research for mental illness. The research field of neuropsychopharmacology, which studies the mechanisms of action and brain circuits that underlie the efficacy of psychopharmaceuticals, paralleled the growing field of biological psychiatry, which studies brain circuitry thought to underlie the major mental disorders of schizophrenia, anxiety disorders, and bipolar mood disorder. By the 1990s, brain circuit and neural network models of mental disorders were proposed and tested both in animal studies and in human brain neuroimaging.

The success of the psychopharmacological revolution in psychiatry fueled the trend toward deinstitutionalization, which was further accelerated with the advent of the community mental health movement in the 1960s. In 1955, when chlorpromazine was introduced into the United States (following its introduction in Europe), there were approximately half a million psychiatric inpatients in public and private facilities. By the mid-1990s, that number had dropped to approximately 20,000. The treatment of three major mental disorders—schizophrenia, mood disorders, and anxiety disorders—all received a specialized psychopharmacology based on drug receptor theories unique to each area. Thus, for example, in the treatment of schizophrenia, high-potency phenothiazines such as fluphenazine and haloperidol replaced the first generation of antipsychotics because they were more potent blockers of dopamine. Since antipsychotic potency appeared to correlate with the degree the pharmaceutical blocked certain dopamine receptors in the brain, it was proposed that an excess of dopamine stimulation caused schizophrenia. These receptor theories have proven to be oversimplifications of the etiology of psychiatric disorders.

Despite these advances in the psychopharmacological area, the drawbacks of side effects such as tardive dyskinesia (embarrassing involuntary movements of lips and tongue), the lack of compliance due to cognitive slowing and restriction of affective tone, and treatment resistance led to a new wave of pharmacological innovation. Attempts at molecular engineering, to produce a safer congener of the pharmaceutical clozapine, which had superior efficacy and tolerability in the treatment of schizophrenia, produced a new family of atypical antipsychotics. These newer antipsychotics were better tolerated and had less potential of producing tardive dyskinesia. The additional features of blocking the 5HT2 serotonin receptor and the histamine receptors also proved effective in the treatment of the negative symptoms of schizophrenia not satisfactorily addressed in earlier generations of antipsychotic medications. The negative symptoms of schizophrenia, such as decreased intensity of pleasure or anhedonia, social isolation, affective flattening, poverty of speech and thought, inattentiveness, apathy, and negative behavior, are very disabling. How positive and negative symptoms link up over the natural course of schizophrenia and which brain circuits are involved in their production are questions currently under intensive psychiatric investigation in the area of schizophrenia research.

Comparable progress has been made in the psychopharmacology of mood disorders. Efforts to target the serotonin transmitter system in the brain and to avoid potential overdose lethality from a toxicity point of view led to the development of a generation of serotonin reuptake inhibitors (SSRIs) as well as norepinephrine reuptake inhibitors (SNRIs), both classes of which showed greater specificity in the enhancement of the synaptic concentration of these vital neuromodulators. Despite showing no greater efficacy in treating the fundamental symptoms of major depressive disorder than that possessed by their predecessors, the tricyclic antidepressants, the removal of histamine, and acetylcholine blocking characteristics liberated these newer psychopharmaceuticals from the bothersome side effects of excessive sedation, weight gain, and dryness of the mouth.

Diminution of these side effects was especially important in considering the use of different combinations of these medications, which is often necessary in severe cases of mental disorder and was virtually impossible with the older medications because of cardiac and other toxicities. Where the dosage of the primary drug has been optimized without full remission, then the choice of the second or third medications must be based on the likelihood of enhancing therapeutic effects while, at the same time, diminishing possible side effects and harmful drug-drug interactions. This problem is especially acute in the treatment of bipolar mood disorder, where a refractory patient may require more than one mood stabilizer, one or more antidepressants, and one or more antipsychotics. Added to this problem is the issue of comorbidity, both medical and psychiatric. The psychiatrist needs specialized expertise to effectively treat a patient who has multiple medical conditions requiring medical and psychiatric drugs with overlapping side effect profiles, if a patient has multiple psychiatric diagnoses requiring medications with overlapping side effect profiles, or if the patient is abusing an illicit substance while requiring a complex medical and psychiatric pharmacological regime. Also, if the patient is a member of a vulnerable age group at either end of the spectrum or belongs to a class of imperiled medical patients—for example, those with cancer, AIDS, or other chronic illness—then the choice of psychopharmaceutical agents becomes highly constrained by many physiological considerations. These problems have further reinforced the need for several psychiatric subspecialties such as child and adolescent psychiatry, consultation-liaison psychiatry, addictions psychiatry, neuropsychiatry, and geriatric psychiatry.

Despite these advances in psychopharmacology, psychiatrists are trained in several forms of psychotherapy. Psychotherapy is essential to psychiatry because even those mental disorders that respond reasonably well to psychopharmacological interventions require supportive psychotherapy as well as medication management to sustain patient compliance. No psychopharmaceutical is curative in the most complete sense, and all mental disorders have a psychological as well as a social aspect. The psychotherapies most used by psychiatrists include psychoanalysis, psychodynamic psychotherapy, cognitive therapy, cognitive-behavioral therapy, interpersonal psychotherapy, integrative psychotherapy, dialectical behavior therapy, psychoeducational therapy, group therapy, and brief dynamic psychotherapy. Certain mental disorders require mainly psychological and psychosocial treatment such as addictive disorders, eating disorders, personality disorders, dissociative disorders, developmental disorders, and the group of sexual disorders termed the *paraphilias.*

In diagnosing and treating the whole range of mental disorders, psychiatry, more than any other medical specialty, incurs an obligation to the greater society to protect those who might be injured as a result of a person acting under the influence of a mental disorder. This duty takes many forms depending on the mental health laws of the country or state in which the psychiatrist practices. The basic principles include involuntary hospitalization for endangerment to self or others, duty to warn a potential victim of a patient's homicidal tendency toward him or her, and duty to inform child protective services of probable child abuse. On the other side of the issue, the psychiatrist has a duty to protect a person who has allegedly committed a crime but who was acting under the influence of a mental disorder. In most criminal codes, this is an important mitigating factor. Because persons with mental disorders can be found in all walks of life and in all institutional settings, psychiatrists can be found in most large institutional concerns. Some of these subfields of psychiatry include forensic psychiatry, or psychiatrists who work primarily with the court system; prison psychiatry, an area of growing importance; military psychiatry, psychiatrists who handle issues of fitness for service; Veterans Administration psychiatry, psychiatrists who treat not only military posttraumatic stress disorder but also the entire spectrum of mental disorder; academic psychiatry, those charged with training the next generations of psychiatrists; and research psychiatry, psychiatrists who are funded by government or pharmaceutical companies to perform research on mental disorders.

—Thomas Jobe

See also Mental Illness; Models; Psychiatric Disorders.

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PSYCHOLOGY

Although psychology did not emerge as a discipline centering on the study of disability, its development as a field dedicated to the understanding of the human mind and behavior has inevitably led to the involvement of psychology in work with individuals with disabilities. Initial psychological models of understanding disability borrowed from the medical paradigm, which emphasizes individual-level factors, pathology, and abnormality. Thus, persons with disability have traditionally been defined as those possessing deficient physical and mental characteristics. Definitions of disability have evolved as historical events such as the World Wars, the eugenics movement, and the disability rights movement both shaped and have been shaped by the involvement of psychology in disability issues. Contemporary models of working with disability are progressing toward a focus on the role of environment in disability issues and an understanding of disability in terms of "differently abled" rather than as deviant from "normal" human functioning. In addition, current psychological practice and research seek to apply an interdisciplinary approach in work with persons with disabilities as a means to address disability issues in their entirety. Overall, psychology's role in disability work continues to generate new roles and responsibilities for psychologists in the areas of research, practice, and training. Doubtlessly, psychology will continue to experience the mutual influence of the changing zeitgeist as it relates to disability issues.

EARLY CONTRIBUTIONS

Much of the work that established psychology as a valid science simultaneously produced both theory and research methods that have aided in psychology's study of disability. In the late 1800s, experimental psychologists Hermann Ebbinghaus, Wilhelm Wundt, and Gustav T. Fechner developed observational methods of measuring psychological processes, including rudimentary forms of learning and sensory experiences. Fechner's work directly contributed to modern sensory screening. In fact, Fechner's techniques of testing vision and hearing are the same that are used in contemporary screening tests. Also, the work of Ebbinghaus, Wundt, and Fechner provided a basis for developing measurement techniques that aid in identifying intellectual, emotional, and other forms of mental disability.

When psychology surfaced as a new field of study, evolutionary theory was guiding much of the intellectual thought of the late nineteenth and early twentieth centuries. Consequently, evolutionary theory had great implications for psychology, which led to a focus on heredity and genetic superiority. In 1865, Sir Francis Galton observed that children of geniuses were more likely to be geniuses themselves than were other children and asserted that through controlled breeding, the human race could develop into one with superior intelligence. In the early 1900s, the development of intelligence tests provided psychologists with an apparently valid method of assessing an individual's intellectual functioning, thereby creating a means of identifying those whose propagation was less desired. It was at this time in the United States that the use of intelligence tests and the eugenics movement in the United States were growing.

PSYCHOLOGICAL TESTING AND THE EUGENICS MOVEMENT

The work of Alfred Binet in France established a standardized measure of intelligence based on average mental levels for various age groups. With this measure, a person would receive a score and be placed in a category according to his or her intellectual functioning. Henry Goddard further developed these categorizations by labeling each group. He is responsible for the term *moron,* which referred to adults who had scored similarly to 8- to 12-year-old children. According to Goddard, this category of individuals, though not the most severely intellectually disabled, posed a threat to society as they were more likely to survive and procreate than were those of lower intellectual functioning. Goddard proposed control of these individuals through strict monitoring and institutionalization.

Goddard continued his assistance of the eugenics movement by developing group testing procedures for the army during World War I. Through such testing, men were identified as having high or low intellectual functioning and accordingly assigned to "appropriate" positions. Men with lower intellectual functioning were systematically assigned to the front lines, as their likely deaths were not considered as great a loss as the death of an individual with higher intellectual functioning.

Henry Goddard's interest in eugenics coincided with the increased institutionalization of people with a number of physical and mental disabilities. In addition, in 1907, sterilization laws, requiring the sterilization of people with disabilities, were put into effect. Beginning in 1910, these laws were challenged by discoveries in genetics. Yet the momentum of the eugenics movement was not immediately slowed, and people with disabilities continued to encounter the effects of the movement for years.

POSITIVE CONTRIBUTIONS OF PSYCHOLOGY

The early 1900s was not merely a time in which psychology provided a scientific basis for discrimination against people with disabilities. Psychological testing did produce a standardized method with which disability could be assessed accurately, one that has remained useful in contemporary psychological research and practice. Moreover, the physician Edouard Séguin, produced work with individuals with developmental disabilities and demonstrated the learning capacity of these individuals. Thus, he directly contributed to the development of special education programs and influenced developmental psychologists' work with persons with disabilities.

VOCATIONAL REHABILITATION

In 1912, neuropsychologist Shepard Ivory Franz developed a training program for persons with brain damage, conducting some of the first disability work that provided evidence of reversing the psychological effects of brain damage. Franz's work marked an important shift toward applied psychological work with people with disabilities. However, the major impetus for psychology's involvement in applied work came at the end of World War I, when veterans with disabilities acquired during the war returned to the United States. Increased need for rehabilitative services for veterans prompted the 1920 passage of the Vocational Rehabilitation Act to "provide for vocational rehabilitation of persons disabled in industry or otherwise and their return to civil employment." This legislation marked the formal beginning of federal support for vocational rehabilitation in the United States.

The early to mid-1900s continued to be an era in which psychologists' primary role in disability was rehabilitative, and with World War II, the need for vocational rehabilitation increased. In 1943, the

Vocational Rehabilitation Act was passed and expanded services to include persons with intellectual and psychiatric disabilities as well as those with physical and sensory disabilities. This act helped to establish additional rehabilitation settings, such as schools and mental institutions, in which psychologists provided services to people with disabilities. Over time, many psychologists became involved in the National Society for Crippled Children and Adults. Founded in 1919, this broad-based organization, now Easter Seals, provided psychologists an arena in which they could discuss disability issues with people with disabilities, family members, and other professionals. Psychology's role in disability grew and led to the formation of a special interest group during annual conferences held by the American Psychological Association (APA) in the 1950s. By 1956, a new division of APA was originated, which focused on rehabilitative work with persons with disabilities. Division 22 was originally named the National Council on the Psychological Aspects of Physical Disability and exists today as Rehabilitation Psychology.

THEORETICAL DEVELOPMENT

While rehabilitation work was at the center of psychologists' involvement with disability during the first half of the twentieth century, concurrent developments in psychological theory provided a framework to guide psychologists' understandings of individuals with disability. These theories are based in the medical model, are individually oriented, and often focus on the individual's emotional and/or behavioral characteristics. Clinical and counseling psychologists have used them extensively in their work with people with disabilities, and their influence continues today.

Among the most influential of these theories is Freud's psychoanalytic theory, which originated in 1910 and was widely known and accepted by the 1920s. The theory was developed to explain and aid in the treatment of neurosis and thus emphasized abnormality. Psychoanalytic theory has undergone much criticism and reform since its origination. Psychologists whose practice is guided by this framework have maintained a focus on treatment of abnormalities, which has influenced clinical and counseling services provided to people with disability. Specifically, persons with psychiatric and emotional disabilities are considered to possess a deficiency that must be treated, much as a physical illness is treated by a medical doctor. Currently, individual adjustment to a disability is largely understood as the stages of coming to terms with an object loss. Because of its focus on individual limitations, critics of the psychoanalytic framework claim that this approach overlooks other important aspects of the person and his or her disability, including both abilities and environmental issues. Conversely, psychoanalysis provides helpful insight into a person's needs and motives, which enables a greater understanding of the individual experience of the psychiatric and emotional disability.

Other theories that arose at this time have a similar focus on individual characteristics and seek to influence the behavioral and mental processes associated with disability. Edward Thorndike's law of effect and B. F. Skinner's operant learning theory provided a theoretical basis for applied behavioral analysis. Applied behavioral analysis focuses on the careful use of rewards to develop specific desirable behaviors. It has been used to help develop many behavioral abilities of people with a variety of disabilities, especially including autism and other intellectual and emotional disabilities. These abilities include speaking, relating to others, and reducing self-injurious acts such as head banging. Applied behavioral analysis has been criticized for its narrow focus on a limited number of behaviors, its occasional use of punishment as well as rewards, and its inability to develop skills that can be used across many situations. More recently, applied behavioral analysis has been used as part of larger interventions to help youth and adults with physical, learning, and other disabilities accomplish educational, employment, and independent living goals.

In mid-century, Albert Ellis's rational emotive therapy and Aaron Beck's cognitive therapy emerged and have been widely used in clinical and counseling practice. These methods aim to challenge unhealthy thoughts and beliefs that are thought to cause emotional or psychiatric disability. These approaches have also been used in work with individuals with other forms of disability, particularly when the individual's stance toward his or her disability is a primary issue. In this case, the psychologist understands that the person's difficulty with disability stems from an unhealthy manner of thinking about his or her disability. According to these approaches, when these beliefs are challenged and replaced with healthy beliefs, individuals with disabilities are more able to think constructively about their impairments. Similar to criticisms faced by psychoanalytic theory, these approaches have been criticized for failing to address possible environmental issues that may contribute to a person's disability.

By the end of the 1950s, psychology's role in service to individuals with disabilities was established as one that incorporated testing, counseling and psychotherapy, and rehabilitative work. As these services were established, the political context within the United States was marked by an increasing awareness of and struggle against discrimination and the injustices that it produced.

PSYCHOLOGY AND THE DISABILITY RIGHTS MOVEMENT

With the *Brown v. Board of Education* ruling of the U.S. Supreme Court in 1954, separate schools for African Americans were declared unconstitutional, and the modern civil rights movement began. By 1964, the Civil Rights Act was passed, outlawing discrimination on the basis of race and consequently providing a model for disability rights legislation. Four years later, the Architectural Barriers Act, requiring access to federally funded facilities, became the first disability rights legislation in the United States.

Meanwhile, psychology was evolving with the changing political climate. Psychologists from various areas of specialization were becoming involved in advocacy efforts for minority groups, which evidenced a shift from a focus on solely individual characteristics to greater attention to environmental factors in the understanding of individual experience. In addition, there was more interaction between psychologists and individuals from other disciplines, further influencing psychological methods of service. Specifically, psychologists began seeing a need to merge traditional research and practice with newly emerging advocacy roles. A number of psychologists organized such efforts by developing the Division of Community Psychology, Division 27 of the American Psychological Association. This division (now the Society for Community Research and Action), among others, helped legitimize the role of psychologists as advocates by establishing a mission that emphasized psychologists' responsibility for promoting social justice.

During the 1970s, the disability rights movement gained momentum and continued seeking legislative protection for the rights of people with disabilities. The movement centered on concepts of the inclusion and autonomy of people with disabilities. In 1972, the Center for Independent Living originated in Berkeley, California, launching a widespread independent living movement. Legislation, such as the Rehabilitation Act of 1973 and the Education for All Handicapped Children Act in 1975, promoted antidiscrimination efforts by explicitly specifying the rights of people and students with disabilities, which aided in developing future legislation.

Psychologists were able to support the disability rights movement during the 1970s and 1980s by supplying empirical evidence for the necessity of inclusion and autonomy as well as develop techniques that would facilitate such inclusion. For example, psychologists produced methods of skill instruction to people with disabilities to aid in community living. They also created assessment tools to measure individual skill levels for people with disabilities. They conducted research that provided evidence of the benefits to both individuals and society when persons with disabilities lived in the community versus in institutions. Furthermore, the 1970s saw some of the first conferences on the psychological aspects of disability, which aided psychologists in working together to develop and implement beneficial services to people with disabilities.

The work of psychologists and other disability right activists in the 1970s laid a foundation for work in the 1980s. Much of the legislation that was passed during this time built on prior legislation. While psychologists continued to be involved in disability rights, other changes that society experienced in the 1980s further influenced how psychologists were involved in disability work.

CONTEMPORARY PSYCHOLOGICAL PRACTICE AND THEORY

A primary influence on psychology's role in disability in the 1980s was the progress in medical technology. Such progress led to a greater number of individuals surviving serious head injuries and other medical conditions and thus a higher need for psychological services. Neuropsychologists who had been trained in the new medical technology became involved in rehabilitation services with these individuals. Today, neuropsychologists continue to contribute to services for people with disabilities by studying the connections between the brain and behavior for those with disabling conditions. Knowledge acquired through these studies enables other psychologists and individuals from other disciplines to provide more appropriate services to these individuals.

In addition to the contributions of neuropsychologists, other clinical and counseling psychologists sought to enhance their methods of serving individuals with disabilities. Specifically, psychologists, such as Beatrice Wright and Hanoch Livneh, developed theory and practice that would address specific disability issues. They drew first on existing individually focused theories of personality and counseling and applied them to their psychological rehabilitation approach to help persons with disabilities. Building on the ecological tradition of Roger Barker and the socially relevant social psychology of Kurt Lewin and Tamara Dembo, Wright later called attention to the importance of improving societal attitudes toward and acknowledging the strengths of people with disabilities. She encouraged rehabilitation professionals to recognize that people with disabilities are not passive and should be actively engaged as "comanagers" of their own rehabilitation and affirmed as in charge of their lives more generally. These approaches incorporated both psychological and social aspects of disability. They explained how the interaction of these components could either promote or inhibit a healthy adaptation to disability. Carol Gill has advanced a positive view of the development of disability identity that describes how individuals with disabilities constructively come to terms with their limitations and engage society based on their own strengths. These developments in practice and theory have guided contemporary methods of counseling and psychotherapy services with people with disabilities.

Psychological views of family members of individuals with disabilities have also evolved. The blaming models of mid-century, such as Bettelheim's "refrigerator mothers" who purportedly caused autism, have been replaced by the more positive views underlying the work of Tamar Heller, Marty Krauss, and others. They recognize the substantial care and support provided by mothers and other family members to children and adults with intellectual disabilities. They are documenting the stress, coping, satisfaction, and fulfillment that can be part of living with and supporting family members with disabilities.

From the area of social cognition, Ronnie Janoff-Bulman, Shelly Taylor, and others have examined the important role that assumptions may play in how individuals respond to major life changes such as becoming disabled. "Positive illusions" can be a coping resource, for example. They also show that major traumatic events can affect views of the world by challenging long-held assumptions such as "The world is a benevolent place" and "I am a worthy person." They suggest that highly emotional events are of great importance in shaping the thoughts persons have about the world.

In their now-classic article on the social model of disability, Michelle Fine and Adrienne Asch recommended questioning the social attitudes and arrangements that limit the opportunities of people with disabilities. They suggest viewing people with disabilities as a minority group whose disabilities are not a matter of shame but a reality to address and who can contribute meaningfully and valuably when given equal access to education and employment and independent living. In that spirit, psychologists have also continued to work as researchers and advocates. In 1990, the U.S. Congress passed the Americans with Disabilities Act (ADA), which provides greater legal protection for the civil rights of individuals with disabilities. Psychologists were active in providing testimony in support of ADA and were influenced by its passage. Currently, psychologists have a responsibility to understand legislation protecting the rights of people with disabilities so that psychological services, research, and advocacy respect, examine, and build on this important legal foundation.

FUTURE DIRECTIONS IN PSYCHOLOGY AND DISABILITY

While psychology has progressed for more than a century and thereby has become a field more knowledgeable about and responsive to disability issues, criticisms of current psychological practice have pressed the field to further develop its involvement with individuals with disabilities. Specifically, some psychologists are challenging traditional definitions of disability, which have significant implications for current psychological practice.

Newer ideas of disability have stemmed from the social model of disability, which conceptualizes disability on a dynamic continuum. That is, the degree to which a person is considered disabled may fluctuate from day to day or from situation to situation depending on the interaction of environmental and/or individual factors. For instance, an individual who uses a wheelchair experiences the disability differently depending on whether he or she is attempting to enter a building that is wheelchair accessible or inaccessible with a wheelchair that can or cannot climb stairs. In essence, the lack of fit between the individual's abilities and the environmental characteristics creates an inaccessibility that becomes a part of the disability. The new social paradigm of disability has begun to influence psychology in the areas of training, assessment, research, and practice. For example, the nature, extent, and role of social support in the lives of persons with disabilities are emerging as areas of research interest with implications for community-based interventions.

Furthermore, although there has been an increase in studying individuals with disabilities, reform efforts suggest that there is also a need for an inclusion of persons with disabilities in areas of psychological study that are not particularly directed toward understanding disability issues. Similarly, psychological training programs are being challenged to address disability issues across the curriculum to enhance disability competence within the field. These methods of including disability issues in broader psychological practice have been recommended to ensure that the perspective of those with disabilities will be considered. This consideration will lead to better informed psychological practices for individuals with disabilities and to greater knowledge about the human condition more generally.

—Jaime Wernsman, Christopher B. Keys, and Scott Feldman

See also Professions; Psychiatric Disorders; Psychiatry.

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PSYCHOSIS

The term *psychosis* refers to an array of symptoms that relate to disturbances in how the brain processes perceptions and thoughts. A narrow definition of psychosis focuses on a cluster of phenomena known as positive symptoms. Positive symptoms include hallucinations and delusions. Hallucinations are said to occur when an individual experiences a sensory impression that has no basis in reality. This impression may involve any of the sensory modalities (i.e., hearing, sight, smell, taste, touch, or body position in space). Delusions are strongly held beliefs that are maintained despite a lack of supporting evidence. A delusional person may believe that others are reading their thoughts or plotting against them. Attempts to persuade the person that these beliefs are untrue generally fail and may even support the paranoia. In addition to hallucinations and delusions, persons with psychotic illness may have disorganized and confused thinking and may exhibit odd or flagrantly bizarre speech and behavior. These symptoms generally cause considerable disability, particularly in interpersonal relationships and work, and in most Western cultures, are associated with high unemployment.

Persons with psychotic illness may also develop what are known as negative symptoms that impair motivated and spontaneous behavior. Negative symptoms can make it difficult to conduct basic activities of daily living such as maintaining personal hygiene or attend to tasks such as grocery shopping and banking.

Psychotic symptoms may occur in a wide variety of mental disorders. Although most characteristically associated with schizophrenia, psychotic symptoms can also occur in severe mood disorders (e.g., major depression and bipolar disorder), as well as in response to underlying general medical conditions, in certain substance-induced disorders, and with some of the more severe personality disorders.

Psychosis caused by an underlying medical condition remits once the condition has been identified and treated. However, the 1.1 percent of the population suffering from schizophrenia may have psychotic symptoms throughout their lives. Following a first episode of schizophrenia, residual psychotic symptoms, negative symptoms, and a variety of cognitive deficits often persist and can cause significant psychosocial impairments. One of the best outcome predictors for first-episode patients with schizophrenia is treatment adherence, and there are compelling data to suggest that earlier, more intense interventions produce better long-term outcomes.

Psychotic symptoms resulting from a variety of disease states seem to share an underlying common mechanism, as they tend to respond as a group to specific pharmacological interventions. Despite the remarkable improvements that are developing in the treatment of psychotic illness, much remains to be learned about the brain mechanisms underlying psychosis so that more complete and predictable symptom abatement may occur.

—Thomas A. Simpatico

See also Psychiatric Disorders; Psychiatry; Psychology.

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PUBLIC STRIPPING

Term used by people with disabilities and disability studies scholars to describe a medical teaching and consultation practice in which disabled people, to receive medical care, were required to display themselves naked (or nearly so) in front of a well-dressed group of physicians, students, and allied health professionals. The practice, often referred to as *grand rounds* by medical practitioners, involves the presentation of a medical case with the actual person present not as a participant but as an object lesson for the assembly. The practice varied from institution to institution and from case to case, but the subjects of these demonstrations describe having hospital gowns and even undergarments taken off so that the professionals and students could examine them more freely. Many report having to walk naked in front of the physicians and others, having their bodies bent, probed, inspected, and exposed in mortifying ways.

The practice has not been limited to the grand-rounds setting. For example, psychologist Carol Gill reports that in 1993, on the popular NBC prime-time news magazine *NBC Now,* a physician pulled up the T-shirt of a 12-year-old girl with cerebral palsy and, without even speaking to her, displayed her scoliotic back to a national television audience.

Disabled people report feeling objectified by this experience, in which their perspectives on their impairment are completely ignored. But worse, they suggest, is the humiliation: These people, whose physical characteristics were the occasion for shame and oppression, were forced to denude themselves and parade those very characteristics for which they were singled out in front of a judgmental group of powerful people who treated them not like a person but like a set of symptoms, like an malfunctioning object.

By the twenty-first century, the practice has become less common, due perhaps to gradual changes in the culture of medicine as well as to changes in medical education, including the advent of advanced information technology. The practice and its impact on its disabled subjects has been explored extensively by crip artists, writers, and performance artists, including Cheryl Marie Wade, Greg Walloch, Mary Duffy, Carrie Sandahl, and Eli Clare.

—Jim Ferris

See also Stigma; Values.

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PUBLIC TRANSPORTATION

As societal divides between domestic and labor environments developed in the Industrial Revolution, public transportation systems were built to address the mobility needs of the labor force. Historically, these systems have been inaccessible to people with disabilities, making removal of transportation barriers a universal disability rights demand. A quick search of the Internet reveals more than 30,000 sites containing information about disability and public transit. Canadian and Australian authorities publish information about how disabled citizens and visitors may access their transit systems. In Great Britain, DAN (Disabled Action Network) has taken to the streets, winning a great victory in Nottingham in 1996. In South Korea, activists have documented their ongoing struggle in a documentary film. In all of these cases, the need for transportation has helped to create and fuel movements for disability rights, making public transportation the fight that is building the disability rights movement around the world.

In the United States, modern public transportation systems began to take shape at the dawn of the twentieth century. In 1895, New York City replaced its steam-powered lines with electric trains, and across the country, horse-drawn omnibuses and carriages were phased out in favor of electric-powered trolleys and streetcars. The first modern city bus, which seated 43 passengers and featured driver-operated doors, was manufactured in 1927. In 1933, Boeing unveiled the first commercial aircraft, which seated 10 passengers, featured upholstered seats and a water heater, and traveled at 155 mph. The development of these early public transportation systems unfortunately coincided with a period of disability history known as the "eugenics" era, in which disabled people were institutionalized, seldom seen in public, and sometimes even prohibited by law from using public streets and facilities. Invisibility led to exclusion so that early public transportation systems evolved for almost three-quarters of a century without considering access for people with disabilities. Transportation equipment and facilities were built without vertical access for people with mobility impairments and without communication access for people with visual or hearing impairments.

With the development of the independent living movement in the 1960s, a new way of thinking about people with disabilities and society emerged. Disability rights activists used the "social model of disability" to move the locus of "the problem" from individual or personal inadequacy (e.g., the inability to climb bus stairs) to society's systematic exclusion of people with disabilities through architectural and attitudinal barriers. In 1973, MAD (Metropolitan Area Disabled), a group of disabled people in Denver, Colorado, began to protest separate and unreliable service for disabled riders. In 1977, the same year that the first wheelchair lift–equipped fixed-route bus was run in San Diego, the Atlantis Community, a client-based organization that provided attendant services to people moving out of nursing homes, filed a lawsuit under Section 504 of the Rehabilitation Act of 1973, demanding access to Denver's public bus system. When a judge ruled against the Atlantis Community in 1978, a group of disabled activists and their allies closed down Denver's bus system for two days until they won agreement to equip all new buses with lifts. By 1982, disabled riders in Denver enjoyed accessible mainline bus service. This group formed the nucleus of what would become one of the most contentious of disability rights groups, ADAPT (American Disabled for Accessible Public Transit).

Throughout the 1980s, the nascent disability rights movement rallied around the demand for access to public transportation. Activists forced public officials to rethink policies that excluded people with disabilities from mainline public transportation systems by debunking inflated cost propaganda and showing that access to public transportation was essential for full participation in educational, social, and vocational activities—integral to connecting with others in the community and moving about freely.

Public transportation authorities through their national association, APTA (American Public Transit Association), vigorously opposed the concept of providing accessible mainline transportation to people with disabilities. Portraying the cost of equipping buses and trains with lifts and other accessibility features as an economic threat, transit authorities appealed to the courts for relief from federal regulations in favor of a "local option" that allowed localities to determine what service to provide to disabled riders. The courts concurred, and in the decade preceding passage of the ADA, most disabled riders continued to be relegated to separate and notoriously unreliable paratransit services, where ride denials were commonplace and spontaneous travel was prevented by laborious administrative and scheduling requirements.

The demand for accessible public transportation was sustained through community activism, protests, and court battles for more than 15 years. In Chicago, disabled riders, many of who were members of Chicago ADAPT, sued for access to the city's buses and rapid rail system under the state human rights law (*Jones v. CTA*). Their victory in 1988 was followed by a sister lawsuit against Chicago's commuter rail system (*Jones v. Metra*), which was also settled in favor of disabled plaintiffs. By the time the Americans with Disabilities Act (ADA) of 1990 was passed, almost half of the nation's bus companies were ordering at least some lift-equipped buses.

With the passage of the ADA in 1990, which established minimum accessibility requirements, many disabled people gained improved access to public transportation systems. Yet compliance has not been easy, and transit entities had to be taken to court, in some cases repeatedly, to enforce compliance. Others have used the "minimum" requirements of the ADA to circumvent accessibility for disabled riders. For example, many public bus companies purchased new inaccessible buses just before effective dates of transportation regulations, with useful lives of 10 to 12 years; this effectively postponed mainline access for a decade. For some, who depended on door-to-door transportation, the ADA resulted in less transportation when not traveling within the required radius of mainline.

"Full compliance" under the ADA does not always translate to equal or full access in practice. For example, as of 2003, the Chicago Transit Authority proclaimed that 35 percent of its stations were ADA accessible, yet the accessibility is unequally distributed, and some key access compliance continues to be deferred into the future. Over time, a key flaw in early disability rights thinking became apparent. Activists in the 1970s and 1980s envisioned a "common" disability population and deprioritized the needs of people with disabilities who could not be accommodated by mainline transportation systems. This includes, for example, people with respiratory impairments who cannot wait for buses in temperature extremes, people with chronic fatigue syndrome, and ambulatory disabled people who cannot stand for long periods of time. While complementary paratransit requirements were included in ADA regulations, service areas are based on travel patterns of mainline bus users, and the regulations allow transit agencies to charge double the standard bus fare for disabled people who cannot access mainline systems, thus effectively pricing public transportation out of reach for many people with disabilities, who remain the poorest minority group in America.

Even where technical compliance on fixed-route services has been achieved, disabled riders are often singled out, separated, and expected to participate in separate additional interactions. "Handicap" turnstiles, separate paths of travel, special call buttons, additional paperwork, separate boarding and debarking processes, and delayed exits from the system all add up to a multiplicity of separate policies and procedures that stigmatize disabled riders.

For many, the promise of the ADA remains out of reach. Just as disabled people were staking a claim to public transportation, funding for public transit declined and private vehicles became a staple of American life. The cost of modifying private vehicles for accessibility is often prohibitive; it is not unusual for modifications to double the cost. Most taxi services also remain inaccessible. Disability rights groups argued that making buses and trains accessible would provide reliable transportation to disabled people and reduce the human and social costs of failing to accommodate—the cost of maintaining millions in unemployed poverty who could work if they could obtain reliable transportation. Yet more than a decade after the passage of the ADA, 65 percent remain unemployed, a significant number cannot or do not drive, and in many parts of the country, people with disabilities, unlike their nondisabled counterparts, remain isolated and excluded from the mainstream of American life.

Despite disappointing progress at times, disabled people continue to press for access to all modes of public transportation. When the Supreme Court found that the Rehabilitation Act did not apply to air travel, disability advocates organized, and in 1986, Congress passed the Air Carrier Access Act (ACAA), which requires the implementation of practices and procedures to ensure access to air travel by people with disabilities, but stopped short of mandating the development of accessible aircraft. At the dawn of the twenty-first century, disabled people would win accessibility on American cruise lines and then go on to press for accessibility on foreign-flagged cruise ships in U.S. waters.

—Sharon Lamp

See also Accessibility; ADAPT; Air Carrier Access; Americans with Disabilities Act of 1990 (United States); Industrialization.

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QUALITY OF LIFE

The measurement of quality of life has become central to the evaluation of health care. This has not always been the case; until recently, quality of life was addressed only through indirect inference from more traditional medical variables. The difficulty of defining quality of life in a meaningful and operational manner was in part to blame for the apparent unwillingness of the medical profession, and those allied with it, to engage in systematic evaluation of quality of life in the past. Indeed, the term *quality of life* is inherently ambiguous, as it can refer both to the experience an individual has of his or her own life and to the living conditions in which people find themselves. Consequently, definitions of the concept have varied widely, with some writers viewing quality of life as in some way akin to the Aristotelian notion of the "good life" and others defining it in terms of capabilities (i.e., having the ability to live a good life in terms of emotional and physical well-being). Within the arena of health care, the latter view has tended to dominate, and the term *quality of life* is typically used to refer to individuals' experiences of their own health.

Academic interest in quality of life grew after World War II, when there was increasing awareness, and recognition, of social inequalities. This provided the impetus to social indicators research, and subsequently to research on subjective well-being and quality of life. The term *quality of life* first appeared in the medical literature in the 1960s, and references to it have grown exponentially ever since. In 2003, the term appeared in more than 6,000 articles referenced on Medline alone. For the most part, health care scholars and researchers use the term to refer to outcomes based on patient self-reports. Historically, this had simply not been an integral part of how health was reported in the scientific literature. Undeniably, the patient's view of his or her own health had played some role in the medical consultation, but in terms of the health care literature, researchers did not begin collecting and reporting such data systematically until the late 1960s.

Within the arena of disability research and health care it has become increasingly commonplace to discuss *health-related* quality of life. Interest in health-related quality of life is in keeping with the World Health Organization's definition of health, which incorporates autonomy and physical, mental, and social well-being; health is not merely the absence of disease. The literature in this field covers a wide variety of areas, including role functioning (e.g., ability to perform domestic and work tasks), degree of social and community interaction, psychological well-being, pain, tiredness, and satisfaction with life. To some extent there is a tendency to equate quality of life with those factors of the health state that are not encompassed by traditional medical assessments. Such a view can lead to conceptual confusion and perhaps highlights more than anything else the difficulty in providing a simple definition of quality of life. Suffice it to say that health status and health-related quality of life have come to mean a combination of subjectively assessed measures of health, including physical function, social function, emotional or mental state, burden of symptoms, and sense of well-being.

Most early attempts to develop measures for assessing health-related quality of life included attempts to measure the specific impacts of disability. For example, the Katz and Barthel measures were designed to assess activities of daily living in patients undergoing rehabilitation programs. Measures of emotional health, such as the Beck Depression Inventory, were designed to assess mental health and to give an indication of the severity of depressive symptoms. However, questionnaires are now often specifically designed to cover a wide range of areas that may affect an individual's quality of life. Two broad categories of measures have emerged: those designed to evaluate health-related quality of life in any group of patients (indeed, in any population sample) and those designed to evaluate health-related quality of life in specific illness groups. The former group include measures such as the Sickness Impact Profile and the 36-item Short Form Health Survey (SF-36). These instruments cover a wide range of aspects of life that can be adversely affected by ill health, such as physical functioning, emotional well-being, and ability to undertake work and social activities. Disease-specific measures, such as the Arthritis Impact Scales Version II (AIMS II), the 39-item Parkinson's Disease Questionnaire, the Endometriosis Health Profile, and the 40-item Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ-40), are designed for use with specific patient groups. They are intended to cover dimensions salient to particular patient groups; thus, like generic measures, they address areas such as physical and emotional functioning, but they also cover issues that may be predominant among patients with particular illnesses (e.g., feelings of loss of control, stigma).

A wide variety of uses have been suggested for quality-of-life data, but the most common applications are the assessment of treatment regimes in clinical trials and health surveys. Other applications include population and patient monitoring, screening, and improvement of doctor-patient communication. One of the most emotive uses of such data, however, is in the economic evaluation of health care, with some measures designed specifically to be used in cost-utility analyses—that is, analyses that attempt to determine the benefits of an intervention in terms of both length of life gained and quality of life. Perhaps the most widely used of these measures is the EuroQol 5D (EQ-5D), which addresses five dimensions of health: mobility, self-care, usual activity, pain, and anxiety/depression. Each of these dimensions is subdivided into three levels according to whether the dimension represents no problem, a moderate problem, or a severe problem. The five dimensions and the three-level classification system generate 243 health states, which the instrument's developers have extended to 245 through the addition of death and unconsciousness. The values attached to these health states, which are based on responses from surveys of the general population, are intended to reflect societal views of the severity of each state. The EQ-5D can produce the quality-of-life component for the calculation of quality-of-life-adjusted years (QALYs), in which quality of life is combined with years of life gained as a consequence of an intervention. Costs of treatment can be linked with the number of QALYs gained to give a cost per QALY.

Clearly, quality of life represents an aspect of health that is different from that generally measured using traditional methods of assessment, such as X-rays, blood tests, and clinical judgment. The latter have tended to dominate within health care and medicine in part because they are seen to be relatively objective. The measurement of quality of life incorporates the subjective views of the patient directly and can provide health care professionals with information that can supplement or, on occasion, contradict traditional assessments. For example, there is evidence that outsiders, such as doctors and relatives, view the quality of life of patients with serious disabilities more negatively than do the patients themselves. Also, in some instances, clinical assessments remain stable over time and yet patients report a worsening of their health. Such divergences between the perceptions of those in a given health state and the perceptions of outside observers highlight the limitations of basing assessments purely on observers' assessments. The main purpose of the health care system is to increase the well-being of those it treats. This can be achieved only if patient views are incorporated into treatment evaluations, thereby ensuring that health and medical care are fully evidence based.

—Crispin Jenkinson

See also Activities of Daily Living (ADLs); Citizenship and Civil Rights; Health; Participation.

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QUEBEC MODEL OF DISABILITY CREATION PROCESS

The disability creation process (DCP) is a conceptual model that enables one to identify and explain the causes and consequences of disease, trauma, and disruptions to the development of a person. It demonstrates that social participation is not only the result of our identity, our choices, impairments to our organs, and our abilities and inabilities, but also of characteristics of our living environment. For example, an individual's preparing meals or going to regular school may be influenced by the reinforcement of that person's capabilities and alteration of his or her functional limitations through rehabilitation, as well as through the reduction of obstacles caused by prejudice, lack of assistance or resources, and absence of accessibility within the home or school.

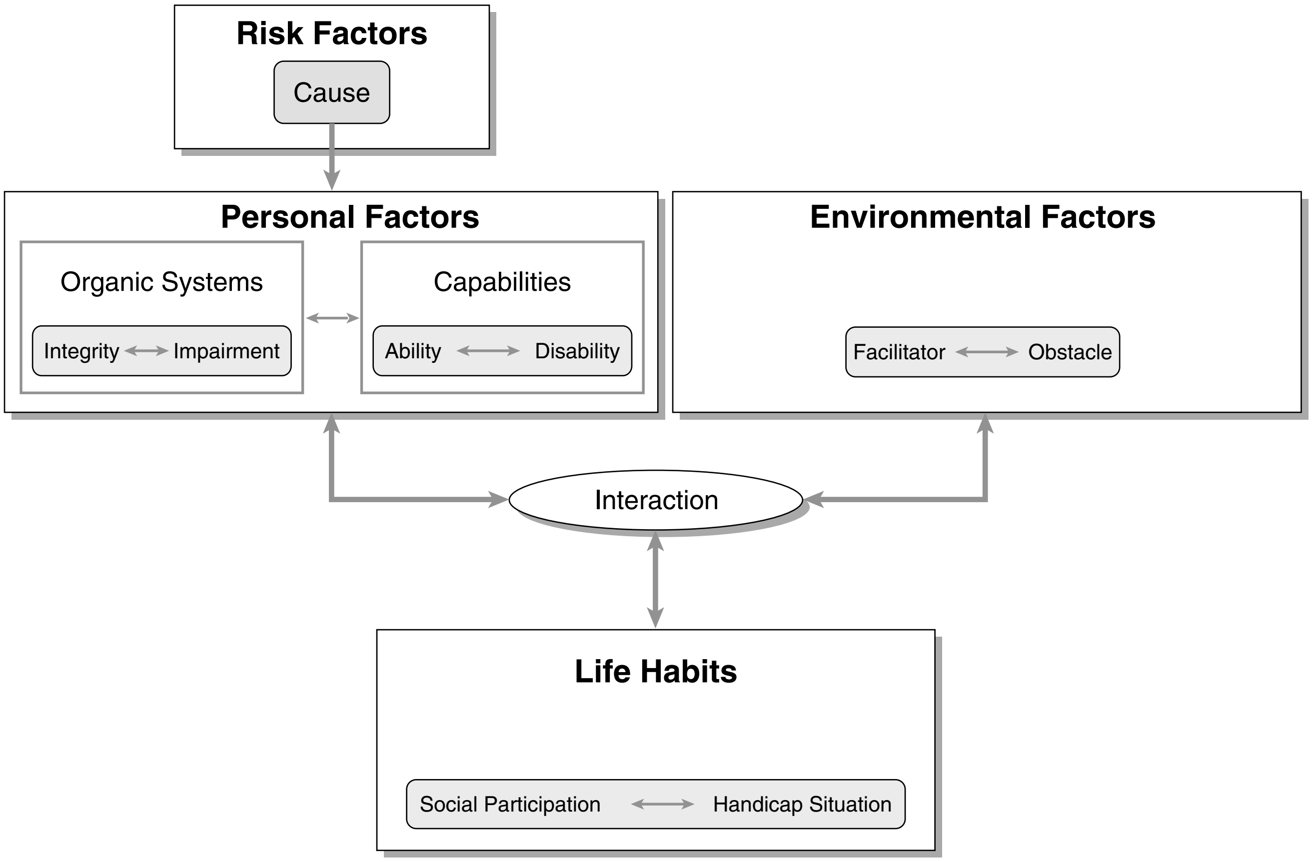

Figure 1 The Disability Creation Process: The Reference Model

The DCP model was developed based on the Quebec government's disability policy, "On Equal Terms," and on the recommendations of international experts, including the World Health Organization, the United Nations, Disabled Peoples' International, and the Council of Europe, at the Quebec Meeting on International Classification of Impairments, Disabilities, and Handicaps (ICIDH) in June 1987. By 1989, Patrick Fougeyrollas, a Canadian anthropologist, and the Quebec Committee on ICIDH published a conceptual framework illustrating the person-environment interactive process of the creation of social participation or exclusion. Throughoout the 1990s, they improved the DCP framework and classification, known also as the Quebec model, and urged the WHO and international partners to revise the ICIDH. From 1993 to 2001, this innovative conceptualization and its scientific applications influenced the revision process that culminated in the WHO's adoption of the International Classification of Functioning, Disability, and Health (ICF).

The DCP model differs from the ICF in its conceptualization of human development and adaptation as well as in its view of the disability process as an interactive person-environment relationship that creates the outcome of quality of social participation. Although the ICF has also adopted a universal, systemic conceptual framework, the DCP illustrates in a heuristic and pedagogical way the dynamics of the interactive process between personal factors (intrinsic) and environmental factors (extrinsic) that determines the situational result of accomplishment of life habits (daily life activities and social roles) corresponding to the person's age, gender, and sociocultural identity. The DCP concepts and taxonomies are mutually exclusive.

The DCP model distinguishes two intrinsic dimensions applicable to every human being: organic systems and capabilities (see Figure 1). The "personal factors" category is larger and more inclusive than the "organic systems" and "capabilities" themselves because other personal identity variables (age, gender, sociocultural identity) must also be considered in the explanation of the performance of life habits. The "environmental factors" category is clearly delimited and includes all dimensions of the context (social, cultural, political, physical, and so on) in which the person lives. The dynamic nature of the interactive process is symbolized by the bold double arrows in Figure 1. The point of central convergence, symbolized in the figure by the word *interaction,* aims at naming the continual relationship and influence of the three conceptual dimensions.

The International Network on the Disability Creation Process is a Canadian nongovernmental organization that promotes the use of the DCP model and the development of applications supporting the exercise of human rights and full citizenship for people with functional and organic differences.

—Patrick Fougeyrollas

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

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Le Réseau international sur le Processus de production du handicap (International Network on the Disability Creation Process), http//:www.ripph.qc.ca

QUEER/DISABILITY STUDIES

As disability studies flourished in the late 1990s, the insights that emerged from points where the field intersected or converged with queer studies proved to be particularly productive. By the turn of the century, this convergence had generated a number of significant texts, events, communities, and institutions. Eli Clare's *Exile and Pride: Disability, Queerness, and Liberation* (1999) was a landmark text in this process, as were a number of edited volumes, including Raymond Luczak's *Eyes of Desire: A Deaf Gay and Lesbian Reader* (1993), Shelley Tremain's *Pushing the Limits: Disabled Dykes Produce Culture* (1996), Victoria A. Brownworth and Susan Raffo's *Restricted Access: Lesbians on Disability* (1999), Robert McRuer and Abby L. Wilkerson's "Desiring Disability: Queer Theory Meets Disability Studies" (2003) (a special issue of the prominent academic journal *GLQ: A Journal of Lesbian and Gay Studies*), and Bob Guter and John R. Killacky's *Queer Crips: Disabled Gay Men and Their Stories* (2003). An efflorescence of cultural work in many other locations both preceded and accompanied these important volumes, including individual memoirs such as Kenny Fries's *Body, Remember* (1997) and Daphne Scholinski's *The Last Time I Wore a Dress* (1998); performance art by Terry Galloway, Greg Walloch, Julia Trahan, and others; the online publication *Bent: A Journal of Cripgay Voices;* and the "Queer Bodies" study and education group, which focuses on queerness and disability, based in New York City at the Center for Lesbian and Gay Studies (CLAGS). A group of activists and academics in the United States initiated a queer disability Listserv on the West Coast in 2000 and, partially through this network, the first international queer/disability conference was organized. That event, which was held at San Francisco State University in June 2002, was attended by artists, academics, and activists, thereby bringing together (in sometimes contentious conversation) the three overlapping communities responsible for generating increased interest in the convergence of queerness and disability.

This wave of interest in queer/disability studies was facilitated both by the perceived connections between some lesbian/gay/bisexual/transgendered (lgbt) subjectivities and some disabled subjectivities and by the affinity certain strands of disability studies seemed to have with what had been known since the early 1990s as "queer theory." Among the perceived connections between lgbt and disabled subjectivities was the recognition that socialization for both people with disabilities and lgbt people often occurred in heterosexual and able-bodied families, isolated from queer and disability communities. Similarly, the rhetoric of coming out that developed in part to resist such isolation and that permeated the disability movement by the end of the century had clear, and sometimes acknowledged, antecedents in the gay liberation movement, and at its best did not signify discovery of some deep essential truth but rather coming out to a vibrant movement intent on collectively and often quite literally rebuilding the world. Both communities have faced ongoing medicalization or pathologization and arguably faced similar new dangers at the turn of the century, normalization perhaps at the forefront. Throughout the 1990s, lgbt communities debated the benefits and liabilities of the normalization process, weighing such factors as increased media visibility and tolerance against the potential loss of a flamboyant and critical militancy, the dangers of tokenism, and the ongoing marginalization of members of the community furthest from what Audre Lorde identified in 1984 as "the mythical norm." For both lgbt and disability communities, the danger of mutual recoil was perhaps the most problematic aspect of normalization: the possibility that acceptance for queers would come first to those perceived as least disabled and that acceptance for people with disabilities would come first to those perceived as least queer.

The origins of queer theory are multiple. Michel Foucault is often located as a founding figure of sorts, with special emphasis placed on *The History of Sexuality,* Volume 1 (1978). In that work, Foucault challenged the notion that sexuality has simply moved from a state of repression or secrecy to liberation and openness. He showed instead the ways in which sexuality in the modern era has emerged as a unique apparatus, composed of and by an array of discourses and institutional practices; he argued that it has not been repressed but *managed.* Foucault made it possible to understand how sexualities (and, indeed, forms of subjectivity and embodiment generally) emerge through the construction, categorization, and dissemination of the "normal" and the "deviant." Foucault's work had affinities with the work of several other gay and lesbian historians and sociologists, who were mostly working outside the academy in the 1960s and 1970s. From Mary McIntosh's groundbreaking "The Homosexual Role" (1968) through Jonathan Ned Katz's *The Invention of Heterosexuality* (1995), these scholars examined the ways in which understandings and experiences of sexual identity (including heterosexuality) are socially constructed, emerging from specific historical and cultural contexts. Since this body of work as a whole focused on embodiment, normality, and deviance as historical entities, other scholars more directly concerned with late-twentieth-century queerness and disability were able to access it to critique the ways in which the institutions and discourses of compulsory able-bodiedness and compulsory heterosexuality worked in tandem to produce and contain both able-bodied heterosexuality and queer disabled subjects who might confirm (by embodying a "deviance" that vouchsafed able-bodied heterosexuality's dominance) or trouble (by resistance to this function and refusal to be kept in place) the larger apparatus.

Queer theory also developed in relation to a late-1980s resurgence of radical lgbt activism, in particular activism that addressed the lack of attention that the medical establishment, the U.S. government, and the media were giving to the AIDS crisis. Although some disability activists resisted the incorporation of HIV/AIDS into the Americans with Disabilities Act (ADA), there were nonetheless many points of identification between AIDS and disability activism. Some AIDS activist groups, in fact, explicitly acknowledged their debt to the disability rights movement, and some disability rights groups, such as ADAPT, in turn developed strategies and styles that explicitly recalled or cited those of AIDS activists, especially activists in the AIDS Coalition to Unleash Power (ACT UP). AIDS activism in the late 1980s and early 1990s was flamboyant and confrontational, stopping traffic on Wall Street, storming the National Institutes of Health, staging a "kiss-in" in front of St. Patrick's Cathedral in New York City (Cardinal John O'Connor had opposed safe-sex education in both private and public schools). The demands of activists included increased funding for education and research; expanded access to treatment, especially for women, people of color, and the poor; and an end to the stigmatization of "AIDS victims," who themselves preferred to be called "people living with HIV/AIDS." AIDS activists, like other disability activists, were also media savvy, recognizing the importance of both challenging dominant media representations and documenting their own movement. A significant body of AIDS cultural theory—including Douglas Crimp's edited volume *AIDS: Cultural Analysis/Cultural Activism* (1987), Cindy Patton's *Inventing AIDS* (1990), Paula Treichler's *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (1999), and Cathy J. Cohen's *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (1999)—emerged from this period and provided an additional context in which queer/disability studies flourished.

Finally, queer theory also developed as an extension of feminism and, in some cases, as a partial break from feminism. Gayle S. Rubin's "Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality" (1984), specifically responding to what Rubin understood as the "sex panics" of the 1980s, called for new and autonomous theoretical tools that could account for, and counteract, the sexual stratification and oppression of our culture; feminism alone, in Rubin's estimation, was not adequate to this task. Similarly, writers such as bell hooks, Audre Lorde, Gloria Anzaldúa, and Cherríe Moraga critiqued white feminists for their universalizing of all women's experiences and for their explicit exclusion of women of color. In calling for a more fluid, oppositional, and coalitional feminism, these women of color either explicitly articulated their demands as "queer" ("We are the queer groups," Anzaldúa [1981:209] wrote, "the people that don't belong anywhere. . . . and because we do not fit we are a threat") or anticipated similar fluid and oppositional theories that would later emerge under the rubric of both queer and disability activism and theory. The call for autonomous or semiautonomous spaces and the simultaneous emphasis on specificity and coalition suggests that queer/disabled thought and activism, in particular, inherit these complex feminist histories. Queer/disabled individuals and communities have worked to secure recognition and respect for the full range of bodies and desires, and have resisted the ways in which they have at times been made invisible by larger lgbt and disability movements.

—Robert McRuer

See also Advocacy; Disability Studies; Gender.

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QUOTA HIRING POLICY

In many countries of the world, programs have been established to seek to create equitable employment opportunities for persons with disabilities. Known as *affirmative action, positive discrimination, employment equity,* or *quota systems,* these programs all have in common the goal of raising the workplace participation rates of disabled people to match those found in the nondisabled general population. In some countries, these programs encompass not just disabled people but other groups as well, such as women, visible minorities, and aboriginal peoples. This entry provides an overview of such programs found in the United States, Canada, France, and Germany.

UNITED STATES

In the United States, affirmative action programs flow from that country’s antidiscrimination legislation and are not based on the imposition of strict numerical quotas. The term *affirmative action* was first used in the United States in the context of civil rights legislation in the early 1960s. In March 1961, President Kennedy issued Executive Order 10925, which established the President’s Committee on Equal Employment Opportunity. The goal of the committee was to end discrimination in employment by the government and government contractors. The order required that every government contract contain the following pledge: “The Contractor will not discriminate against any employee or applicant for employment because of race, creed, color, or national origin. The Contractor will take *affirmative action,* to ensure that applicants are employed, and that employees are treated during employment, without regard to their race, creed, color, or national origin.” However, the term *affirmative action,* in this context, meant only that the organization should not discriminate.

In 1964, the U.S. Congress passed the Civil Rights Act, Title VII of which outlawed discrimination on the basis of race, color, or national origin in programs and activities receiving federal assistance. The act was amended in 1972 to include in this list religion, sex/gender, and national origin. However, in 1965, President Johnson noted that “fairness” means more than a commitment to impartial treatment. In his commencement speech at Howard University in Washington, D.C., that year, he said:

> You do not take a person who, for years, has been hobbled by chains and liberate him, bring him up to the starting line of a race and then say, “you are free to compete with all the others,” and still justly believe that you have been completely fair.
>
> Thus it is not enough just to open the gates of opportunity. All our citizens must have the ability to walk through those gates.
>
> . . . We seek not . . . just equality as a right and a theory but equality as a fact and equality as a result.

These concepts were embodied in Executive Order 11246, which President Johnson issued in 1965 and amended in Executive Order 11375 in 1967. These orders required that all federal government contractors develop “affirmative action programs” to “promote the attainment of equal employment objectives.” The orders authorized the use of goals but prohibited quotas in regard to race, religion, national origin, color, and sex. In 1971, President Nixon extended affirmative action by issuing Revised Order 4, which required that each contractor develop “an acceptable affirmative action program,” including “an analysis of areas within which the contractor is deficient in the utilization of minority groups and women, and further, goals and timetables to which the contractor’s good faith efforts must be directed to correct the deficiencies." Goals were not to be quotas; rather, they were to be seen as targets that were reasonably attainable.

In 1973, the U.S. Congress passed the Rehabilitation Act, in which Section 503 required government contractors to take affirmative action to employ and promote qualified handicapped individuals. The act also prohibited employment discrimination against qualified persons with disabilities. In 1990, the Americans with Disabilities Act (ADA) was signed into law. This legislation outlawed discrimination against persons with disabilities in employment and in the provision of goods and services. Provisions of the ADA cover both public and private employers. The law does not specifically mandate the creation of affirmative action programs, but the remedies available for violations of the ADA are the same as those available under Title VII of the 1964 Civil Rights Act. In cases of systematic discrimination, the courts may require that an affirmative action order be established, requiring the employer to establish outreach programs to increase the hiring and promotion of disabled people.

Affirmative action programs in the United States, then, are not based on one law but instead have evolved over the years through the adoption of a number of statutes, coupled with the issuance of various executive orders. In recent years, however, these programs have become the subject of much controversy in the United States. Critics of affirmative action contend that it is nothing less than discrimination in reverse, and that affirmative action policies amount to de facto quotas. Supporters of affirmative action programs argue that such efforts are necessary to balance the history of barriers faced by racial minorities, women, and persons with disabilities. A key element in the U.S. debate is the absence of an equality rights provision in the U.S. Constitution that would furnish a constitutional basis for the implementation of affirmative action programs.

CANADA

Canada's affirmative action program for persons with disabilities, known as *employment equity,* also flows from antidiscrimination laws. And, as in the United States, Canada does not impose on employers any requirement to hire specific numbers of disabled employees.

In 1978, Canada's federal Parliament passed the Canadian Human Rights Act. As originally enacted, the law outlawed discrimination in employment and in the provision of goods and services on 10 grounds: race, national or ethnic origin, color, religion, age, sex, marital status, family status, disability, and pardoned conviction. Some years later, sexual orientation was added to this list. This law provided that it is not a "discriminatory practice" for a person to "carry out a special program, plan or arrangement designed to prevent disadvantages that are likely to be suffered by, or eliminate or reduce disadvantages that are suffered by groups of individuals . . . when those disadvantages . . . would be based on or related to the prohibited grounds of discrimination." Thus, this antidiscrimination legislation first allowed employers to implement affirmative action *passively,* with no actual requirement to do so.

In 1982, Canada's Constitution was amended to include the Charter of Rights and Freedoms. Section 15 of the Charter, the equality rights provision, provided the constitutional underpinnings for the mandatory employment equity (i.e., affirmative action) programs that were soon to be enacted.

Despite the antidiscrimination legislation in place, it became evident that existing laws could not deal with structural or "systemic" discrimination that certain groups, including persons with disabilities, found in the Canadian workplace. In 1984, a Royal Commission on Equality in Employment, chaired by Madame Justice Rosalie Abella, issued a report that provided the philosophical rationale for affirmative action:

> Sometimes equality means treating people the same despite their differences, and sometimes it means treating them as equals by accommodating their differences.
>
> Formerly, we thought that equality only meant sameness and that treating persons as equals meant treating everyone the same. We now know that to treat everyone the same may be to offend the notion of equality.

In 1986, Canada passed the Employment Equity Act, which mandated the institution of *positive* policies and practices to ensure that persons in designated groups (women, aboriginal peoples, visible minorities, and persons with disabilities) "achieve a degree of representation in the various positions of employment with the employer that is at least proportionate to their representation (i) in the workforce or (ii) in those segments of the workforce that are identifiable by qualification, eligibility or geography and from which the employer may reasonably be expected to draw or promote employees." The law requires employers to eliminate structural or systemic discrimination and to institute measures that will ensure that persons who belong to one of the four designated groups subject to the law achieve a degree of representation in the various positions of employment with their employers that is proportionate to their representation in the workforce. The law also requires employers to prepare yearly plans that outline the employment equity goals that they propose to reach as well as timetables for achievement of those goals. The requirements of the Employment Equity Act apply to employers that have more than 100 employees and are under federal jurisdiction.

It is important to note that the Employment Equity Act does not contain any provision that actually forces employers to hire anyone. Rather, the law requires that employers prepare annual reports and send copies of those reports to the Canadian Human Rights Commission, the agency responsible for enforcement of the act. Although employers are not required to hire anyone, these reports are public documents, and employers' progress is subject to public scrutiny. Moreover, the Canadian Human Rights Commission may conduct audits of employers and may issue directions to them.

The affirmative action program in Canada has been subject to the same criticisms as such efforts in the United States. However, because of the existence of the equality provisions of the Canadian Charter of Rights and Freedoms, the Canadian program has not been subject to the same intensity of legal challenges that have taken place in the United States.

QUOTA SYSTEMS

In contrast to the programs in place in the United States and Canada, affirmative action efforts in many countries of Europe (France, Germany, Italy, Austria, Poland) do not flow from antidiscrimination legislation, but rather are based on strict numerical quotas. Thus, they are fundamentally different from U.S. or Canadian affirmative action programs, which rely on targets or objectives rather than on requirements concerning fixed percentages of the workforce. Moreover, the quota programs in Europe cover only disabled people, not a broader range of "designated groups" such as racial minorities or women. For the purposes of this entry, the systems in place in France and Germany are described briefly below.

France

In France, a law enacted in 1987 established a quota-levy program. The law stipulates that enterprises with 20 or more workers must have 6 percent of their workforces composed of disabled workers. The legislation also allows for the application of branch or enterprise agreements by which the company agrees to the recruitment and retention of persons with disabilities. These agreements may cover a single enterprise or an entire sector of economic activity. Most of these agreements include job retention objectives for injured workers.

A company that fails to observe its quota obligation is charged a levy commensurate to the number of workers by which it falls short of the quota. The levy averages 2,000 euros (approximately $2,300 U.S.) annually for each employee by which the company falls below the quota. The funds collected by the quota program are administered by the Association Nationale de Gestion du Fonds pour l'Insertion Professionelle des Personnes Handicapées, or AGEFIPH, which is made up of representatives from government, trade unions and employers, and organizations of persons with disabilities.

Germany

Germany has had a statutory obligation for companies to hire disabled workers in place since the end of World War I. In 1917, the German Parliament passed a law requiring companies to hire 1 disabled war veteran for every 50 employees. This was later broadened to require companies to fill 1 percent of all jobs with severely disabled persons, defined as war victims,

victims of industrial accidents, and other persons entitled to public pensions and compensation.

In 1974, the Severely Disabled Persons Act was enacted. This legislation provides, with some exceptions, that all companies with more than 16 employees must fill at least 6 percent of positions with severely disabled persons. This figure represents the proportion of severely disabled persons of working age in the German population as a whole. Under the legislation, severely disabled persons are defined as individuals who have been assessed with as a disability of 50 percent or more from any cause. Companies that do not comply with their quota requirements must pay a monthly levy of approximately 102 euros, or $120 U.S. Certain positions, such as part-time jobs of less than 18 hours weekly and jobs of less than eight weeks' duration, are exempt. It is noteworthy that the compensatory levy is payable solely on the basis that disabled persons are not employed in the firm; it is not predicated on whether disabled persons have actually applied for positions.

CONCLUSION

Despite the existence of quota and affirmative action programs, persons with disabilities continue to experience levels of unemployment far above those experienced by their nondisabled fellow citizens. Unfortunately, this is a statement that is valid for all countries.

Very little evaluative research has been conducted on this topic, so there is insufficient evidence to allow us to state with any certainty whether the affirmative action or quota system models are effective vehicles for the integration of persons with disabilities. However, what these programs have done is place the equity issue in the forefront of public awareness and encourage employers to embark on equity activities they might not otherwise undertake. Certainly in the North American context, it is rare to see a job advertisement that does not proclaim that the company is an "equal opportunity employer" or that it is dedicated to employment equity. Finally, it should be noted that the goal of both quota and affirmative action programs is the establishment of a workforce that accurately reflects the participation rates and percentages of disabled people in the general population. As such, these programs must be seen as works in progress.

—Carl Raskin

See also Disability Law: Europe; Disability Law: United States; Employment; Employment, International; Work.

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U.S. Equal Employment Opportunity Commission, http://www.eeoc.gov

R

▣ RACE AND ETHNICITY

Historically, the two social categories of race and disability have had a contentious relationship. Race theorists have sought to distance themselves from any association with disability because such associations have supported, justified, and enacted centuries of oppression, exploitation, and even genocide against bodies marked as racial Others. Even today, the racialized body continues to remain central to the maintenance of a hierarchical social-political world order. For disabled people of color, the double jeopardy of both race and disability continues to locate them at the margins of society.

Despite their contentious relationship, the academic areas of critical race theory and disability studies draw on similar foundational concepts. Both begin with the assumption that race and disability are, in fact, social constructs. For examples, critical race theorists depict race as a product of "human rather than abstract forces," produced through a process often called "racial fabrication." Similarly, some disability studies scholars have described disability as "the attribution of corporeal deviance—not so much a property of bodies [but rather] . . . a product of cultural rules about what bodies should be or do." Both perspectives argue that race and disability are relational concepts. Some theorists, consequently, have argued that races are constructed relationally against one another rather than in isolation, such that the privileges that "whites" (i.e., Nordic Europeans) enjoy are linked to the subordination of people of color. Similarly, in the context of disability studies, scholars point out that "our construction of the normal world is based on a radical repression of disability."

Notwithstanding these commonalities, because disability has historically been associated with "deviance" and "the lack of intelligence," race theorists have attempted to distance race from these attributes. By doing so, however, race theorists have invoked the biological definition of disability as an abnormality rooted in the medical language of symptoms and diagnostic categories. It is this definition that disability studies scholars have critiqued, describing it as a "deficit" model, and have instead opted for an alternative definition of disability as a socially constructed category that has historical, cultural, political, and economic implications for social life. Drawing on this reconceptualization of disability, some disability studies' scholars have foregrounded the theoretical linkages between disability and race by arguing that disability is an ideological construction used to justify not only the oppressive binary cultural constructions of normal/pathological, autonomous/dependent, and competent citizen/ward of the state but also the racial division of labor and other forms of racialized oppression.

EUGENICS AND THE BIRTH OF A RACIST SCIENCE

Theoretical linkages between disability and race have historical roots in Enlightenment thought, where philosophers such as David Hume and Immanuel Kant sought to distinguish between what they thought of as "different breeds of men." Hume's naturalism drew him to identify what he termed nature's "original distinction" between "inferior" breeds of men that were nonwhite (e.g., the Negro) and an "eminent" breed that was white—distinctions that extended to their intellectual and moral aptitudes. Similarly, Kant, in pursuit of an objective scientific theory of human differences, established a meticulous conceptual distinction between "race" and "species" and gave credence to the argument of intergenerational permanence of racial traits. Such theorizations of human difference in the late eighteenth century occurred at the same time as slavery and colonialism were flourishing and served as justification for the brutal violence meted out against nonwhite people who were assumed to be subhuman.

Paralleling the social construct of race as a category of human difference, disability studies scholarship reports that during the latter half of the eighteenth century, "disability" became tied to discourses aimed at remediating, curing, and cataloging variation in human bodies. This argument does not imply that disabled people did not exist in earlier times. Rather, such arguments suggest that while disability in earlier times was seen more as an individual event, in the late eighteenth century, the disabled person was "seen, drawn, dissected, legally placed, morally and ethically determined" (Davis 1995) and, as a result, became associated with a genetic entity or group defect, which was, in turn, also linked to race, class, and gender differences.

Leading scientists of the late eighteenth and nineteenth centuries, such as Carl Linnaeus, Georges Cuvier, Charles Lyell, Charles Darwin, and J. F. Bluemenbach, made linkages between human character and human anatomy and drew on the racial politics of the time to link Africans and other nonwhite races and disability in demeaning ways. By the beginning of the twentieth century, the intimate relationship between nonwhite races and disability was institutionalized by the racist science of eugenics. The term *eugenics* was coined in 1883 in Britain by Francis Galton to describe a program of selective breeding. By the late 1890s, eugenics as a scientific idea crossed the Atlantic and found support in U.S.-educated society frightened by the radical changes in society brought about by economic transformations caused by industrialization and the cultural disruptions caused by new waves of immigration from southern and eastern Europe and the migration to the North of newly freed slaves from the South.

Amid these social upheavals, the fear of racialized Others was fueled by associations of race with genetic degeneration and disease. Medical historians and anthropologists define degeneration as losing properties of the genus. The fear of the loss of this generative force encouraged typological as well as physical and biological speculation and, in doing so, supported unscientific stereotyping of many human differences. As a result, degeneration became a compelling racial metaphor such that certain races were assumed to be intrinsically degenerate and, as a result, could never be improved in any way. Because racial biology was a science of boundaries between groups, the threat of degeneration was seen to occur when boundaries were crossed and certain races found themselves "out of place." This definition was extended to describe the urban poor, prostitutes, criminals, and even the insane, who were now also seen as a "race apart."

By hinting at the imminent possibility of social decay if these degenerate "bodies" were not brought under control, the segregation of race was regarded as a necessity because maintaining biological distance was critical to preventing degeneracy. This fear of degeneracy was attributed not only to nonwhite populations (e.g., African Americans, Mexican Americans, Chinese Americans, and Native Americans) but also to lower-class white populations. Fearing that lower-class whites may overpopulate the nation and weaken the superior stock of the dominant race, eugenicists deemed it necessary to "purg[e] the blood of the American people of the handicapping and deteriorating influences of defective anti-social classes" (Jackson 2000). Scholars have described this eugenic practice as "a white-on-white racial discourse" that required that whiteness be purged and sterilized until anyone who disrupted the social order was eliminated. Like degeneracy, disease was also something to be feared, especially when it was seen as the very embodiment of racial difference. Thus, for example, the travel memoirs of Mark Twain's *The Innocents Abroad or the New Pilgrim's Progress* have been interpreted as equating the Jew with disease and death. In Mark Twain's travel writing, the Jew was represented as illness incarnate. Since Jews were seen as intransigent to the assimilation process because they clung to their language, customs, dress, and habits, the

Jewish body was read in generalized terms as immutable, and by extension, what was translatable was his or her immutable relationship to disease, pathology, and death. Physically, Jewish bodies were described as repellant with "big heads, big mouths, everted lips, protruding eyes and bristle eyelashes, large ears, crooked feet, hands that hang below their knees and big shapeless warts or are otherwise asymmetrical and malproportioned in their limbs" (Twain, quoted in Gilman 1995, p. 107). In other words, the Jew's disease was written on his or her skin.

The association of degeneracy and disease with racial difference also translated into an attribution of diminished cognitive and rational capacities of nonwhite populations. Disability-related labels such as "feeblemindedness" and "mental illness" were often times seen as synonymous with bodies marked oppressively by race. As a result, the presumption of an inbuilt biological inferiority was seen to be both the cause and result of degeneracy. The most terrifying aspect of such biological deterministic ascriptions was that they attributed to nonwhite populations of African Americans, Native Americans, Mexican Americans, Chinese Americans, and Jewish Americans a shared incapacity to assimilate into dominant society—characteristics that eugenicists described as biological rather than cultural. Fearing that such characteristics could be passed down from generation to generation and further pose a threat to the dominant white race, "protective" practices such as forced sterilizations, rigid miscegenation laws, residential segregation in ghettoes, barrios, reservations and other state institutions, and sometimes even genocide (e.g., Holocaust) were brought to bear on nonwhite populations. Thus, disability studies scholars have pointed out that in an attempt to regulate and control differences seen as disruptive to the "natural" order in society, violent schemes were developed to expunge undesirable biological variations that were identified as uniquely racial.

Although the above discussion clearly designates the intricate interconnections between the social constructs of disability and race, it is this discussion that also foregrounds the real tensions between racialized and disabled bodies. Race theorists have critiqued eugenics as a racist science that falsely attributes racial differences as examples of biological defect. By doing so, disability studies scholars point out that race theorists run the risk of achieving "'liberation' from dehumanizing constructs by distancing people of color from their association with the bearers of 'more real' (or material) biological incapacities [i.e., disabled people]" (Mitchell and Snyder 2005). Such a project, contends disability studies scholarship, fails to recognize eugenics as a transnational ideology that used the social category of disability to produce constructs such as IQ (intelligent quotients) and practices such as institutionalization, sterilization, segregated education, and restrictive immigration policies that had detrimental effects not only on persons of color but also on disabled people—all of them grouped under the limited but all-encompassing heading of "defect." By regarding the category of "defect" not as a biological given but instead as a social construct invoked so as to regulate, control, and eradicate difference, scholars in both areas of race theory and disability studies can more effectively expose the oppressive violence enacted against humanity that was inspired by the eugenicists' worldview.

In addition, disability studies scholarship has described the trans-Atlantic cultural exchange in discourses of race in the early twentieth century as the "Eugenic Atlantic" in an attempt to demonstrate the parallels between race and disability as dehumanizing ideological practices that have had devastating material effects on both populations. Some disability studies scholars are critical of how most academic discussions of eugenics dedicated to the engineering of a "healthy" body politic have failed to describe disability as a social category that was "the hub that gave the entire [eugenic] edifice its cross-cultural utility." Thus, the use of term *Eugenic Atlantic* is instrumental in describing how "*the discourse of disability functioned in a diasporic manner*" in the transnational phenomenon that was eugenics and, as a result, permitted scientists and other professionals both in Europe and North America to justify oppressive social, political, cultural, and economic policies based on the argument that racial difference represented pathological defect.

THE ENFREAKMENT OF POPULAR CULTURE: DISABILITY AS RACIST DISCOURSE

Disability's central role as the ideological discourse deployed so as to legitimate racist oppression in the early twentieth century via the practices of colonialism and slavery was played out on hundreds of stages across the country in the form of freak shows. It was at these freak shows that race and disability were brought together via the creative, dishonest, and exotic maneuverings of opportunistic show managers. Scholarship on the U.S. freak show meticulously records the chicanery rampant in these shows where disabled people of color, especially those with mental retardation from other parts of the world, were exhibited in the exotic mode as "savages" and "cannibals." These studies cite several examples of occurrences such as the "Wild Australian Children," who were the African Americans Tom and Hettie, severely retarded microcephalic siblings from Circleville, Ohio; the "Wild Men of Borneo," who were Hiram and Barney Davis, listed in court records as "dwarfs" and "imbeciles" who came from a working-class farming family in Ohio; the "Last Ancient Aztecs of Mexico," who were El Salvadoran peasant children, Maximo and Bartola, bought by a Spanish trader on account of their "dwarfish and idiotic appearance"; and, perhaps the most famous of all, the "What is it? or The Man Monkey!" exhibit, who was William Henry Johnson, an African American from New Jersey with microcephaly.

Other freak show scholarship defines the public's encounter with the "freak" as one where the audience crosses both corporeal and psychic boundaries to experience the terror and the excitement of coming face-to-face with examples of "monstrous" humanity while being reminded of the "unbearable excess that has to be shed to confer entry into the realm of normalcy" (Adams 2001). If this is the case, it is possible to see the significant role that freak shows played in the ideological construct of racial discourses when the exhibits just described as both disabled and racially marked were exhibited as subhumans, cannibals, and savages. To give credence to these racist mythologies, disability studies scholars describe how show managers designed publicity materials, stage settings and props, and a colorful commentary to advertise and exhibit the exotic aspects of their exhibits while contributing to racist knowledge by linking race, disability, and subhumanness all together.

For example, publicity materials for the American Museum, responsible for exhibiting Johnson as the "What is it? or the Man Monkey!" took advantage of the public's interest in the relation of humans to primates to describe Johnson as the connecting link between human and ape. Foregounding his physical features that were a result of his microcephaly, Johnson's "keeper" is quoted as saying, "The formation of the head and face combine that of the native African and of the Orang Outang . . . he has been examined by some of the most scientific men we have, and pronounced by them to be a CONNECTING LINK BETWEEN THE WILD NATIVE AFRICAN AND BRUTE CREATION." Thus, one can see how freak shows drew on scientific discourses of disability, the racial politics of the era, and fears of a public steeped in eugenic thought to produce a discourse that justified and thereby propagated race and disability inequality.

Because persons of color were often seen to dominate freak shows, it is often assumed that a predominantly white audience was attracted to these shows to encounter the deviance of the racial freak. This was not always so. On the other hand, these shows were mostly frequented by populations who were otherwise disenfranchised in U.S. society and who derived some comfort from the sight of Other bodies radically different from their own. Other scholars point out, however, that encountering the freak show produced not just the repudiation of difference but sometimes a painful identification with the object of difference—the Freak. Thus, disability studies reports that when African American audiences came face-to-face with "Ota Benga: The Pygmy in the Zoo," they were faced with "the monstrosity of U.S. racism embodied in the spectacle of a black man in a cage." It is narratives such as these that demonstrate the very painful relationship between race and disability for African Americans, in particular, and people of color, in general.

RACIALIZED SUBJECT AS DISABLED CITIZEN: THE DISCIPLINARY PRACTICES OF THE NATION-STATE

Likewise, some critical race theorists have argued that for a nation to be itself, it has to be perceived as racially and culturally pure. Thus, to come into being, the nation-state embarks on an obsessive imperative of setting up a "stigmata of exteriority and impurity" and, in doing so, produces a double-edged racism—a racism of extermination to purify the social body from the dangers of inferior races (an exclusive racism) and a racism of oppression and exploitation to hierarchize and partition society (an internal racism). What these studies do not explicitly say is that, once again, the category of disability is deployed by the nation-state to police its borders to keep "unfit" immigrants from entering and to control "unfit" citizens who are seen as a threat to the nation-state.

For example, the nation-state supported immigration laws and regulations that drew on discourses of disability by requiring checks on the mental competencies of newer immigrants. Thus, scholars describe how immigrants were faced with batteries of tests at Ellis Island, in an effort to screen for "mental defectives." Similar practices have been reported in Canada, where immigration policies drew on the profession of psychiatry and invoked concepts such as lunacy and idiocy to exclude certain categories of citizens to maintain a more "sanitized" Canadian society. That these practices are not just historical but have contemporary relevance is apparent in Richard Herrnstein and Charles Murray's (1994) book, *The Bell Curve*, which recommended that immigrants be allowed into the country based on an IQ test. Critical of the 1965 Immigration Act that allowed previously excluded immigrants into the country to be unified with their families, Herrnstein and Murray argue that immigration should not be based on what they call nepotism but on competency. Herrnstein and Murray's arguments could be dismissed as the surviving relics of eugenic practices of the past that are now no longer in vogue, but recent policies related to immigration belie that claim. Thus, for example, Proposition 187, which denies vital and legally guaranteed services to anyone suspected of being an illegal immigrant, was passed with overwhelming support in California and funded by a foundation that backed race-based intelligence research. In the most recent election of November 2004, Arizona passed a similar bill that was on the ballot. Thus, once again, it is possible to see that social categories of race and disability are deployed together to police the boundaries of the nation-state.

Birth control is another example of how the ideological category of disability is deployed by the nation-state in its attempts to police the bodies of its racialized citizen-subjects in very intimate ways. At the height of the eugenics era, the state, drawing on eugenicist fears of the deterioration of the Caucasian race, sought to control the reproductive capacities of those it deemed "deviant" and therefore dangerous. Thus, in the early twentieth century, a large number of poor white people, along with Native Americans, Puerto Ricans, Chicanas, and African Americans, were forcibly sterilized in an era that was obsessed with issues such as "racial hygiene" and the spread of "feeblemindedness." While overt sterilization of these populations is no longer in vogue today, several scholars have argued that new discourses, such as "gene therapy" and "health care rationing," and new birth control technologies, such as Norplant and Depo-Provera, are imposed mostly on poor women of color on welfare who, because of their "dependency," are deemed to be unfit for reproduction. Thus, even though birth control drugs such as Depo-Provera were banned in 1978 because of the side effects, which included cancer, long-term sterility, and osteoporosis, to name a few, Depo-Provera reappeared in the late 1980s and was still being prescribed by doctors to poor women of color in cities and to Native American women living on reservations. In addition, current scholarship cites an early 1990s report on HIV-positive Haitian women held at the naval base at Guantanamo Bay being forced to choose between Depo-Provera or permanent sterilization while in captivity.

But the nation-state not only justifies its control of its citizens of color by deploying the category of disability; it also contributes to the construction of disabled citizens of color. In both urban and rural United States, for example, poverty conditions, lack of access to affordable health care, rampant unemployment, and violent neighborhoods contribute to the onset of disability in communities of color living below the poverty line. In addition, working-class communities of color, especially migrant workers—many of whom are considered undocumented immigrants—labor in factories, sweatshops, and nursing homes where wages are low and where working conditions can create disabilities. Moreover, in the armed forces, where many poor and working-class people of color enlist, deployment in a war also produces disability. In each of these contexts, then, there exists a population of disabled people of color who were either born with a disability or acquire a disability during their lifetime and who are therefore forced to negotiate double oppression on account of both their race and their disability. This experience of double oppression has been especially well documented in the United Kingdom by disabled scholars of color. In each of these accounts, what is often foregrounded is that their oppression, on the basis of disability, is often compounded by their racial affiliation in areas such as employment, access to culturally responsive services, and resources. Sometimes, they have even experienced social and cultural marginalization in both their racial/ethnic as well as disability communities. It is in such contexts that the need to examine race and disability in dialectic relationship to each other becomes a necessity for survival.

SPECIAL EDUCATION AS RACIAL GHETTO: THE DIALECTICS OF RACE AND DISABILITY

The dialectical relationship between race and disability is clearly foregrounded in the specific context of education. Advocates for the inclusion of persons marked by race and/or disability in educational contexts have drawn on similar philosophical and constitutional arguments to frame educational policies that support this inclusion (e.g., *Brown v. Board of Education* [1954] and the Education of All Handicapped Children's Act of 1975, now renamed the Individuals with Disability Educational Act [IDEA] of 1990). More recently, race and disability have once again reappeared together on the educational stage in recent court cases (e.g., *Lee v. Macon Board of Education,* Alabama), in which critiques have been made regarding the overrepresentation of minority students in segregated special education classes. This, however, is not a recent phenomenon. As early as 1968, educational research pointed out that nearly 60 to 80 percent of students labeled mildly mentally retarded were from "low-status backgrounds" and included African American, Latino, and Native American children. Nearly 20 years later, in the Woodstock Report of 1993, F. D. McKenzie, a former superintendent of schools in the District of Columbia, observed that although African American students made up approximately 16 percent of the school population, they made up 35 percent of the students assigned to special education classes.

This overrepresentation of students of color in special education classes can be accounted for in different ways. Recent scholarship has described how the predominance of asthma and lead poisoning among poor children contributes to neurological damage that manifests itself as mild disabilities and behavioral disorders in schools. In terms of race, 36.7 percent of African American children compared to 17 percent of Latino children and 6.1 percent white children have been identified as experiencing lead poisoning. Such statistics point to environmentally induced damage that is a direct result of inadequate housing, health care, clean air, and other basic necessities. Students of color also get banished to alternative schools (special education programs for students identified as "behaviorally disordered" or "emotionally conflicted") as a result of the new zero-tolerance policies that were put into place after the slew of school shootings by white students in middle-class suburbs in the United States. Ironically, once again, students of color, especially African American and Latino males, were the ones most often disciplined as a result of this law. According to a study undertaken in 2000, when all socioeconomic indicators are held constant, African American children were noted as being suspended and expelled at much higher rates than white students within the same schools. In both examples, what becomes apparent is that students of color are increasingly "pathologized" in schools—a practice that has become a lucrative business where professionals interact with these children armed with a battery of tests, boot camps, and other behavior management programs that are more profitable to the professionals than to their clients.

George W. Bush's plan for education, which claims to "leave no child behind," furthers supports the oppressive relationship between race and disability. One important aspect of the Bush Education Plan is Project Sentry, whose main goals are to identify, prosecute, punish, and supervise juveniles and to empower teachers to remove violent and disruptive students from the classroom. Such policies draw on philosopher Louis Althusser's concept of "interpellation"—where *interpellation* is the process by which individuals (subjects) are inserted into practices governed by the rituals of ideological state apparatuses (ISAs) such as schools. Thus, it could be argued that schools use the logic of disability to "interpellate" students of color into "disabled" subject positions that marginalize them in both educational and social life. In other words, understood in a racialized context, special education programs become the most effective way of disciplining, regulating, and controlling students of color and teaching them their places within a racial and class hierarchy. By bringing into line through special education those who comply with ideological mandates, as well as by excluding and containing those who insist on staking their claim for recognition as human beings, these policies become the most effective way of supporting the *racialization of disability* and the *disabilization of race* in the ghettoes of special education. Thus, it is in the interests of theorists working on race and disability to continue to pursue collective deconstruction of social categories of difference to ensure their collective empowerment.

—Nirmala Erevelles

See also Eugenics; Freak Show; Race, Disability, and Special Education; Racism; Stigma.

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RACE, DISABILITY, AND SPECIAL EDUCATION

The long-standing and problematic relationship between race, disability, and special education continues to be evident in the disproportionate placement of students from racial and ethnic minorities in special education programs. Landmark legal cases such as *Diana v. State Board of Education* (1970) and *Larry P. v. Riles* (1971–1979) challenged biases inherent in standardized testing procedures used to identify students as eligible for special education. In *Diana,* a class action suit was filed on behalf of nine Latino/Latina children who were forced to take an individually administered IQ test in English and, as a result, were classified as EMR (educable mentally retarded). Interestingly, when retested by a Latino examiner, only one of the nine children was classified as EMR. In a similar suit, *Larry P.,* the overrepresentation of minority children in EMR classes throughout San Francisco, was determined to be due to educational practices, including teacher bias. Both cases illuminated the role of school personnel, tests, and testing practices in erroneously labeling students of racial and linguistic minorities as disabled and placing them in segregated special education classes. These legal cases demonstrated how special education, like ability tracking, served as a mechanism to resegregate classrooms after the historic *Brown v. Board of Education* (1954) ruled that racially segregated schools were unconstitutional.

These cases drew attention to the ways that special education labeling and placement decisions reflected stereotypic beliefs about white intellectual superiority. Both *Diana* and *Larry P.* called into question the widespread use of "scientifically" objective measures to gauge intellectual ability. The intelligence quotient (IQ) score that had once been viewed as measuring innate, fixed, unidimensional, and naturally distributed "ability" along racial and class lines would now be cast in a different light. As a result of these cases, it became increasingly clear that evaluation instruments and their use falsely reinforced presumed intellectual hierarchies among racial and ethnic groups. Although tests continued to be seen by many as relatively neutral and valid, others came to view standardized tests as forms of institutionalized racism, based on cultural and linguistic biases and norms and predicated on the supposedly universal values and experiences of American, white, middle-class citizens. Because the special education eligibility process typically begins with teacher referral, the widening racial imbalance between the teaching corps and an ever-more diverse population of public school students remains a concern. Recent reports show that 90 percent of public school teachers in the United States are white, while 40 percent of public school students in the United States belong to racial/ethnic minorities. Because cultural, social, class, and linguistic biases often influence teacher perceptions of students' ability, students from racial/linguistic minorities continue to risk having their differences pathologized when measured against exclusionary and ethnocentric norms and standards.

Despite reforms, a disproportionate number of students from racial, ethnic, and linguistic minorities continue to be placed in special education classes. Since the early 1970s, the U.S. Office of Civil Rights (OCR) has reported a persistent problem of minority children being overrepresented in *certain* disability categories. Specifically, racial disparities are highly pronounced in categories requiring specialized clinical judgment. These categories include Mental Retardation (MR), Emotional Disturbance (ED), and Learning Disability (LD). Thus, "invisible" and more subjective disabilities of a cognitive and/or social nature are overly ascribed to racial and linguistic minority students, while less subjective categories such as blindness or deafness are ascribed proportionately to all student groups. In other words, overrepresentation is much more pronounced for more subjective special education labels than in diagnoses that are more obvious or objectively determined.

The most recent government reports reveal that although blacks constitute 14.8 percent of the population, they represent 20.2 percent of all students in special education. Black students remain three times as likely to be labeled MR as white students, two times as likely to be labeled ED, and almost one and a half times as likely to be LD. In fact, black students remain the most overrepresented of all groups in 10 out of 13 disability categories nationwide. Among these categories, MR remains most likely to be assigned to black male students. Furthermore, black students who attend school in wealthier communities are more likely to be labeled MR and assigned to segregated classes than those attending predominantly black, low-income schools. Thus, depending on context, both social class and racial biases can increase the risk of minority children being labeled and placed in segregated classrooms.

The category of LD has also been deeply implicated in the problem of overrepresentation. The label, which emerged during the 1960s, characterized a student with LD as having average or above-average intelligence, specific rather than generalized deficits, and a cultural/familial background unrelated to the academic difficulties experienced in school. This category became associated with white students to such a degree that students of similar levels of achievement were given different labels along racial, ethnic, and class lines. In fact, in the first 10 years following the emergence of the category (1963–1973), the vast majority of students labeled LD were white middle-class boys. Because students were placed in separate classrooms according to their label/disability category, special education became as racially segregated as general education had become with the practice of "ability" tracking.

In states with high Latino/Latina or Native American populations, these students are more likely to be overrepresented in special education.

Data on Latino/Latina students are complicated by the fact that they tend to be underidentified for special education in elementary school but overidentified in high school. Furthermore, students who are English language learners (ELL) or labeled limited in English proficiency (LEP) are overrepresented in special education, especially in the upper grades. Once labeled, minority students are educated in more restrictive/segregated placements in comparison to their white peers. An exception to this trend is the underrepresentation of Asian American students with disabilities. Stereotyped as the "model minority," Asian students are far less likely to be labeled in subjective categories of MR, ED, or LD than any other minority group. Further research is needed to determine if there are within-group differences, especially among newly arriving Asian immigrants, or if there are differences in schools with and without English as a second language (ESL) classes.

Inappropriate classification of racial/ethnic/linguistic minorities for special education leads to lowered achievement and poor postschool outcomes. Students in segregated special education classrooms are denied access to the general education curriculum and their typically developing peers. Often, the instruction provided in segregated classrooms results in poor transition outcomes after the child leaves school. Finally, the child is more likely to experience lowered teacher expectations as a result of being labeled. These factors combine to negatively affect the academic performance of students of color who are labeled disabled, who have higher rates of suspension, face more severe disciplinary actions, and experience a higher dropout rate compared to their white and/or nondisabled peers. It has been documented that failure to obtain a high school diploma further restricts occupational opportunities and leads to the increased likelihood of poverty. These problems are not diminishing but rather are starting earlier with children from economically poor, black, or Latino/Latina families being labeled with the ill-defined "at-risk" category even before they enter school.

Although many have suggested that socioeconomic status accounts for some or even all of the racial disparities in special education identification, the problem cannot be explained by any one factor. There remain large variations within district-to-district and state-to-state levels of overrepresentation in special education, suggesting that the degree of overrepresentation is affected by many variables and contexts. Southern states, for example, continue to have some of the highest incidents of disproportionality, regardless of social class, suggesting that overrepresentation is connected to a longer legacy of racial segregation. Moreover, there are substantial within-group differences, in terms of gender and age of diagnosis. Black females, for example, are less likely to be overidentified than black males but more likely to be labeled than white females and males. In addition, when language is taken into consideration, Latino/Latina students who are learning English are much more likely to experience overrepresentation. Such within-group differences point to an urgent need for more sophisticated research methodologies to fully understand the relationship of race, disability, and special education. Finally, in this era of high-stakes testing, we must also consider how many of our current educational practices are serving as tools of social control and exclusion rather than as tools of social transformation and democracy.

—Beth A. Ferri and David J. Connor

See also Learning Disability; Race and Ethnicity; Special Education.

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RACIAL HYGIENE (*RASSENHYGIENE*)

The German concept of "racial hygiene" was the predominant term for *eugenics* until the end of the

Third Reich (1933–1945). It comes from physician Alfred Ploetz (1860–1940), who founded the Deutsche Gesellschaft für Rassenhygiene (German Society for Racial Hygiene) in 1910, the main organization of the racial hygiene movement. It committed itself to the introduction of eugenic measures such as marriage bans, forced institutionalization, and sterilization of the supposedly hereditarily ill, alcoholics, and criminals. German racial hygiene, which presents a specifically radical variant of eugenics in comparison to international development, is rooted in racial anthropology. This approach influenced German eugenics/racial hygiene considerably. The French aristocrat Joseph Arthur de Gobineau (1816–1882) formulated the basic ideas of racial anthropology. He started from the assumption that only white, Aryan, Germanic, or "Nordic" races are culturally constructive; all other races are culturally destructive. Racial anthropologists were convinced that racial differences are objective facts. Skull measurements and the diagnosis of other bodily characteristics established so-called racial types, such as the white, black, red, or yellow race. Specific cognitive and spiritual qualities were attributed to individual races. Racial anthropologists believed that miscegenation would lead to the inevitable downfall of the Volk. A strongly hierarchically organized social model was therefore designed in which the upper strata of society dominated as the noblest race. Selection, the battle for existence, and measures against degeneration promoted the "Nordification" (*Aufnordung*) of the race. Racial anthropological approaches pushed forward nationalist thinking and were connected with an extreme anti-Semitism. Main representatives of this extreme line of thinking were engineer Otto Ammon (1842–1915) and doctor and philosopher, Ludwig Woltmann (1871–1907).

Racial anthropology gained influence in Germany before and during World War I in nationalist circles and also determined the eugenic/racial hygiene movement of the Weimar Republic. With their seizure of power in 1933, the National Socialists fell back on a multitude of already existing eugenic, racial hygienic, and racial anthropological proposals for the improvement of the *Volkskörper* ("body of the Volk"). In 1931, the Nationalsozialistische Deutsche Arbeiterpartei (NSDAP) (National Socialist German Labor Party) became the first party in Germany that incorporated racial hygienic thinking into its political program. It strove for a rapidly growing population that consisted of "racially pure," "hereditarily healthy," "Aryan," and productive individuals. To achieve this, the carriers of "foreign" blood should be eradicated. "Foreign" for the National Socialists included those who carried either "hereditarily" or "racially" so-called inferior blood. Many laws were enacted to fulfill these objectives. Already in July 1933, the *Gesetz zur Verhütung erbkranken Nachwuchses* ("Law for the Prevention of Hereditarily Diseased Offspring") was passed, which, in contrast to the drafted sterilization law of the Preußische Ministerialverwaltung (Prussian Ministry of Administration) from 1932, provided for compulsory sterilization. In November 1933 came the *Gesetz gegen gefährliche Gewohnheitsverbrecher* ("Law Against Dangerous Habitual Criminals"), which allowed not only the sterilization of repeat offenders but also the castration of sex offenders. In total, about 400,000 people were forcefully sterilized by 1945, more than in any other country in which a sterilization law existed. In addition, from the beginning, National Socialist politics were focused especially against Jews and gypsies. The first measures taken were the systematic destruction of the economic existence of the Jewish population and the racially biological registration of the Sinti and Roma (gypsies), who were confined in work camps as so-called asocial people and often also sterilized. In 1935, various laws followed that forbade marriage between *Deutschblütigen* (those of "pure" German blood) and Jews, as well as between the "hereditarily diseased" and "hereditarily healthy." In *Beratungsstellen für Erb- und Rassenfragen* (advice centers for heredity and race questions), hereditary and racial "inferiors" were identified. In this way, essential preconditions were put into play, leading to the Holocaust of the Jews and the "euthanasia" action on disabled people.

—Volker van der Locht

See also Eugenics; Eugenics: Germany; T4 Program.

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RACISM

Racism remains, in many minds, a term whose ultimate definition is but vaguely understood. Identification of absolute instances of racism is still contested in scholarship and public discourse much in the way that charges of ableism (or disableism, in some vocabularies) now often prove hotly contested. However, an examination of the development of racism can also demonstrate that a history of systemic discrimination against people with disabilities develops in a somewhat parallel manner. In both cases, the discrimination faced by these populations (not to mention those who find themselves marked as racialized *and* disabled) functions in a much more pernicious manner than mere active group snobbery. Before we can parallel these types of oppression, however, a working definition of racism should be outlined.

Scholars have suggested that formalized racism can be recognized whenever the following conditions exist: (1) publicly sanctioned restrictions on a group's ability to participate in wider social rituals and institutions, (2) formalized segregation policies, (3) demotion to lower caste/class status of a majority of group members, (4) active circulation of propaganda that bolster perceptions of inferiority, and (5) the deepening of legal prejudice over time and, perhaps most important, fears of reproductive contamination. The latter point is key because formal racism—at least our own modern variety—operates as a social guarantee that race purity will be actively policed and maintained. Prohibition from reproductive participation (i.e., miscegenation or sterilization laws) erupts from a belief that one group of individuals represents a biological threat to the integrity of the species. In other words, rather than subordinating an entire group on the basis of faulty beliefs, such as in cases of religious bigotry, modern racism may be said to operate on the principle of in-built inferiorities that cannot be overcome. Such differences (particularly of a visible, physical nature) become a racist formation when characteristics that might be considered "cultural" become associated with innate (i.e., biological) features. This is the key linkage between racist and ablest beliefs—group-based inferiority appears indelible and biologically encoded.

Scholars of the history of racism have placed the origins of such practices somewhere in the fourteenth or fifteenth centuries—specifically, in early modern Spain, when religious intolerance gradually transformed into forms of body-based intolerance. While religious antipathy for another group expressed itself in persecution based on adoption of the wrong faith, there was little sense that such differences were intrinsic to a population's bodily constitution. The key qualifier here depends on the capacity of a despised population to assimilate (even theoretically) to the persecuting culture's status—either through rituals of conversion, renunciation, shifts in habits, ways of communicating, and so on. If members find a way to become integrated into the dominant community, then a racist system may not be operative. Of course, this also suggests that modes of assimilation are primarily cultivated through efforts by members of stigmatized groups to actively participate in the devaluation of their former culture's values, aesthetics, attitudes, practices, and so forth. In other words, the demands of assimilation require a stigmatized member to recognize his or her prior self as inferior. There is a hierarchy of communities that individuals learn to solidify and substantiate in the process of assimilation.

Yet, in the case of racism, such an avenue of escape is closed. Members of the stigmatized group find themselves positioned in an impossible coexistence with the dominant group—specifically, an existence that requires their simultaneous sequestration and subordination. In such a situation, segregated locations—such as reservations or custodial institutions—become a metaphor for the group's individual as well as collective predicament. Identity itself becomes fixed, and ethnic or racial differences cannot be mobilized beyond the boundaries of deviancy established by the enforcers of the norms. No transcendence of one's racial circumstances avails itself, and thus cultural differences transform into markers for inferiority itself. Thus, the superiority of one group is based on a subjective valuing of arbitrary qualities it associates with itself in contradistinction to another (i.e., pigmentation). The presumed characteristics of the marginalized group become synonymous with subjective values of undesirability.

Just as Carolinus Linnaeus sorted vegetation into particular species groups in 1735, he also classified human populations into distinct racial types. While this racial taxonomy was not delineated as hierarchical, the characteristics attributed to each population supported perceptions of northern European superiority. The practice of drawing distinctions based on biological characteristics began as early as the fifteenth century in campaigns such as the Spanish policy of requiring blood certificates (or *limpieza de sangre*), where ethnic belonging became increasingly biologized. Such efforts, not coincidentally, paralleled the rise of modern nation-states, where connections began to be drawn between the attributes of individual physiology and the nation's body as a whole. In each of these cases, we witness the formation of investments in biological determinism where one's birthright preordains some members to increased social status; others inordinately comprise the lowest spheres of social hierarchy—including economic immobility and lack of access to influential social institutions. Thus, the Enlightenment arrived replete with ideological investments in "proving" that social hierarchies exist due to the in-built incapacities of some as opposed to the natural abilities of the fully enfranchised.

While formalized racism has been reported to exist on the basis of group-based limitations that cannot be overcome, physical, sensory, and intellectual differences—often designated today as disabilities—also began to serve scientific systems of differentiation. No longer did those labeled "deviant" exist within relatively amorphous groupings such as the "monstrous," the "crippled," or as "fools," but rather the eighteenth century oversaw the rise of individuated human taxonomies. Debates over the relationship of racial characteristics as environmentally produced effects of climate and geography ultimately lost support in the wake of more biologically determinist models. Thus, human divisions, as expressed in Linnaeus's racial classifications or in the arguments against polygenesis (the development of separate, distinct bloodlines across racial groups) offered by Blumenbach in 1771 and others later in the century, laid the groundwork for discriminatory beliefs about bodies/minds designated as inferior. Consequently, one can witness the parallel cultivation of empirically based hierarchies based on racial, ethnic, and functional identifications in this period. In all cases, a group's failure to thrive socially came to be increasingly associated with in-built insufficiencies rather than cultural inequalities.

Even within the most liberal schemes of their day, those identified as possessing inferior anatomies were used to justify "progressive" science. For instance, single bloodline arguments that situated all peoples as participating in a shared human origin (usually placed in Africa) positioned racial (i.e., "savage") and disabled (i.e., "feebleminded") populations as "proofs" of common human ancestry with animals. In *Descent of Man* (1871), Darwin, the great champion of shared species origins, employed racialized and microcephalic populations as key evidence of primordial "arrested development" in his influential, mid-nineteenth-century theory of evolution. Likewise, his cousin, Sir Francis Galton, coined the term *eugenics* (Latin for "good seed") by arguing that breeding practices in horticulture and animal husbandry could be applied to the artificial cultivation of superior races of human beings. In making such arguments, nineteenth-century science, particularly after the rediscovery of Mendel's recessive/dominant theory of inheritance, rejected a previous era's metaphorical investments in blood as a "carrier" of magical properties in favor of a more literal hereditary vehicle (i.e., germplasm and later genes).

Thus, the late nineteenth and early twentieth centuries increasingly paved the way for science to influence public policy with respect to restrictive legislation toward "flawed" biologies: Jim Crow–era miscegenation laws, marriage laws, coerced institutionalization, segregation, sterilization, and, ultimately, under German National Socialism, state-sponsored murder of disabled, sexually "deviant," ethnic, and racial populations. As historians of racism have argued, the great irony of such developments occurred with respect to "radical" social discourses of human equality and formal emancipation efforts to free marginalized populations from various forms of enslavement. Thus, racism, homophobia, sexism, and ableism all come to fruition as a "back-door" form of discrimination that undermines more egalitarian principles of "all *men* being created equal." The perpetuation of social inequalities, consequently, functions in tandem with scientific justifications of biologically based insufficiencies. The more we classify, the farther we seem to get from a realization of just societies. The history of racism helps to demonstrate—at least to this point—that empirically sanctioned differentiations between individuals and populations inevitably lead to more "modern" forms of inequality (i.e., ideologies and practices that sanction socially derived inequalities on the basis of biologically deterministic criteria).

Late twentieth-century arguments about the fiction of race have been recently championed as a reversal of such trends. If genetic variation between human beings is no greater than 0.01 percent, then investments in genes as the basis for population differentiation based on innate capacities may finally fail from lack of a true biological basis. However, given our modern predisposition for investments in differentiation inherited from the Enlightenment, new efforts to define a distinctive racial genome seem to renew, rather than undermine, biologically encoded distinctions across human communities. For instance, witness recent efforts to establish racial genome banks in order to sponsor a racially specific health care research industry. While science may have lost some ability to sponsor and steer state policy-making agendas since the heyday of eugenics, investments in empirical taxonomies of inferiority based on characteristics marked as racial and/or disabled still garner a great deal of sway over aesthetic and cultural value systems.

—David T. Mitchell

See also Eugenics; Race and Ethnicity; Race, Disability, and Special Education; Stigma.

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RAMABAI, PANDITA

(1858–1922)

Sanskritist and social reformer

Pandita Ramabai was a Sanskritist who earned the honorific "Pandita" from the male scholarly community of her time, an almost unique achievement. She travelled to Oxford to study medicine, but her health deteriorated, and impaired hearing prevented her from enrolling at medical college. Instead, Ramabai became an aggressive campaigner for the social uplift of women in India and established a home for child widows at Kedgaon. Ramabai embraced some Christian beliefs that she integrated with her personal selection from the ocean of Hindu faith and practice, thereby infuriating the orthodox of both religions. She started a mission organization with both Indians and Westerners working under her leadership, another scandalous arrangement in her time. A deaf widow who wanted to join the Kedgaon community had difficulty convincing Ramabai but eventually overcame her resistance and proved willing and competent at work and worship. Apart from her own substantial writings, there is a large hagiographic literature about Pandita Ramabai, in which her significant hearing impairment is almost entirely ignored.

—Kumur B. Selim

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RAPE

Rape is a sensitive and complex topic. A comprehensive discussion of rape must take into account the legal, medical, psychological, and emotional issues that result from this act. When exploring the experience of rape from the perspective of individuals with disabilities, the complexities increase, and several key issues emerge. One major problem is that numerous definitions permeate the literature for sexual violence, sexual abuse, sexual assault, and rape. While there is a sizable body of literature on rape and sexual abuse in the general population, there is very little literature on rape in the disability community.

The following discussion provides the reader with a better understanding of the issues surrounding terminology. In addition, it provides an overview of what is known about risk factors for rape in the disability community, as well as prevalence estimates of rape. The last section highlights gaps in our current understanding of rape and disability. Furthermore, it suggests directions for future research efforts. These include the benefits of using the social model of disability to understand how social and cultural forces negatively affect the abilities of disabled survivors of rape to move beyond this experience.

THE LANGUAGE OF RAPE IN DIFFERENT CONTEXTS

When attempting to understand rape, in any context, it is important to first identify the words used to represent this act, why they are used, and what they mean. This task is important because language has power, and the ways in which we use language give insights into the social and cultural meanings of behavior. Thus, the way terms such as *sexual abuse, sexual violence,* and *rape* are used gives us insights into how society views appropriate and inappropriate sexual behaviors within and across communities.

No formal definitions were identified in the literature for the term *rape* in a disability context. This is not to say that the term *rape* is never seen; rather, it is used as part of a larger discussion of sexual abuse. Within the disability context, rape is subsumed under the labels of *sexual violence* and *sexual abuse.* These definitions are critical for understanding how the intersection of rape and disability is interpreted across contexts (e.g., the legal system, the medical system, the social service system, and within a social network or societal context). One must also note that not only are definitions different, but the nature of the content is different as well. For example, a general definition of sexual abuse "includes molestation, incest, rape, prostitution, or use of a child for pornographic purposes" (*Columbia Encyclopedia* 2001). This definition provides a laundry list of inappropriate sexual behaviors but does not necessarily leave us with a better understanding of what sexual abuse means. A more useful definition for sexual abuse among individuals with physical disabilities comes from the Center for Research on Women with Disabilities. In this definition, sexual abuse is "being forced, threatened, or deceived into sexual activities ranging from looking or touching to intercourse or rape" (Cole 1984; Soeken et al. 1998; Nosek et al. 2001). When referring to individuals with developmental disabilities, sexual abuse has been defined as "occurring where sexual acts are performed on or with someone who is unwilling or unable to consent to those acts" (Brown and Turk 1992) or "being forced, threatened, or deceived into sexual activities ranging from looking or touching to intercourse or rape" (Young et al. 1997). "Sexual abuse of a person with learning disabilities can take place where that person's willingness is unacceptably exploited" is another definition that warrants inclusion in this discussion. This definition is useful in that it moves away from the complexities of consent. It acknowledges that while a developmentally disabled person may willingly engage in a sexual encounter, the act may still be abusive because of the motivation and position of the other person (McCarthy and Thompson 1996). However, from a disability studies perspective, it is troubling in that it seemingly negates a disabled individual's ability to consent in instances where he or she willingly participates in a sexual encounter that is not abusive.

Studies of sexual violence among nondisabled individuals distinguish between sexual abuse in childhood and sexual assaults and/or rape in adulthood. In studies of sexual violence among the disabled, this differentiation of terms does not occur. Specifically, in a disability context, *sexual abuse* is commonly used to describe sexual violence rather than *rape.* One possible explanation for this is the pervasive view of disabled individuals as childlike and powerless. Since sexual transgressions against children are defined as abuse, the able-bodied population perpetuates this usage for adults with disabilities. Another possible explanation for this misuse of terminology is that, like children, individuals with disabilities are viewed as asexual and undesirable.

The legal system offers definitions of two different types of rapes. The first type is simple rape, whereby the victim and attacker(s) have a prior relationship, there is a lack of force and resistance, and there is an absence of evidence corroborating the victim's account. The second type is aggravated rape, in which there is extrinsic violence, multiple assailants, and no prior relationship between victim and offender(s) (Estrich 1987). These distinctions become important in discussions of what happens within the legal system after a rape occurs.

Research conducted on rape within the general population shows that district attorneys are more likely to move forward in the prosecution of an aggravated rape than a simple rape. In cases of simple rape, societal attitudes about sexuality and promiscuity make successful prosecution difficult. In a disability context, the prosecution of simple rape is complicated further because of the societal misconceptions surrounding the sexuality and desirability of individuals with disabilities. In addition, able-bodied persons generally question the ability of a disabled person to consent to sexual activity and to act as a competent witness against the attacker.

THE STATISTICS OF RAPE WITHIN THE DISABILITY COMMUNITY

The overall prevalence of sexual abuse across the spectrum of disabilities is unknown. Research in this area suggests that women with disabilities are assaulted, raped, and abused at a rate two times greater than nondisabled women (Waxman and Wolfe 1999). According to the Centers for Disease Control and Prevention (CDC), the reported rates of sexual violence range from 51 to 79 percent against women with disabilities. When the discussion is limited to cognitively impaired individuals, there are wide variations in the reported prevalence rates of sexual abuse. For example, it has been suggested that women with developmental disabilities face a 68 to 83 percent chance of being sexually assaulted in their lifetime, a rate that is 50 percent greater than that for nondisabled women (Sobsey 1994; Waxman and Wolfe 1999). The CDC estimates that the reported rates for cognitively disabled individuals' lifetime experience of sexual violence range from 25 to 67 percent, which is significantly different than the aforementioned percentages. These variations result from differences in definitions of abuse, differences in populations sampled, and differences in research methodology (McCarthy and Thompson 1996). The discrepancies highlight the need for more research on this problem.

FACTORS PUTTING THE DISABLED COMMUNITY AT RISK

It is a common misperception that the disabled are not at risk of being raped. However, research has shown that disability is not a protective factor against sexual abuse. Rather, disability has been hypothesized to reduce an individual's emotional and physical defenses, making him or her more vulnerable to abuse (Nosek et al. 2001). Researchers have identified several factors that increase disabled individuals' vulnerability to sexual abuse, including dependency on others for long-term care, life in an institution, denial of human rights that results in perceptions of powerlessness, the perpetuator's perception of limited risk of discovery, the difficulty some survivors have in being believed, lack of education regarding appropriate and inappropriate sexuality, social isolation and increased risk of manipulation, physical helplessness and vulnerability in public places, and the emphasis on mainstreaming and integrating disabled individuals without evaluating their capacity to protect themselves (Andrews and Veronen 1993; Groce 2003). It has also been suggested that economic dependency greatly increases the risk of abuse among the disabled. Specifically, individuals with disabilities have fewer opportunities in the labor market than able-bodied individuals.

The overall lack of attention to the issue of abuse against the disabled by both violence and disability researchers has contributed to the invisibility and continuation of misconceptions regarding disability and victimization (Curry, Hassouneh-Phillips, and Johnston-Silverberg 2001). Moreover, while it is increasingly recognized among professionals that individuals with cognitive disabilities or mental illnesses are more vulnerable to sexual abuse and exploitation than the general population (Mansell, Sobsey, and Moskal 1998; Tharinger, Horton, and Millea 1990; Furey 1994), there continues to be limited recognition that the physically disabled are also at significant risk for being raped. For example, it has been suggested that the tendency for women with physical disabilities to be devalued by society is one reason that this group is not included in research on sexual abuse (Coleman 1997, in Curry et al. 2001). This assertion is indirectly supported by the fact that as recently as 2001, fewer than five studies examined the sexual abuse of individuals with physical disabilities (Curry et al. 2001).

Discussion regarding sexual abuse and the cognitively disabled focuses heavily on cognitively impaired individuals' ability to give consent and their competence to give evidence against their attackers. However, several dialogues are equally important and yet virtually absent from the literature. The first emerges from the recognition that discussions of disability and rape are specific to individuals within a disability category (e.g., physical or cognitive). There is little, if any, research that explores sexual abuse across disability types. This points to the need to explore what, if any, differences in service needs exist between physically disabled and cognitively disabled rape survivors. The second area that must be addressed is the identification of the emotional and psychological service needs of cognitively impaired individuals in the aftermath of rape.

GIVING VOICE TO RAPE SURVIVORS

The literature proves that we do not currently have a full understanding of disability and rape. Although sexual abuse and rape are increasingly recognized as significant problems for those with disabilities, research that gives a voice to the survivors of rape has not been conducted. The unique challenges that individuals with disabilities face in bringing charges against their attackers and accessing supportive services to assist them in moving forward with their lives are important topics that have been neglected. An integral piece to gaining understanding is a social model analysis of the intersection of disability and rape. A social model analysis lends itself to the identification and acknowledgment of social barriers surrounding rape: the barriers that isolate and impoverish disabled individuals and put them at risk for rape; the barriers to reporting rape; the barriers to prosecuting perpetrators of rape; the barriers to overcoming the physical, emotional, and psychological effects of rape; and the barriers to overcoming the shame and stigma that having been raped brings.

Proponents of the social model of disability view disablement as the consequence of society's failure to recognize and account for the differing needs of disabled people and to eliminate the barriers they encounter (Oliver 1996). One could also argue that society has failed to recognize that disabled individuals have significantly different risk factors for being raped. In addition, legal and social service systems are nearly impossible to negotiate for individuals with disabilities because they have different needs and abilities that these systems do not recognize. Therefore, a social model analysis challenges societal misconceptions about the disabled and calls for a better understanding of the rape experience within the disability community. The current lack of knowledge on this experience within the disability community denies rape survivors an opportunity to heal on multiple levels. First, it denies them the opportunity to find meaning through talking about their experiences. Second, it prevents them from accessing much-needed legal, medical, and social services following rape. Third, it prevents service providers from fully recognizing and understanding the barriers faced by this community in dealing with the experience of rape. Finally, this lack of understanding perpetuates the isolation of this already marginalized group of individuals.

Another crucial component of this analysis is the lived body experience of rape and disability. Throughout their lives, disabled people are routinely dehumanized by the medical system under the guise of correcting medical conditions and minimizing impairments. As part of this process, disabled individuals are forced to believe that they are not the experts on their bodies. Rather, it is the doctors and therapists who are the experts. This psychological framework, which leads many to try to escape their "deficient" bodies for normal ones, has significant consequences for the healing processes of disabled rape survivors. The reality of this statement is reinforced in the narrative of a disabled rape survivor. In the process of diagnosing her disability, she describes how she was accused of fabricating and exaggerating symptoms as a means of getting attention. The lack of support from family and the "experts" led her to question her authority over her body. Subsequently, while in college, she was raped. This experience, coupled with her lived body experience of disability, led to increased feelings of lack of authority over her body, which drove her to "escape" through drug use and other self-destructive behavior.

To truly understand the intersection of rape and disability, researchers must move beyond traditional research strategies that rely on surveys of service providers and family members of rape survivors. Specifically, researchers must engage in qualitative participatory research strategies that incorporate the experiences of disabled rape survivors in all aspects of the research design. It is only through the inclusion of those who have experienced both disability and rape that we can truly understand the experience.

—*Amy Paul Ward*

See also Child Abuse; Empowerment and Emancipation; Social Model; Violence.

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RAU, FEDOR ANDREEVICH
(1868–1957)

Director of the Arnoldo-Tretiakov School for the Deaf in Moscow

Fedor A. Rau was director of the Arnoldo-Tretiakov School for the Deaf in Moscow. He was also the founder of special education training at the university level and organized the first Russian congress on deaf education in 1910. From 1922 to 1948, he was the head of the faculty of deaf education in the Moscow

State Pedagogical University and the author of many textbooks and manuals for deaf schools, including the *ABC Book for Deaf Children* (1903).

—*Anna Komarova and Victor Palenny*

See also Natalja Aleksandrovna Rau.

RAU, FEDOR FEDOROVICH (1908–1977)

Speech therapy specialist

Fedor F. Rau was a professor at the Institute of Defectology (now the Institute of Special Education) and a speech therapy specialist. Together with N. F. Slezina, he developed the "concentric" method of speech therapy.

—*Anna Komarova and Victor Palenny*

RAU, NATALIA ALEKSANDROVNA (1870–1947)

Founder of a kindergarten for deaf children

Natalia Rau, Fedor Andreevich Rau's wife, founded the first kindergarten for deaf children in Europe in 1900. After 1917, she worked as an inspector for a deaf children's kindergarten. In 1922, she organized lip-reading classes for deafened and hard-of-hearing people. She wrote *Pre-School Education of Deaf-Mute Children* (1947).

—*Anna Komarova and Victor Palenny*

See also Fedor Andreevich Rau.

RAY, ISAAC (1807–1881)

Father of American forensic psychiatry

Isaac Ray was one of a handful of men in mid-nineteenth-century America who were largely responsible for establishing the first generation of public institutions specifically aimed at serving the mentally ill population. Along with his fellow asylum superintendents (e.g., Pliny Earle, Thomas Kirkbride, Amariah Brigham), Ray supported the early optimism about the curability of insanity if individuals were housed in specialized hospitals carefully constructed along specific architectural plans, supported with generous funding by the state, supervised by a new class of medical professionals with expertise in mental illness, and handled according to the latest principles of "moral treatment." For 20 years, Ray served as the superintendent of the Butler Asylum in Providence, Rhode Island. In 1844, he was one of 13 asylum superintendents to gather in Philadelphia and found the Association of Medical Superintendents of American Institutions for the Insane (now the American Psychiatric Association). Ray published numerous articles throughout his career that were intended for both an audience of asylum administrators as well as a more general readership of policy makers and influential philanthropists. Ray, who had a special interest and wrote extensively on the need for the reform of criminal insanity laws, is sometimes referred to as the "father of forensic psychiatry."

—*Philip M. Ferguson*

See also Institutionalization and Segregation; Mental Illness; Psychiatry.

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RECREATION

Recreation is any pleasurable activity that is freely chosen. It is an activity that diverts, amuses, or stimulates. It is an activity that refreshes and recreates, that renews health and spirits by enjoyment and relaxation. Recreation can be done alone or with others, it can be active or passive, and it can be artistic or athletic. Recreation has both intrinsic and extrinsic benefits.

Recreation is an important part of life for all people. It is a powerful force in people's lives. Recreation makes people feel good about themselves and helps people to stay socially connected to other people. Recreation is revitalizing and rejuvenating. Research shows that higher levels of involvement in recreation activities are associated with increased ratings of well-being and life satisfaction. Yet, people with disabilities are often less involved in recreation. Some people with disabilities do not have access because of a lack of exposure to and training in recreation settings. There are myriad reasons, but the fact remains that people with disabilities are involved in recreation less than their typical peers.

Recreation enhances self-esteem and the quality of a person's life as well as the ability to occupy one's free time in a socially valued and acceptable manner, which has a significant impact on where a person is able to live, whether he or she functions successfully in the community, and the quality of relationships that a person develops. Social and recreation experiences have the power to generate skills that can be transferred to work, housing, family relationships, and so on. Thus, recreation experiences can facilitate an individual's successful integration into other spheres of life.

In practice, there are three distinct types of recreation services. They include *inclusive recreation* (often simply called recreation), *special recreation* (sometimes referred to as specialized or segregated recreation), and *therapeutic recreation* (also called recreation therapy). Each will be described below.

INCLUSIVE RECREATION

Inclusive recreation includes pleasurable activities or experiences in naturally occurring environments alongside people with and without disabilities rather than in settings that only include people with disabilities. In inclusive settings, necessary accommodations and supports are provided to ensure that people with disabilities can be involved on as equal a basis as possible. Even when the disability is too severe to "level the playing field," some people with disabilities or their advocates may choose an inclusive recreation setting in which "partial participation" is allowed.

Including people with disabilities in the fabric of life strengthens the community and its individual members. Recreation in naturally occurring environments rather than in special, segregated settings can offer flexibility, choice, self-determination, individuality, and decision making. Inclusive recreation experiences encourage and enhance opportunities for people of varying abilities to participate and interact in life with dignity. The availability of inclusive recreation provides the right to choose from the full array of recreation opportunities offered in diverse settings and environments.

For inclusive recreation to be effective, necessary support, assistance, and accommodations must be provided. This support, assistance, and accommodation must be responsive to each person's needs and preferences. Types of support, assistance, and accommodations include but are not limited to qualified staff, adaptive equipment, alternative formats for printed or audio materials, trained volunteers, and/or flexibility in policies and program rules.

In addition, to facilitate inclusive recreation, environments should be designed to encourage social interaction, risk taking, fun, choice, and acceptance that allow for personal accomplishment in a cooperative context. All physical and programmatic barriers should be eliminated to facilitate full participation by individuals with disabilities.

Inclusive recreation means that all recreation programs are available to all people, regardless of ability level. Ensuring that all people have equal opportunity to participate in recreation activities of their choice can be difficult. A detailed, systematic procedure to facilitate inclusive recreation is outlined in the LIFE (Leisure Is for Everyone) materials and can be found in Bullock and Mahon (1997).

Not everyone believes that inclusive settings and experiences are the best for people with disabilities. Some believe that it is better for people with disabilities to participate in recreation activities alongside peers with similar abilities. In that case, there are many opportunities for recreation involvement in special or segregated settings.

SPECIAL RECREATION

Special recreation is the provision of recreation services and programs in settings only with other people with disabilities. Necessary accommodations and modifications are made to assist the person with a disability to enjoy the activity. Many of these programs occur in municipal parks and recreation departments. Examples of other special recreation programs/activities include the Special Olympics and Wheelchair Sports.

For those who believe that it is best for people with disabilities to be with other people of similar ability levels, there are special or segregated recreation opportunities. Many people believe that it is necessary to first learn skills and have experiences in separate settings and then move to inclusive settings. Others believe that requisite skills can and should be learned in inclusive settings. Whatever the belief, in the United States, it is required by law (Americans with Disabilities Act) that when separate recreation programs exist, there must be options for participation in regular, typical (inclusive) recreation as well. For example, a local parks and recreation agency can offer beginning guitar lessons open only to persons with severe mental retardation; however, any person with severe mental retardation must be allowed to participate in the regular guitar lessons alongside people without retardation, and appropriate accommodations must be made to facilitate participation in the regular (inclusive) setting. Most special recreation programs exist in municipal parks and recreation departments, YM/YWCAs, Boy and Girl Scouts, and similar programs. The Special Olympics is one of the best-known examples of a separate program.

There is another category of specialized recreation programs. These are competitive sport programs for people with disabilities, such as wheelchair sports, that are not available to people who do not have disabilities. Competitive sport for people with disabilities can be traced back to the 1870s in the United States with the beginning of sport programs for students at a state school for the deaf in Ohio. However, sport programs flourished following World War II as a part of the rehabilitation of disabled veterans in the United States and Europe. The disabled sport movement grew steadily and is now characterized by national and international competitive events, the best known and respected of which is the Paralympics, which is held in conjunction with the Olympics.

THERAPEUTIC RECREATION

Therapeutic recreation is the purposive use of recreation/recreative experiences by qualified professionals (therapeutic recreation specialists) to promote independent functioning and to enhance optimal health and well-being of people with illnesses and/or disabling conditions. Therapeutic recreation often occurs in hospitals and other treatment facilities.

Therapeutic recreation is founded on the basic premise that recreation has therapeutic value. Various researchers have found that recreation experiences can assist people to manage and reduce the impact of stressors in their lives, to cope with the transitions of aging, and to maintain overall physical and psychological health. The National Consensus Conference on the Benefits of Therapeutic Recreation in Rehabilitation (1991), funded by National Institute on Disability and Rehabilitation Research (NIDRR), found that recreation had therapeutic benefits in (1) physical health and health maintenance, (2) cognitive functioning, (3) psychosocial health, (4) growth and personal development, (5) personal and life satisfaction, and (6) societal and health care system outcomes (Coyle et al. 1991:353).

As therapeutic recreation has evolved over the years, several different models, or sets of assumptions and beliefs, have emerged. For example, the "medical model" is based on the assumption that growth and development are biological processes that occur in a predictable fashion, that there is a "normal" and an "abnormal" way to grow and develop, that health represents an absence of illness or symptoms, that illness represents a breakdown of biological processes, that the goal of treatment is the removal of symptoms of illness, and that the health care provider possesses the knowledge, expertise, and ability to restore the individual to a state of health.

Working within the medical model, the recreation therapist would take the role of the expert who determines the problems to be addressed, the desired outcomes of treatment, and the specifics of how the intervention will occur. The goal of the recreation therapist's interventions would be to remove or reduce the symptoms of the illness. The client's role would simply be to comply as closely as possible with the therapist's instructions and recommendations.

In contrast, a more "wellness-oriented" model is based on the assumption that growth and development are unique to each individual and occur in response to both internal biology and a supportive and nourishing environment; that "health" represents a full and optimal expression of the individual's capacities and uniqueness, that illness occurs in response to an interaction between internal and environmental conditions and represents a restricted or limited expression of the self, that the goal of treatment is to enable the individual to fully experience his or her own uniqueness and health, and that the health care provider cannot control the process of healing but rather can only support it.

The recreation therapist working within a wellness model would tend to take the role of a facilitator and supporter. The recreation therapist would collaborate with the client in defining the problem, the desired outcome, and the means of achieving that outcome. The client, rather than being asked to comply, would be asked to be essentially an expert on his or her own health and asked to join actively with the therapist in their common pursuit.

Historically, most recreation therapists have worked either in hospitals or long-term care settings. More specifically, most recreation therapists have worked in psychiatric services, physical medicine services, or nursing homes. Today, recreation therapists work in a broader range of environments, including inpatient health care (hospital) settings in many service areas, outpatient health care settings, schools, and community- or home-based contexts. These contexts are described in detail by Kraus and Shank (1992).

THE PROCESS OF THERAPEUTIC RECREATION INTERVENTION

The practice of therapeutic recreation encompasses a wide and varied spectrum of individuals, interventions, activities, and contexts. "Clinical process" in therapeutic recreation provides consistency—that is, regardless of the context or content of the intervention, recreation therapists follow a systematic sequence of assessment, planning the intervention, implementing the intervention, planning for transition, and evaluation to systematically document the outcomes of their interventions. These processes and activities maximize the likelihood that the services provided by the recreation therapist are individualized, purposeful, outcome focused, and, ultimately, effective.

Assessment is the first step undertaken by the recreation therapist because it sets the direction for the "purposeful intervention" by enabling the therapist to focus specifically on the strengths, needs, and health concerns of the individual being served. Assessment may be defined as a systematic process of gathering and synthesizing information about an individual and his or her world to determine the most effective course of intervention. Some assessments are standardized, while some are more flexible, allowing the therapist more latitude in how and when to administer them. Generally, it is recommended that more than one method or instrument be used to gain the most accurate and complete "sense" of the individual. An effective assessment will provide information about the individual's functioning at the beginning of the intervention, his or her desires and goals for intervention, and some possible ways to structure the intervention. It provides a "baseline" against which to measure progress and outcomes.

The planning phase (sometimes called "treatment planning," "individualized program planning," or "care planning," depending on the setting) is one in which the strengths, needs, and goals of the individual, as well as the expertise and contributions of the therapist, are organized into a coherent plan that maximizes the chance that the individual will reach her or his desired outcomes. This phase of the therapeutic recreation process is often as much an "art" as a "science," as it involves creatively and sensitively combining many elements of skill, timing, and relationship to achieve a positive and meaningful goal.

Many settings have particular guidelines or requirements for the development and formatting of intervention plans. In some settings, the recreation therapist will develop specific "recreation goals." For example, "the patient will be able to fish independently" is a possible recreation-based goal for an individual who has experienced a stroke and needs to master the use of adaptive equipment to continue his or her most valued recreation pursuit, fishing. In others, the recreation therapist will develop goals pertaining to aspects of functioning that are more generalized and are attainable through participation in recreation pursuits. For example, "the client will reduce perceived levels of stress through increased physical activity" is a possible goal for an individual who is experiencing symptoms of anxiety disorder.

The next phase of the therapeutic recreation process is implementation, or the actual delivery of services. Recreation therapists have a wide spectrum of options for their interventions, allowing them to tailor to the needs of the individuals being served. A significant portion of the recreation therapist's training is devoted to studying and mastering these intervention options. Interventions may be conducted one-on-one or in groups. Ideally, the needs and preferences of the client and the professional judgment of the therapist should drive the decision about how services are offered, and many times, a recreation therapist will have the opportunity to work with a client in both one-on-one and group contexts, as needed. Each modality has advantages and appropriate uses. One-on-one services allow for maximum flexibility in individualizing and contextualizing interventions and in truly moving at the client's own pace. They allow the therapist to devote all attention to the individual client, which may be important when a great deal of hands-on assistance is needed. Group interventions, on the other hand, allow for the development of interpersonal relationships and for the reinforcement and encouragement that arise from working together with a group of peers on a common goal or concern.

Services may be provided in a relatively segregated setting, as in a classroom or treatment center, or in an inclusive setting, as in a restaurant or movie theater. It is common practice in therapeutic recreation interventions to deliver interventions in both settings, in a sequenced manner, so that the client may receive instruction and rehearsal opportunities in the safety of the classroom but then will have the opportunity to master those skills in his or her natural environment, at first with support and then with increasing independence.

The next phase of the therapeutic recreation process is sometimes called *discharge planning* (in inpatient, residential, or medical model outpatient facilities) or *transition planning* (in educational contexts). It is a crucial part of the process that provides continuity, as it is the phase in which the individual and the therapist have the chance to look at what has been accomplished, what challenges will emerge in the future, and what supports are needed as the individual moves on to a more independent setting.

Ideally, transition planning should begin during, rather than at the end of, treatment, so that the client will have the opportunity to plan for and preferably visit or experience some of the settings that will be encountered in the next phase of his or her life. Comprehensive transition planning involves exploration of the places, persons, opportunities, and resources that will be part of the individual's life; exploration of the supports available; and identification of "next steps" for that person's development.

The final phase of the therapeutic recreation process is the evaluation of the effectiveness of the intervention. As discussed in the "planning" phase, the therapist does not wait until the end of the intervention to evaluate its effectiveness; rather, built-in mechanisms are already in place for evaluation or monitoring along the way. Various aspects of the intervention may be evaluated, depending on the requirements and needs of the setting, including attainment of identified goals, effectiveness of the intervention over time, satisfaction with services for clients and families, and cost-effectiveness of services.

CONCLUSION

There are increasing efforts to involve people with disabilities in recreation activities and programs. Whether it be inclusive recreation, special recreation, or therapeutic recreation, attention is being paid to the importance of choice to ensure individuality and dignity in the pursuit of pleasurable activity by people with disabilities. Within the recreation field, there is a recognition by professionals that extra efforts are required to ensure that people with disabilities have opportunities to be involved in activities and experiences that refresh, recreate, and renew health and spirits by enjoyment and relaxation of a full array of recreation offered in diverse settings and environments.

—Charles C. Bullock

See also Classification in Paralympic Sport; Exercise and Physical Activity; Paralympics; Sports and Disability.

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American Therapeutic Recreation Association, http://atra-tr.org

National Alliance for Accessible Golf, http://accessgolf.org

National Center for Physical Activity and Disability, http://ncpad.org

National Council on Therapeutic Recreation Certification, http://www.nctrc.org

National Therapeutic Recreation Association, http://www.nrpa.org/content/default.aspx?documentId=530

Special Olympics, http://www.specialolympics.org

Wheelchair Sports, USA, http://wsua.org

REFUSAL OF LIFE-SUSTAINING TREATMENT

A competent person has the right to refuse medical treatment, even when that treatment may be necessary to preserve the person's life or prevent serious illness or disability.

The right to refuse treatment stems from the right to control what is done to your body. This is sometimes referred to as the principle of self-determination or bodily inviolability. In the British common-law tradition, this is best illustrated by the law of battery, where it is said that the merest touching of a person's body without that person's consent is an actionable wrong. Similarly, in the American common-law tradition, it has been held most famously by Justice Cardozo in *Schloendorf v. Society of New York Hospital* (1914) that

> every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.

This common-law right to refuse treatment is also accepted in South Africa, Australia, New Zealand, and Canada.

A RIGHT TO MAKE AN UNREASONABLE DECISION

The right is so fundamental that a person's reasons for deciding to refuse treatment are not subject to review, no matter how objectively unreasonable the decision is. For example in the New Zealand case of *Smith v. Auckland Hospital* (1965), Justice Greeson stated that "an individual patient must, in my view, always retain the right to decline investigation or treatment however unreasonable or foolish this may appear in the eyes of his medical advisers." In Britain, Lord Donaldson, in the case of *Re T* (1922), stated that "this right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent."

In the American case of *Lane v. Candura* (1978), it was said that "the law protects [the patient's] right to make [his or] her decision to accept or reject treatment, whether that decision is wise or unwise."

The right to refuse treatment has other sources apart from the common-law principle of self-determination. In some cases, the right to refuse has been sourced in the common-law doctrine of informed consent or in rights to privacy. Constitutional guarantees of privacy and freedom of religion have also been found to support the right.

TYPES OF TREATMENT THAT MAY BE REFUSED

A person has the right to refuse all treatments, even minor or minimally invasive treatments that will preserve life. A commonly occurring example is the refusal of blood products, due to religious beliefs, such as those held by Jehovah's Witnesses and Christian Scientists.

People can also refuse artificial ventilation, resuscitation, and artificial feeding in circumstances where they will die without them. This position was accepted in Canada in *Nancy B v. Hotel-Dieu de Quebec* (1992), where the patient's right to refuse ventilation was held to be almost absolute. In *Bouvia v. Superior Court* (*Glenchur*) (1986), the Californian courts upheld the right of a cerebral palsy sufferer to remove a nasogastric tube that was keeping her alive. In *Blackman v. New York City Health and Hospitals Corporation* (1997), a competent 88-year-old woman who was on a ventilator and feeding tube was successful in seeking an order that all medical treatment being provided to her cease, barring treatment to alleviate pain.

Other examples of treatment that have been refused include operations to remove gangrenous limbs (see, e.g., *Lane v. Candura* [1978] and *In Matter of Quakenbush* [1978]) and the administration of psychotropic medication (*Fleming v. Reid* [1991]).

ADVANCE DIRECTIVES OR LIVING WILLS

It is possible to make a decision to refuse treatments that might be offered to you sometime in the future, when you may be unable to communicate a competent decision. Such decisions are most commonly referred to as *advance directives* or *living wills.*

In most common-law jurisdictions, advance directives can be made orally or in writing. To be valid, an advance directive must have been made by a competent person and must be specific enough to be able to be applied in the circumstances that have arisen. Ordinarily, clear and convincing evidence is needed show that the decision was based on an informed opinion and was intended to apply to the circumstances that arose. In addition, weight is also accorded to the question of whether the directive was made thoughtfully, seriously, and in circumstances free of the undue influence of others.

Many jurisdictions have also legislated for advance directives. Every state in the United States has advance directive legislation. Legislative schemes also exist in parts of Australia, and there are also moves toward introducing legislation in England and Wales.

LIMITATIONS ON THE RIGHT TO REFUSE TREATMENT

The right to refuse treatment is not absolute. The first limitation is that a patient be competent before his or her decision to refuse treatment is considered as binding.

The second limitation consists of public or state interests that may override a competent person's refusal. There are several situations in which the courts have upheld the state's interest in preserving life over the individual's right to refuse treatment. Among these are the interests of the state in compulsory vaccination (*Jacobson v. Massachusetts* [1905]), preventing children from becoming orphans when their parents are refusing treatment (*Holmes v. Silver Cross Hospital of Joliet* [1972]), and safeguarding the ethical integrity of the medical profession (*R v. Ashworth Hospital; ex parte Brady* [2000]). Over time, these state interests have become less likely to justify the overriding of a competent refusal of treatment.

Most troubling are those cases where the rights of pregnant women to refuse treatment are balanced against the state interest in protecting the unborn child. Earlier cases indicated that women could be forced to undergo procedures such as caesarian sections, if they were necessary to save the life of the unborn child (*Jefferson v. Griffin Spalding County Hospital Authority* [1981]). Later cases have shown a judicial reluctance to override the rights of competent women on grounds that it would be discriminatory to do so as it would severely limit pregnant women's rights of autonomy. This is the accepted position in many U.S. states and in the United Kingdom (*Re Fetus Brown* 689 [1997] and *St. George's Healthcare NHS Trust v. S; R v. Collins; ex parte S* [1998]).

The state's interest in maintaining order and discipline in prisons has also been used to override a prisoner's right to refuse treatment (including force feeding; see *Laurie v. Senecal* [1995]), but there is a wide variation in the types of rights enjoyed by prisoners across jurisdictions, and in some jurisdictions, it has been said that prisoners even have a right to die (*Reeves v. Commissioner of Police* [1999]).

The state also has an interest in preventing suicide. While committing suicide is no longer criminalized in most jurisdictions, assisted suicide remains a crime. The courts have limited the right to refuse treatment so that it does not extend to cover assistance from a third party to commit suicide. The right to refuse treatment only extends to the withdrawal of life-sustaining treatment, not active voluntary euthanasia. The courts have therefore been very careful to distinguish decisions to refuse treatment from requests for assisted suicide.

This is illustrated by *Rodriguez v. British Columbia* (*Attorney-General*), where a patient with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, wished to have a physician supply her with a "suicide machine" that she could activate when she could no longer tolerate her condition. She sought a declaration that would invalidate the criminal provisions that made the aiding and abetting of suicide an offense.

The majority of the Canadian Supreme Court found that the provisions of the criminal law did not infringe on the guarantees of the Canadian Charter of Rights and Freedoms. According to the court, the criminal prohibition may have deprived the patient of her autonomy and caused her physical pain and distress, but such a deprivation was not found to have been contrary to the principles of fundamental justice, as secured by the charter. The court could not make fundamental changes to the long-standing and almost universal policy against euthanasia.

There are several difficulties with the prohibition against assisted suicide and its relationship with refusals of treatment—namely, the logical and legal distinction between the two. The courts have attempted to distinguish active euthanasia from treatment refusal on two grounds. The first ground is that the person is not suicidal because this individual does not desire death: he or she only wishes for treatment to cease. The second ground relied on by courts is to say that death is not caused by the person refusing treatment but by the underlying disease or disability.

Many commentators see these arguments as spurious. First, while it may be true that some patients do not desire death in refusing life-sustaining treatment, there are several cases where patients expressly stated that death was their aim (see, e.g., *State v. McAfee* [1989]). Second, to say that death is caused by disease or disability ignores the fact that the disease or disability would not have caused death without the treatment being ceased. Moreover, it ignores the active role played by physicians in actively helping the patient by administering sedatives or painkillers that accelerate the dying process.

Regardless of these logical problems, the law in several jurisdictions has upheld the distinction between refusing treatment and assisted suicide, accepting the former and criminalizing the latter.

—Cameron Stewart

See also Euthanasia; Physician-Assisted Suicide.

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REHABILITATION ACT OF 1973 (UNITED STATES)

The roots of today's rehabilitation system for civilians with disabilities in the United States, particularly those with work injuries, lie in the Smith-Fess Act of 1920. The act was based on the belief that, with professional training and intervention, people with disabilities could return to productive employment. Support for vocational rehabilitation (VR) programs grew during the years that followed until finally, in 1935, the law made the provision of VR services by each state mandatory.

During the next several decades, the act was expanded to broaden the definition of eligibility for rehabilitation services to include people with more severe, congenital disabilities, such as blindness, mental illness, and mental retardation. Services were expanded to include physical restoration and living expenses, as well as vocational evaluation and work adjustment. The act provided funds for graduate programs in rehabilitation and funded construction of rehabilitation centers and sheltered workshop facilities, although these activities are no longer funded. In 1973, the act was again amended to mandate that agencies establish an "order of selection" to ensure that people with severe disabilities receive services before individuals with less severe disabilities and to require that a written rehabilitation plan be developed to ensure that clients themselves have a strong voice in the services they receive.

The 1973 amendments also included Title V, the first civil rights legislation for individuals with disabilities. Passing with little congressional debate, Title V bans discrimination against people with disabilities in programs receiving federal financial assistance. Section 503 requires that federal contractors adopt affirmative action programs to hire individuals with disabilities. Section 504 requires that programs receiving federal financial assistance make "reasonable accommodation" for individuals with disabilities to participate fully in their programs and activities, in addition to the nondiscrimination requirements. For the first time, accessibility was required of federally funded transit systems, colleges and universities, health care institutions, and state and local programs that receive federal financial assistance. But for Section 504 to be implemented, federal agencies must adopt regulations implementing this legislation. When President Jimmy Carter refused to sign the regulations without significantly weakening the language, hundreds of individuals with disabilities protested. They occupied regional offices of the Department of Health Education and Welfare, the agency responsible for promulgating the regulations, until the regulations were finally signed into law.

In 1990, the Americans with Disabilities Act (ADA) was passed, which broadened these nondiscrimination and access requirements to include public services and other entities that did not receive federal dollars. The ADA's drafters incorporated many of the provisions of the Section 504 regulations into the act.

In 1998, the Rehabilitation Act and other employment programs were incorporated into the Workforce Investment Act (WIA). The goal of the WIA is to increase the employment, job retention, and earnings of people who participate in employment-related activities, including people with disabilities. The intent of the WIA is to create a user-friendly, one-stop system of service delivery through the coordination of multiple workforce development programs. This one-stop system must be designed to address the needs of all individuals and must be accessible to people with disabilities as required under the ADA and Section 504 of the Rehabilitation Act of 1973. The state rehabilitation program must be an integral part of this one-stop system.

Today, the Rehabilitation Act is guided by strong principles, including respect for the dignity of all individuals, personal responsibility, self-determination, and pursuit of meaningful careers; the act promotes inclusion, integration, and full participation of people with disabilities. The Rehabilitation Act contains seven titles that regulate and fund disability employment and independent living programs. Some of the key titles are the following.

Title I provides grants to each designated state agency, which employs rehabilitation counselors to provide job training, advanced education, job placement, postemployment support, assistive technology, and other services to assist individuals with disabilities to find and keep work.

Title III establishes the National Institute on Disability and Rehabilitation Research, to promote and coordinate research, demonstration projects, and training related to people with disabilities.

Title V requires affirmative action by federal contractors in hiring individuals with disabilities (Sec. 503) and nondiscrimination against people with disabilities in programs and activities receiving federal financial assistance (Sec. 504). In 1998, Section 508 was added to require that electronic and information technology purchased by or used in federal programs be accessible to people with disabilities.

Title VII regulates and funds independent living services and centers for independent living, which provide services and advocacy for individuals with significant disabilities. Chapter Two of this title provides services to older blind individuals.

—Bonnie O'Day

See also Accessible Internet; Americans with Disabilities Act of 1990 (United States); Vocational Rehabilitation; Vocational Rehabilitation: Law and Policy.

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Workforce Investment Act of 1998, 29 U.S.C. § 794d.

REHABILITATION COUNSELING

Rehabilitation counseling is a pragmatic, strength-based approach to counseling persons with disabilities. It shares similarities with certain aspects of a number of related disciplines, including physical rehabilitation and occupational therapy, psychiatry, psychology, nursing, and social work. Rehabilitation counseling is most commonly provided to individuals newly disabled by a physical event or injury or to those with a serious mental health or substance abuse problem. What makes rehabilitation counseling distinct from other disciplines is that it is activity focused, involving learning by doing within real-world contexts. Other disciplines tend to be therapy focused, usually occurring in institutional settings. The evaluation component of rehabilitation counseling typically involves the assessment of a client's problems or goals and the formulation of a treatment plan. The counseling component may seek to assist clients across a wide range of life domains, including activities of daily living, vocational functioning, social functioning, advocacy and resource acquisition, coping, and lifestyle change. The central aim of rehabilitation counseling is to empower clients to live more independently and satisfactorily while also advocating for clients' rights, needs, and hopes. Rehabilitation counselors help to reduce the cultural stigma that persons with disabilities experience. Generally, society views persons with disabilities as flawed and needy. This cultural milieu promotes feelings of dependence and inadequacy in persons with disabilities. Rehabilitation counselors counter these attitudes by helping persons with disabilities to function and excel in real-world educational, vocational, domestic, and familial contexts.

One of the hallmarks of rehabilitation counseling is that it is a pragmatic approach that facilitates rehabilitation through the use of techniques found across multiple fields. Frances Reynolds (1999) distinguishes it from other approaches to physical rehabilitation in that it may borrow techniques from a variety of orientations to facilitate adaptation and adjustment to a disability. For example, rehabilitation counselors such as Richard Hardy, Warren Rule, and John Cull have described using various psychodynamic approaches in rehabilitation counseling contexts. Hardy (1999) has also described the use of Gestalt therapy and hypnosis, while Joseph Ososkie (1998) has described existential perspectives, and Gerald Gandy (Gandy, Martin, and Hardy 1999) and a number of others have used cognitive-behavioral therapy and integrative techniques to facilitate a person's acceptance and adjustment to a disability. Nancy

Crewe (1997) has contributed a number of articles on functional assessment and outcomes rehabilitation counseling for individuals with spinal cord injury and traumatic brain injury that have provided valuable insight into the lives of persons with disabilities. Brian McMahon has written a number of articles about rehabilitation counseling and supported employment for individuals with a wide range of disabilities, including traumatic brain injuries that have moved the field toward a more empowerment-focused ideology (e.g., McMahon and Shaw 1996). In sum, the field of rehabilitation counseling can be characterized by a wide variety of approaches that are drawn from the distinctive psychological issues facing people with disabilities and from the theory, research, and practice of general counseling and psychotherapy. To an important extent, these approaches are framed by the goal of a person retaking his or her full potential and ability after the onset of a disability.

With respect to training and certification, two initiatives in the United States have worked to ensure that rehabilitation counselors are adequately educated and sufficiently competent to enter the profession: program accreditation and certification for practice. These two movements have helped set national standards for skill-level proficiency and knowledge adequacy of rehabilitation counselors. National standards include knowledge about vocational counseling and consultation, effective counseling, case management, service availability, medical and psychosocial aspects of disability, and history and systems of rehabilitation. A similar movement has taken place in Canada. Michael Leahy has written about perceptions of knowledge requirements among certified rehabilitation counselors in Canada (see, e.g., Leahy, Chan, and Magrega 1997). Domains of required knowledge identified by Canadian counselors were very similar to the domains of knowledge that U.S. rehabilitation counselors endorse, including knowledge of psychosocial aspects of disabilities and systems of rehabilitation.

Scholars such as Jared Schultz, Joseph Ososkie, and Elias Mpofu have commented on the state of the field of rehabilitation counseling. The field of rehabilitation counseling tends to serve a diverse population of individuals with disabilities using a wide range of approaches. In addition, rehabilitation counselors work in varied settings. These settings range from private settings, such as private rehabilitation centers and hospitals, health insurance companies, and employment counseling firms, to public settings that include the state agencies of rehabilitation services, the federal Social Security Administration, and other governmental organizations. For these reasons, these scholars argue that many may not understand the unique and cohesive mission and vision of the field. In addition to this challenge of understanding breadth, the field has been forced to confront changes in practice settings, evolving federal legislative regulations, and the certification movement. The field has attempted to respond to these challenges by explicitly defining major areas of required knowledge and skills. Recently, Leahy, Chan, and Saunders (2002), as well as others, have sought to describe the job functions and training requirements of certified rehabilitation counselors for the twenty-first century. One set of core job functions concerns employment and includes vocational assessment, counseling, and consultation to identify interests and competencies, provide job retraining and practice, identify potential job placements for clients, and, ultimately, increase client readiness for and likelihood of stable employment. Another central role of the rehabilitation counselor concerns promoting effective coping with daily and community life. It involves counseling activities that range from assessment of clients in terms of resource needs to case management. It also includes specific counseling interventions that are designed specifically for the consumer's abilities and environment. Rehabilitation counselors also conduct community-based rehabilitation service activities, where their knowledge of health care and disability systems empowers them to engage in professional advocacy. In sum, rehabilitation counselors work with the psychological, medical, functional, and environmental implications of disability to support and ready their clients for independent functioning and community integration.

Over the past 30 years, the profession has expanded outside of state vocational rehabilitation agencies and into schools, medical settings, mental health settings, substance abuse settings, geriatric settings, employee assistance programs, private practice settings, and community-based organizations. Relatedly, a growing number of integrative, community-based approaches to rehabilitation counseling have developed. These approaches seek to combine counseling and advocacy efforts. David Hershenson (1998) has described one approach that involves four elements of rehabilitation. These include restoring or replacing assets and skills, reintegrating identity and self-image, reformulating goals, and restructuring the environment. Lloyd Goodwin (1986) described another approach that involves eight dimensions of rehabilitation: supporting wholeness of the client, wellness, responsibility taking, prevention, uniqueness, disability as an opportunity for growth, healing and rehabilitation approaches, and environmental sensitivity. Other fundamental principles of rehabilitation counseling include normalizing roles and relationships within society, building informal and egalitarian relationships, emphasizing empowerment, focusing on present-moment concerns, and promoting community integration. Principles that have emerged more recently within rehabilitation counseling include multicultural sensitivity, evaluating outcomes, incorporating family members into treatment, and interdisciplinary collaboration. All these new approaches signify the strength of the rehabilitation counseling field as it evolves and adapts to new political, cultural, and fiscal contexts.

—Renee R. Taylor and
Curtis J. Jones

See also Community-Based Rehabilitation; Employment; Independent Living; Vocational Rehabilitation.

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REHABILITATION ENGINEERING

Rehabilitation engineering is a field that brings the art and science of engineering to the assistance of persons with disabilities. It encompasses engineering research and development activities but also includes direct engineering services to persons with disabilities.

Rehabilitation engineering is frequently viewed as a component of the more general field of biomedical engineering, which brings together engineering with medicine and biology. As a direct service to people, it is related to occupational therapy and, to some extent, physical therapy. Although examples of rehabilitation engineering are almost as old as civilization itself, the field was not identified widely as "rehabilitation engineering" until the 1960s, when health agencies in a number of countries began to recognize the benefits of engineering insights and methods in the provision of assistance for persons with disabilities.

DEVELOPMENT AND SCOPE

Limb prosthetics is a subspecialty of rehabilitation engineering. It is concerned with the replacement of arms, hands, and legs with artificial components. Since antiquity, specialists have provided artificial replacements for lost limbs, particularly limbs lost in the conflicts of wars. After World War II, persons with limb loss often reentered society successfully, and high-quality artificial limbs coming out of federally sponsored research and development programs in prosthetics at that time contributed to this success. Consequently, in the late 1960s, the generalizing concept of rehabilitation engineering evolved, based on the thought that if engineers could work creatively with rehabilitation physicians and clinicians to improve limb prosthesis outcomes, they probably would also be able, through engineering techniques and scientific principles, to assist with the rehabilitation process for many other disabling conditions. Thus, the generalized field of rehabilitation engineering was launched.

In the late 1960s, one of the original objectives for the new field of rehabilitation engineering, as proposed by James B. Reswick, was "to improve the quality of life of the physically handicapped through a total approach to rehabilitation, combining medicine, engineering, and related science." Today, this field is viewed much more broadly, placing many chronically disabling conditions under the possible purview of engineering approaches. Physical disabilities such as limb loss are only one aspect of this field that now also includes communication disabilities, sensory disabilities, cognitive disabilities, and the many disabling conditions resulting from spinal cord injuries, head injuries, strokes, blindness and visual impairments, hearing impairments and deafness, neuromuscular diseases, musculoskeletal conditions, arthritis, orthopedic disabilities (bone and joint), cerebral palsy, pulmonary insufficiencies, cardiac deficits, disabling conditions from birth, disabilities of aging, disfigurement, and numerous other traumas, conditions, and diseases.

TECHNOLOGY SERVES THE PROCESS

Rehabilitation engineering is connected with treatments and therapies (e.g., robotic-aided therapy). It is associated with the avoidance of secondary disabling conditions and with comfort and alleviation of pain (e.g., witness the significant role engineering played in the orthopedic success of total joint replacements). This field also has to do with access to medical and rehabilitation services, tele-rehabilitation, and a wide scope of health care and possible cures that may result from genetics and stem cell medicine.

PERSONAL AIDS

The possibilities and prospects of rehabilitation engineering are as broad as life itself, which makes them innumerable. There are walking aids, functional electrical stimulation of muscles, manipulation aids, and wheeled mobility (e.g., powered chairs such as the unique iBOT Mobility System). Issues to be addressed include proper seating and positioning in wheelchairs and elsewhere, and management of pressure on body tissues. There are memory aids, and self-care aids (e.g., for handling one's medical prescriptions), speaking aids, reading aids, writing aids, hearing aids, visual aids, eating aids, teeth hygiene, toiletry aids, bladder and bowel management, recreational aids, temperature and lighting controls, telephone controls, control of entertainment equipment, assistance for caregivers, and attention in general to as many aspects of independent living as are feasible and reasonable. Modern computer-based technologies and wireless communication systems are making many of the aids listed available and easily customized to individual needs.

ASSISTANCE ON A LARGER SCALE

Rehabilitation engineering deals with aspects of the built and natural environments that may be inhibitory to persons with disabilities. The elimination of architectural barriers, development of universal designs for home and public environments, and the arrangement for home and work site modifications are all within the domain of rehabilitation engineering. There is need for access to secure living quarters, access to transportation and travel, and access to education and employment opportunities. Access to information (e.g., the Internet) and to the origination of information is highly desirable. With the right technical tools, meaningful work can be made accessible. This kind of technology may also permit pursuit of hobbies and avocational activities that can be invigorating and life enriching.

MULTIDISCIPLINARY INVOLVEMENT

As a general rule, engineers in rehabilitation cannot be successful alone with their efforts. They need to work together with physicians, surgeons, nurses, therapists, prosthetists, orthotists, and people with disabilities, their family members, and friends. This need for multidisciplinary experience exists both for engineers who conduct research on new methods and technologies to better serve persons with disabilities and for engineers who directly delivery rehabilitation engineering services to people. Nevertheless, the two kinds of rehabilitation engineers—the service-providing engineer and the research and development engineer—work in fundamentally different ways.

RESEARCH AND DEVELOPMENT

The rehabilitation engineer who conducts research and development (R&D) work usually is employed by a company that designs and/or manufactures rehabilitation engineering equipment or is involved in R&D work through a university-based laboratory that is funded by research grants. The R&D employee usually is a research engineer or scientist, often with a Ph.D. in biomedical engineering or some related area of science or engineering. The researchers usually work closely with rehabilitation professionals and ideally may have disabilities themselves. The aim is to develop new knowledge (science and engineering) concerning rehabilitation processes and new superior ways to solve problems that persons with disabilities experience. Much of the R&D work in rehabilitation is what might be described as applied research and development. However, new approaches at the cellular and molecular levels, new concepts in tissue engineering, new nanotechnologies, and new biomaterials are basic research arenas that may open up completely new concepts in rehabilitation.

SERVICE PROVIDERS

Engineers who deliver service directly to individuals with disabilities work basically as clinicians. Through training and experience, through working with other rehabilitation professionals, and through close interaction with the persons being served, they can begin to help their clients with rational decisions about which rehabilitation engineering approaches and assistive devices may help them. Many providers of rehabilitation engineering services in the United States are credentialed by RESNA (Rehabilitation Engineering and Assistive Technology Society of North America). The positions examined are assistive technology practitioner (ATP), assistive technology supplier (ATS), and rehabilitation engineering technologist (RET). The credentialing process attempts to provide safeguards for clients and to increase client satisfaction.

Clients usually should have their medical conditions stabilized before being seen for rehabilitation engineering consultation. Modes of communication also need to be established beforehand, if possible, so that the client can interact in the discussions and in decision-making processes. After communication has been achieved, it is important to determine if the person is comfortable. If not, the possible causes of discomfort need to be investigated and eliminated. For example, good seating and positioning frequently need to be established to help clients relax and be more comfortable. After the client can communicate and is comfortable, an early step is to try to provide that person with independent mobility. From this point on, it is usually possible to begin to address the many individual and unique needs of each client. Inevitably, this process usually involves many compromises as well as medical, engineering, and financial constraints.

A HUMAN ENDEAVOR

In the end, rehabilitation engineering methods and techniques cannot rehabilitate a person with disability. True rehabilitation must somehow come from within the person with disability, aided primarily by human love and compassionate care. Nevertheless, if one is truly rehabilitated, the methods and techniques provided by rehabilitation engineering can indeed greatly enlarge the scope of his or her life.

—Dudley Childress

See also Activities of Daily Living (ADLs); Independent Living; Assistive Technology; Mobility Aids; Physical Activity.

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REHABILITATION ENGINEERING AND ASSISTIVE TECHNOLOGY SOCIETY OF NORTH AMERICA (RESNA)

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) is an interdisciplinary association composed of individuals interested in technology and disability. Professionals in RESNA include occupational therapists, physical therapists, rehabilitation engineers, speech-language pathologists, special educators, manufacturers, and durable medical equipment suppliers. Consumers of assistive technology also belong to RESNA.

RESNA started in 1980 as early research and development work in the field began at federally funded rehabilitation engineering research centers (RERCs). Each RERC focuses on one specific area of assistive technology, developing new technology, training new professionals, and providing information to the public.

RESNA provides a forum for individuals with a common interest in a particular area of assistive technology, through special interest groups (SIGs). In addition, RESNA's professional specialty groups (PSGs) provide a way for specific disciplines to communicate with one another.

Through the Technical Assistance Project and Alternate Financing Project, RESNA provides assistance to the 56 state and territory assistive technology programs. These programs are funded under Public Law 105–394 to increase awareness of and access to assistive technology in each area.

Through its credentialing program, RESNA provides a mechanism for professionals to demonstrate a knowledge and skill base critical to the delivery of assistive technology services. Three credentials exist: assistive technology practitioner (ATP), assistive technology supplier (ATS), and rehabilitation engineering technologist (RET).

RESNA's international sister organizations—the Association for the Advancement of Assistive Technology in Europe (AAATE), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation and Assistive Technology Association (ARATA)—provide forums for similar work around the world. On August 26, 2000, the leaders of the four organizations signed the Tokushima Agreement to promote exchange of information and collaboration.

—Glenn Hedman

See also Rehabilitation Engineering Society of Japan (RESJA).

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REHABILITATION ENGINEERING SOCIETY OF JAPAN (RESJA)

The Rehabilitation Engineering Society of Japan (RESJA) was established in 1986 and is composed of approximately 1,000 members. RESJA's membership is interdisciplinary, including engineers, occupational therapists, physical therapists, speech therapists, educators, physicians, and consumers.

RESJA organizes an annual conference, the Japanese Conference of Advancement on Assistive and Rehabilitation Technology (JCAART). The conference provides a forum for the presentation of approximately 700 papers. An additional dissemination avenue is the *Journal of RESJA,* which is issued four times each year.

RESJA is organized around 10 special interest groups (SIGs). Current SIG topics include the following: automobile, communication, functional electrical stimulation, house design, seating, self-help devices, wheelchairs, special education, transfer aids, and devices to prevent pressure sores.

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

—Glenn Hedman

See also Rehabilitation Engineering and Assistive Technology Society of North America (RESNA).

Websites

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REHABILITATION MEDICINE, INTERNATIONAL

Rehabilitation is used as a term for different medical, psychological, social, and vocational measures that aim to support a person with disability to regain as normal a life as possible. The ultimate goal for rehabilitation is that the person will participate actively in life roles of importance for that person. This entry concentrates on rehabilitation within medicine, with special emphasis on the situation in Europe.

GENERAL ASPECTS AND DEFINITION

For the development of rehabilitation, the concepts first given by the World Health Organization (WHO 1980) in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and recently (approved 2001) in the International Classification of Functioning, Disability, and Health (ICF) have played a great role. Rehabilitation works on all levels in ICF (body function and structure, activity, and participation), also taking environmental factors into account. Impairments (the level of body function and structure) can be treated to reduce or eliminate the reduction in function by pharmacological means, training through physiotherapy, occupational therapy, speech therapy, neuropsychological means, and so on, or they can be compensated for by assisted devices. Rehabilitation aims at reducing the activity limitations (the level of the individual) by training, changing an activity pattern (e.g., more appropriate way to handle objects for a person with joint disease), and using assistive devices and modifications of the environment (e.g., housing adaptation). Finally, the aim is to increase participation, where social and psychological factors play a great role and should include attention to the attitudes of relevant other persons. Emphasis may be placed differently on those three levels, depending on the phase and actual goal of rehabilitation, but all should always be kept in mind. In the early acute stage, measures to reduce impairment and limitation in basic daily activities may dominate, whereas in the more subacute stage of rehabilitation, reduction of activity limitation in a broader sense may be the dominant goal. The need for treatment of specific body functions (impairments) should therefore be analyzed in such a perspective. In a later stage, after an individual leaves the hospital, social aspects related to family life, occupation, hobbies, and leisure activities will be given an increasing importance for the rehabilitation efforts.

Rehabilitation measures and programs can be divided into different categories:

- separate rehabilitation measures, which may or may not be coordinated, such as physiotherapy, occupational therapy, and speech and language therapy;
- coordinated rehabilitation within different clinical specialities, but without participation of a clinical specialist in rehabilitation medicine;
- team-based rehabilitation in specialized rehabilitation units (clinics) and led by a specialist in rehabilitation medicine (in the United States, a physiatrist).

The activity of the rehabilitation team should essentially be goal oriented and should take account of the preferences and goals of the patient, who is an active participant in the rehabilitation process.

Many medical disciplines have a rehabilitation component within their work, but of special note are psychiatry, rheumatology, cardiology, neurology, orthopedics, and respiratory medicine. Specialized clinics are established by specialists in physical and rehabilitation medicine to address the needs of special groups of patients, where a broad and more timely approach is required. Thus, the medical speciality that is most greatly concerned with the medical rehabilitation of physically disabled people is physical and rehabilitation medicine. It goes under a variety of names in different countries, reflecting different priorities:

> Rehabilitation medicine: Hungary, Ireland, Luxembourg, the Netherlands, Poland, Portugal, Sweden, United Kingdom
>
> Physical and rehabilitation medicine: Official Title in the Union of European Medical Specialists (UEMS) and also in France, Germany, Denmark, Greece, Switzerland
>
> Physical medicine and rehabilitation: Austria, Belgium, Croatia, Czech Republic, Denmark, Estonia, Finland, Greece, Italy, Latvia, Liechtenstein, Lithuania, Norway, Slovakia, Slovenia, Spain, Turkey, United States

The term *physical medicine* is still used in some countries but represents a slightly different activity from rehabilitation medicine. In some countries, such as in the United States, a specialist in physical and rehabilitation medicine is named a physiatrist.

Definition

The speciality will hereinafter be referred to as physical and rehabilitation medicine (PRM). So what is PRM? The European Union of Medical Specialists (UEMS) section of PRM has defined it as follows:

> PRM is an independent medical specialty concerned with the promotion of physical and cognitive functioning, behaviour, quality of life (activities and participation) and with the prevention, diagnosis, treatment and rehabilitation management of people with disabling medical conditions and co-morbidity across all ages.
>
> Specialists in PRM have a holistic approach to people with acute and chronic conditions, examples of which are musculo-skeletal and neurological disorders, amputations, pelvic organ dysfunction, cardiorespiratory insufficiency and the disability due to chronic pain and cancer.
>
> PRM specialists work in various facilities from acute care units to community settings. They use specific diagnostic assessment tools and carry out treatments, which include pharmacological, physical, technical and educational and vocational interventions. Because of their comprehensive training, they are best placed to assume responsibility for the activities of multi-professional teams in order to achieve optimal outcomes.

There are variations from country to country, but the common aspect is the relationship of the rehabilitation physician to other members of the multiprofessional team. This is quite different from that found in acute medicine.

Aims of Physical and Rehabilitation Medicine

The concepts in the ICIDH, published in 1980 by WHO, have made a great impact on rehabilitation. However, the terms have changed in the recently published ICF. The overall aim of rehabilitation is to reduce or eliminate disability, as its definition in ICF still applies. Rehabilitation is a precise activity and is quite different from care and describes a goal-oriented activity. Similarly, it is quite different from "therapy," which contributes to the rehabilitation process in individual recipients but may not always be required for everyone. *Therapy* and *rehabilitation* are not synonymous.

Rehabilitation—WHO Definition. This is an active process by which those disabled by injury/disease achieve a full recovery or, if full recovery is not possible, realize their optimal physical, mental, and social potential and are integrated into their most appropriate environment.

Health-Based Rehabilitation: Working Definition. This dedicated, designated, multiprofessional activity, which takes an active and holistic approach to care and is centered on the individual needs of patients and carers, starts in earnest when the patient is medically stable and continues through community reintegration and beyond, is goal oriented, and is easily and appropriately accessible.

Rehabilitation Medicine. This is a consultant subacute speciality concerned with the secondary and tertiary management of the medical aspects of physical disability (especially in the fields of neurological and musculoskeletal disease, trauma, and amputation), which require specialist rehabilitation expertise.

Rehabilitation Therapy. This includes treatment provided by, or under the direction of, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, dieticians, chiropodists, and so on. They each have their professional philosophies, but space prevents from describing each.

Medical practice is based on the concept of arriving at a diagnosis and providing a treatment that aims to cure the patient. In the context of medical and social progress and the increasing importance of degenerative diseases in medical practice, the relatively new concepts of improving quality of life and preventing deterioration and complications have assumed greater priority.

General Structure in Europe

The general structure of PRM services across Europe is fairly similar despite the differences between health care systems. PRM is recognized as a core service in each of the 19 member states of Europe and the new associate members also adopt the same principles. The names may be different from place to place, but the essential services appear in the following form.

> *General Rehabilitation:* Characterized by health professionals working within their professional roles in relative isolation from others.
>
> *Special Services:* Dedicated areas of working, where individual professionals have varying degrees of contact with others involved in the rehabilitation process—for example, continence and tissue viability services, dysphagia services, and so on. For specific conditions, such as multiple sclerosis, Parkinson's disease, and back pain, individuals may have a general clinical role working within a team and an extra responsibility to these respective patients.
>
> *Specialized Rehabilitation:* Dedicated multidisciplinary or interdisciplinary rehabilitation, where the team meets to define the rehabilitation objectives and activity and professionals work together to achieve the aims of the process. It is often inpatient based, but there are now a number of community teams working in this way.

The numbers of specialists in PRM across Europe varies considerably, and this depends to a large extent on geography.

Training in PRM

Specialist training covers a four- to five-year course in UEMS member states. The route to start training is slightly different in each country, but, despite different entry points to a four- to five-year training program, the curriculum has much similarity across the continent. The European Board of PRM has the task of harmonizing specialist training across Europe and has taken on the following roles.

- European examination for recognition of specialist training
- Continuing professional development and medical education with five yearly revalidations
- Recognition of the European trainer and training unit through site visits

The eventual aim of this harmonization is to produce specialists who can work across European health care systems and allow national medical authorities/employers the knowledge of the training content and experience of the specialists working for them.

DELIVERY OF REHABILITATION SERVICES

With such a burden of physical disability in the population, adequate and equitable delivery of health care to the disabled population is clearly a major logistical problem. Services provided in most countries are patchy, fragmented, and overall inadequate. Facilities are needed for both inpatients and outpatients, and the criteria for inpatient rehabilitation are as follows:

a. patients requiring 24-hour nursing and medical supervision for their rehabilitative needs;
b. patients with neurological and locomotor disorders who have the capacity for, require, and will benefit from rehabilitation (i.e., patients in whom the evidence shows that active intervention improves function and life satisfaction or prevents deterioration);
c. severely disabled patients, whose needs can only be met by a multiprofessional team practicing interdisciplinary rehabilitation;
d. patients with complex needs (i.e., requiring more than two professionals working in a team);
e. some very severely disabled patients with little hope of improvement in personal functioning but who require assessment and appropriate equipment and whose families require education for caring purposes.

A number of basic core services are required in each area. Logistics demand that rare and complex conditions require designated specialist services, and because they will not be available in each locality, an access network is necessary.

Acute Services

As the pressure on acute facilities increases, rehabilitation in acute hospital beds should be available to achieve optimal outcomes, reduce complications and disability, and allow a clear pathway for efficient ongoing rehabilitation after discharge. The barriers to achieving this are as follows:

- lack of recognition by the acute care team of what the specialist center can offer in addition to that provided by the acute physician/surgeon,
- lack of access (availability of services, waiting time to enter rehabilitation),
- financial restrictions (hospital/clinician/insurance).

Specialist Centers

Certain individual groups of both old and younger adults and children require dedicated centers/services for specialized rehabilitation, and the standards proposed by the British Society of Rehabilitation Medicine on the number of required beds per district for rehabilitation medicine only account for younger adults. These centers need both inpatient and outpatient rehabilitation facilities, which are separated from acute beds and long-term care facilities for the elderly.

Disease-Specific Clinics

Specific clinics and activities have been developed for managing certain long-term conditions, such as multiple sclerosis, epilepsy, Parkinson's disease, or inflammatory joint disease. In addition, back pain services have been set up, and these clinics certainly have the advantage of providing an expert multidisciplinary approach, which is familiar with the specific problems of that disorder. The team can supply information and counseling support and can act as a focus for self-help groups.

Community Rehabilitation Teams

Follow-up from the acute hospital-based rehabilitation team is essential for many people with significant disabilities to provide continuity of support and access to appropriate health resources after discharge. A community team can still work in a multi- or an interdisciplinary manner in the same way as the acute rehabilitation team but tends to concentrate on changing abilities in activities and participation rather than on the relationship between impairments and abilities. A team is effective for a population of about 120,000. Teams may be peripatetic, based in health/community centers or in community hospitals. Their essential aims are to ensure the well-being of disabled people in the community by organizing therapeutic interventions to ensure optimal outcomes following hospital stays and prevent hospital admissions.

Case Management

Disabled people, particularly those with severe and wide-ranging disabilities, will need a complex array of health and social services. The concept of case management has been developed as a way of assisting disabled people with the coordination of the necessary professional staff. Case management can include the following:

simple coordination within a single agency;

coordination across agency boundaries;

service brokerage, in which the case manager negotiates with the key agencies on the client's behalf;

budget-holding responsibility, where services can be purchased on behalf of the client from statutory bodies or other voluntary or private agencies.

There have been very few controlled studies of the efficacy of case management, which is widely practiced within the United States, Canada, and Scandinavia. It may provide a better and more coherent service, particularly for those who have a degree of cognitive impairment who are unable to find their own way through the maze of services.

Links with Other Agencies

Health-based rehabilitation goes hand in hand with social and vocational rehabilitation, and services need both formal and informal means to break down the artificial barriers between the participating agencies. Cross-representation is necessary at both the strategic and operational levels, and disabled people not only need to be involved but also should lead when and where it is appropriate. There is no single preferred model to suit every location, and each will depend on the local facilities and assets of the participating individuals. However, all new services should take into account the views and advice of users and disabled people's groups on disabled living (Living Options principles and European Year for Disabled People 2003).

REHABILITATION RESEARCH–ACADEMIC BASE

Rehabilitation research is growing in activity and sophistication. However, randomized controlled trials are, to some extent, difficult to perform in this field, but a recent increase in the publication of such studies can be seen. There are now a lot of data about the effectiveness of rehabilitation, and what is now required are data on the value of rehabilitation through cost-effectiveness studies, some of which are under way. Rehabilitation will also have a more solid theoretical basis as the perspectives of fields such as neurobiology, applied physiology, and biomechanics increasingly provide a background for rehabilitation. There is also an increasing use of modern and relevant methods to treat ordinal scale data from various instruments to assess activity limitation, participation restriction, quality of life, and perception of health—all very useful in rehabilitation research.

—Anthony B. Ward and
Gunnar Grimby

See also Assistive Technology; Case Management; Mobility Aids; Physical Medicine and Rehabilitation; Rehabilitation Engineering.

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REHABILITATION PSYCHOLOGY

Rehabilitation psychology is a specialty area of practice that applies psychological knowledge and understanding on behalf of individuals with disabilities and society through research, clinical practice, teaching, public education, development of social policy, and advocacy. Rehabilitation psychologists participate in a wide range of activities, including clinical care and direct service, program development, research, education, administration, and public policy.

They work in acute care hospitals and medical centers, inpatient and outpatient physical rehabilitation units, nursing homes and assisted living centers, and community agencies serving people with specific types of disability or chronic illness (e.g., vision loss and low vision, cerebral palsy, multiple sclerosis, deafness). Their employers include private facilities and government facilities such as Veterans Administration hospitals and centers, industry, and universities, colleges, and private practice. The focus of rehabilitation psychology covers the lifespan from early childhood through late adulthood. Advocacy is an important activity for rehabilitation psychologists as they seek to improve the life conditions for people with disabilities and chronic illnesses; many have sought to develop and promote legislation such as the Americans with Disabilities Act of 1990.

Clinical and counseling services provided by rehabilitation psychologists assist individuals to cope with and adjust following the onset of chronic, traumatic, or congenital injuries or illnesses. These conditions include spinal cord injury; brain injury; stroke; amputations; neuromuscular disorders; medical conditions with the potential to limit functioning and participation in life activities such as cancer, AIDS, multiple sclerosis, or limb weakness; chronic pain; congenital or chronic developmental disorder such as mental retardation; chronic mental illness; alcohol and other drug abuse; impairments in sensory functioning; burn injury; deafness and hearing loss; and blindness and vision loss. Many of these impairments are compounded by cultural, educational, and/or other disadvantages and social stigma.

Psychological services often have the goal of reducing the consequences of impairment, activity limitations, and societal participation restrictions. Persons served are engaged as active partners in the rehabilitation process by taking into account the person's preferences, needs, and resources. Following the World Health Organization's International Classification of Functioning, Disability, and Health (ICF), rehabilitation psychologists have helped address personal factors affecting the ICF domains of impairments, activities, and participation. They do this by addressing neurocognitive status, mood and emotions, desired level of independence or interdependence, freedom of movement, self-esteem and self-determination, subjective view of capabilities and quality of life, and satisfaction with achievements in specific areas such as work, social relationships, and community access. Rehabilitation psychologists consider the influence of culture, ethnicity, gender, residence and geographic location, visibility and assumption of disability on attitudes, and available services when planning services. Also explored are environmental barriers to participation and activity performance, including accommodations and adaptations in existing structures or materials and the use of assistive technology and personal assistance services.

Families, primary caregivers, and other significant people in the individual's social life and community are valued and engaged in rehabilitation activities so as to assist the individual with disability or chronic illness achieve optimal physical, psychological, and interpersonal functioning.

Rehabilitation psychologists work within a wide variety of health care settings and with a broad range of persons with varying disabilities and illnesses. Some specialize in a particular area of clinical practice, while others' practice is broader. Interdisciplinary teamwork is a hallmark of rehabilitation psychology practice across settings and the area of specialization. Rehabilitation psychologists are respected and provide services within existing networks of biological, psychological, social, environmental, and political environments to assist the persons served in achieving their rehabilitation goals. Consultation regarding disability and health issues is another important professional role of rehabilitation psychologists. Attorneys, courts, government agencies, educational institutions, corporate facilities, and insurance companies are the recipients of these services.

Rehabilitation psychologists complete doctoral degrees in psychology and have had extensive predoctoral and postdoctoral training in health care settings. Rehabilitation psychologists who provide clinical services are usually required to be licensed to provide services in their state of practice and to receive reimbursement for services from health insurance payers. The American Board of Professional Psychology (ABPP) recognizes rehabilitation psychology as a specialty area of practice within psychology; the board's definition of rehabilitation psychology was an important source in the development of this description. Rehabilitation psychologists belong to many professional organizations relevant to their area of practice and specialization. The major organization representing rehabilitation psychology is the American Psychological Association (APA), Division of Rehabilitation Psychology. Division 22 publishes a scholarly journal and newsletter; it also sponsors sessions relevant to rehabilitation psychology research and practice at the annual APA conference held annually in August, a midwinter meeting, and other education venues for psychologists and other health professionals. Several excellent textbooks are available on the general topic of rehabilitation psychology, as well as books on areas of specialization within this field.

—Allen Heinemann

See also Physical Medicine and Rehabilitation; Psychiatry; Psychology.

Note: Information for this entry was drawn from the description written by Marcia Scherer, Kelly Blair, Martha E. Banks, Bernard Brucker, John Corrigan, and Stephen Wegener and appears at http://www.apa.org/divisions/div22/RPdef.html.

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REHABILITATION ROBOTS

There are two main types of rehabilitation robots. The first type is an assistive robot that substitutes for lost limb movements. For example, the MANUS robot arm attaches to a wheelchair. The user controls MANUS using a chin switch or other input device. This process is called "telemanipulation" and is similar to an astronaut controlling the space shuttle's cargo bay robot arm from inside the shuttle's cockpit. Powered wheelchairs are another example of teleoperated, assistive robots.

The second type of rehabilitation robot is a therapy robot, which is sometimes called a "rehabilitator." Neuroscience research over the past 20 years has shown that the brain and spinal cord retain a remarkable ability to adapt, even after injury, through the use of practiced movements. Therapy robots are machines or tools for rehabilitation therapists that allow patients to perform practice movements aided by the robot. The first robot used in this way, MIT-Manus, assisted patients with stroke in reaching across a tabletop if they were unable to perform the task by themselves. Patients who received extra therapy from the robot improved the rate of their arm movement recovery. Another recent therapy robot, the Lokomat, supports the weight of a person and moves the legs in a walking pattern over a moving treadmill, with the goal of retraining walking after a spinal cord injury or stroke.

Assistive robots are not yet widely available because of limited functionality and cost. Teleoperating a robot arm to pick up a bottle of water and bring it to the mouth is time-consuming and requires an expensive robot. Robot arms on wheelchairs will become more common as engineers build more intelligence into them. Making robots understand voice commands, recognize objects, and agilely manipulate them in the "real world" is a cutting-edge research area in robotics. Another promising area of research is at the cutting edge of neuroscience: implanting computer chips directly into the brain so that all a user has to do is "think" a command and the robot will do it. This sounds like science fiction, but researchers have recently shown that monkeys can be trained to move a robotic arm in just this fashion—through thought alone.

The main issue limiting therapy robots is that researchers do not understand what exactly the nervous system needs to adapt. Hard work by the patient is important, but what should the robot do? Researchers are developing therapy robots that assist in movement, resist movement when it is uncoordinated, or even make movements more uncoordinated in an attempt to trick the nervous system into adapting. Therapy robots will become more prevalent as researchers figure out the best training techniques. Therapy robots will also likely play a role in assisting the nervous system to regenerate appropriate neural connections following stem cell and other medical treatments.

Finally, the distinction between assistive and therapy robots may fade in the future. Imagine wearing a robotic exoskeleton that helps you to get tasks done but also teaches you to get better at doing those tasks. Such a rehabilitation robot will help people with disabilities by gradually making itself obsolete.

—David J. Reinkensmeyer

See also Assistive Technology; Rehabilitation Engineering.

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RELIGION

A religion is a system(s) of belief(s) and ritual through which people relate to and express their experience of

God(s), the sacred or divine dimensions of life, and their understandings of the meaning of life. Religion includes the practices whereby people live out their faith, and both historically and today, it is a major force in the lives of cultures and civilizations. Hence, people with disabilities and their families are influenced by those religious traditions and systems. In turn, the experience of impairment, as well as its social expression, disability, affects religious understanding and practice as people with and without disabilities seek to understand the meaning of disability, God's relationship to disability, and the subsequent understandings of practice and relationship to which a belief and tradition calls them.

The intersection of disability and religion has complex historical, practical, scientific, and theological dimensions. Disability is paradoxically often central to religion (such as the brokenness of God in Christianity) yet has, in large part, been overlooked in systemic research and the study of religious systems. A critical understanding assists in understanding the historical treatment of disability and its intersection with culture and faith traditions. Religion can be a force for both good and ill regarding disability.

EXPLORING THE COMPLEX RELATIONSHIP

There is no one generalized definition or explanation of the relationship between religion and religion. While religion is a major force in societies, many other factors influence people. Adherence to, or interpretation of, a faith tradition is also shaped by numerous other forces that influence personal and social understandings of disability.

Religion and faith can endorse and enshrine social attitudes and practice or challenge them. There are many examples of ways that faith and religion have been a support to people with disabilities and their families. Likewise, there are many examples of its use to exclude, dehumanize, or harm people with disabilities.

Certainly, there is no central understanding of how religious tradition or faith relates to disability. Reflecting dominant power relations, in faith traditions, disability is not a major focus. Most religious leaders do not live with disability, and few cite sermons or teachings on disability and religion. There are also many different understandings, doctrines, beliefs, and approaches about many issues within a specific religious tradition, including disability.

Hence, even if there were a central understanding or practice within a given tradition about disability, it does not mean that practice would be uniform. Many different forces and experiences shape attitudes and practice.

EXPLORING RELATIONSHIPS AND EMERGING RESEARCH

Despite this, the relationship between religious beliefs and practice and disability (or disabilities) is an area for rich and powerful exploration and research. Having a disability or close relationships with people with disabilities raises many questions about the meaning of life, the nature of suffering, the role of God and divine purpose, difference and community, and understandings of individual rights and justice. Religion and faith shape personal and communal identity, help people to find meaning and purpose regarding core life questions, express understanding of the sacred/divine, and guide ethical practice. Religious traditions and faiths can sustain people in times of crisis, through belief systems, practice, and a wide variety of supports and services within one's religious community (church, synagogue, mosque, etc.). As already stated, these can effect change, both for good and ill.

Religions can support a wide range of beliefs and practices in societies and cultures. This is an area of emerging research in both religious and secular disciplines—for example, strategies shaping inclusive/accessible faith communities or understandings of how faith and religion affect attitudes and coping skills within families and people with disabilities. There is a growing impact of the disability rights movements on religious understandings and practice. This relationship illustrates how disability may not have played an obvious role in its early development of central beliefs, practices, or sacred texts of most religious communities, yet core beliefs and practices (or first principles) can be used to address these issues. Two further areas of research/study arise. First, scholars and practitioners can reexamine religious texts and traditions via social, cultural, and rights understandings of disability, helping shape new appreciation of disability in tradition. Second, disability stories/experience can shape belief and revised practice within a given religious community, often in the name of inclusion or acceptance.

CORE RELIGIOUS QUESTIONS

A common thread in religions about disability is the human search for meaning in the world. There are also common questions about life in different faith traditions and similar forms of exploration. Comparative religion scholars approach those in numerous ways. Two basic dimensions have already been noted: belief and practice.

Four questions/dimensions identify the ways religions and faith traditions understand and relate to disability:

1. What is the belief about the source of disability (i.e., why it happened) and the role of God or the divine?
2. How does that understanding of source affect the understanding and identity of a person with disability?
3. What, then, is the role and purpose of the person with disability in society? In other words, "what am I called to do?"
4. What is the role of the community of faith—that is, what are others called to do, out of their faith, toward persons with disabilities?

EXPLORING WHY: DIVINE ROLE AND PURPOSE

All religious traditions struggle with asking and answering the question "Why?" regarding suffering, death, and difference/deviation. The answer is usually in terms of divine origin (God caused it or sent it) and/or personal responsibility (my fault or someone else's). Given that most faith traditions envision the divine in charge of events in life and mostly have understood disability as misfortune, a central thread in many faith traditions is that disability is a sign of punishment, moral deviance, or some kind of fallen state.

Thus, in Christian traditions, a disability such as epilepsy might be seen as demonic, or the control of an evil spirit, as in the story of the Gerasene demoniac in the Gospel of Mark. In Judaism, the exclusion of some forms of disability from religious practice or community has often been quickly interpreted as a sign of divine disfavor or as the result of punishment or sin ("The sins of the parents are visited upon the children. . . ."). In Islam, disability has been interpreted as a misfortune sent by Allah or as a challenge to the individual and his or her faith. In Hinduism and Buddhism, disability has been interpreted as something fearful, a punishment for a misdeed in a former life, or one's karma. People with disabilities and families across many faith traditions can recount stories of the ways that blame, fault, or sin has been ascribed to them by others, with the added weight of God's will and punishment.

Disability has also been portrayed as a sign of evil or fallen state, with its absence portrayed as a sign of healing or of paradise. Thus, people with disabilities struggle with common understandings of the healings by Jesus in which their disability is cured, or their capacity for healing is equated with the depth of their faith. In Zoroasterism, there was a core vision of a perfect world in which there was no disability or death, a vision with similarities in heaven in other religions. The contrast of a perfect, disability/disease/suffering-free society is central to the founding story of Buddhism, where the young Buddha, raised in a world free of suffering, encounters it for the first time as he moves out of the castle into the world. His life, and the world's, is forever changed.

But there are also interpretations within major faith traditions that see disability as more neutral, as a challenge to the individual and his or her soul. Going further, in Judaism, Christianity, and Islam, there is a strong belief in the sacredness of every life, and in Eastern religions, there is more focus on the importance of the connection of the individual to the community and the whole of creation. A famous text in the New Testament (John 9) disconnects the equation of disability with sin when the disciples ask Jesus why a man was born blind. The disciples asked whether it was the fault of the blind man or his parents. Jesus' response was, "Neither . . . he was born blind so that God's works might be revealed in him." That captures an understanding of the role of people with disabilities in wider society, in which religious traditions see the disability as an opportunity to teach lessons to others. In Buddhism, the question is not whether God caused the disability but how one's mindfulness and spiritual discipline might shape one's response.

The importance of historical, exegetical, and theological research in this area is shown by the ways that popular religious understandings equating disability with sin or punishment by God are in fact challenged by a more disciplined exploration of religious texts. Religious credence has often blessed or enshrined social attitudes, even perpetuating rather than challenging them. Yet careful research begins to note, for example, that Jewish understandings of disability did not equate it with deviance. Disabled people continued to be part of the community. The blind Levite could not be a priest because one of the functions of a priest was to examine sacrifices for the lack of blemish. A disability did not keep a person from being a major religious leader (e.g., Moses and his speech defect, Jacob and his limp, and Paul and his "thorn in the flesh"). Religious leaders in many traditions have been blind or had other disabilities that were thought to imbue them with special vision and insight. A careful exploration of the understandings of disability as karma can reframe that understanding of disability as punishment for a sin in a former life to a belief that, in a former life, one might have mistreated a person with a disability or been guilty of pride or arrogance, and thus this current disability is a time for rehabilitation, a necessary corrective stage in the journey of one's soul.

Largely nondisabled accounts of divine purpose regarding suffering led to understandings of disability as punishment or evil when the divine is understood as all powerful or in battle with other gods (demonic) or when disability is interpreted only as misfortune and suffering. In more recent times, as science and other disciplines have shaped new religious understanding, religious leaders such as Rabbi Harold Kushner (also a parent of a child with a disability) have questioned whether God is all-powerful. Disability begins to be understood in terms of physical origins, just like other conditions and differences. Other religious traditions and understandings have claimed the "specialness" of people with disabilities in divine creation. Whether that comes out as "angels unaware" or "inspiring example," it is the opposite end of the spectrum of religious interpretation of misfortune as either evidence of bad/evil or good/blessing. Some theologians have also begun to explore the question of how disability relates to our understanding of the divine (e.g., Eiesland 1994).

DISABILITY AND IDENTITY: RELIGIOUS DIMENSIONS

The spectrum from "evil/demonic" to "good/special" also reflects disability as a major characteristic shaping and defining personal identity. Disability is defect, and thus the person is defective. The individual or family becomes the bearer of whatever religious interpretation is placed on the disability, ranging from demonic, curse, and punishment to special and holy. Disability is the fault of the individual/family, the fault of a former incarnation, or God's will/design. Disability thus controls and is a person's identity, rather than being just one of many characteristics. Thus, people with disabilities were seen within religious traditions as they were within society, as "the blind," "the lame," "the possessed," the "idiot," "the deaf," and so on.

Social and religious identities and roles are thus intertwined. Evil and thus shunned or avoided, people with disabilities were often scapegoats for religious questions and social worries. Social and economic factors combine with negative attitudes to create structural disadvantage. In some societies, that led to the religiously sanctioned practices of killing infants with severe disabilities. In others, identity meant a life as "beggar," with the expected religious custom and behavior of supporting those who were weak, a feature in Judaism, Christianity, Islam, and Eastern religions.

The opposite is also true when identity was seen as "special" or "holy." Those traditions ranged from practices of having people with disabilities as jesters in courts, or collected by royalty for entertainment, to beliefs that a person with a disability may have a special ability and capacity to reveal the divine. As will be noted later, in some Eastern religious and cultural traditions, people with various disabilities were expected to develop particular gifts, such as becoming musicians or storytellers. In the Christian tradition, the "deaf" shall in fact "hear," the "blind" see, and "last" be "first."

In contrast to an either/or spectrum of identity, many religions also affirm the value of each person. In Judaism, all humans are a disclosure of the divine, each created "in the image of God." All life has value. All life is a gift. All life has strengths and weaknesses. Christianity is full of stories of Jesus recognizing and affirming the humanity of each person and using the gift of healing not only to remove a disability but also to overcome projections of sin and punishment and restore a person to the community. In Islam, all creation is to be honored. Allah's measure of worth for a person does not depend on physical attributes or achievement but on spiritual maturity and development. Thus, for example, Islam was one of the first faiths to see deaf sign language as valid social and religious communication.

Hence, in all major faiths, there are affirmations of the worth and value of each person. However, evidence of disablism, as well as an illustration of the way that religious attitudes both shape and are shaped by social attitudes and understanding, is found when the language and terms of disability are used as metaphorical descriptions of defective faith and character. For example, in the Qur'an, people could be deaf to the law of Allah or blind to the true path. Lack of faith could be described in terms of disability, and disability was then seen and interpreted as a lack of faith or evidence of wrongdoing. There are many forms of diminishment found in disability labels, with their negative meanings to describe "nondisabled" people whose faith or practice was considered inadequate, wrong, or defective. Yet the ways that people with disabilities have been treated by religious people, communities, or societies can also be used as examples and metaphors of faith that is righteous and just.

As disability is increasingly seen as one part of a person, with difference an expression of human diversity rather than disease, there are new frameworks from which to explore the religious understandings of the giftedness, value, limitations, vulnerabilities, and call of every person and community.

A CALL? THE ROLE AND PURPOSE OF DISABILITY

The purpose of life is a central theme in all faith traditions, with wide variation. For some, it is to follow an individual call, to be a disciple in the Christian tradition, to continue learning in Jewish circles, to keep seeking truth in Islam, to move toward mindfulness and understanding in Buddhism, and so on. The sense of vocation, or following the purpose of one's life, has been much proscribed for people with disabilities by others. Thus, one might ask, was the role for people with disabilities often that of beggar because of their disabilities—that is, was that the only thing they were allowed to do? Or, conversely, we might wonder how social conditions and poverty contribute to disability over time, as they do today, and thus prescribe roles from another direction. This is one area where the social and contextual understandings of disability need profound study and reflection in faith traditions.

Many faith traditions also have affirmed that people with disabilities face the same obligation to obey the divine and practice their beliefs as anyone else, with considerations taken for their disabilities. In Judaism, the person with a disability was obliged to observe the Sabbath and, if a man, could be counted in the minyan for a worshipping community. People with disabilities could not be priests, but in Leviticus, only Levites could be priests, and Levites with disabilities could still eat the food in the temple. In many faiths, rites of passage could be adapted for people with various forms of disability. A fascinating debate in early Islam was about whether people with intellectual disabilities could inherit family resources. That gave rise to some of the first guardianship provisions, as well as a debate that said to take away a right to inherit and the right to make a mistake like anyone else was worse than losing a family fortune.

In Islam, if one could not make a living because of a disability, then one could appeal to Allah and the community for justice, not necessarily charity, because if Allah deprived one of the ability to earn, then it was the duty of everyone to give that person his or her due. People with disabilities were exempt from military service but could serve if they wanted. There was no blame for the lame or blind if they could not participate in other duties, but everyone should still respond to the call of God as much as they can. A Christian understanding of people with intellectual disabilities as "holy innocents" often exempted them from any responsibility and thus denied them a capacity to learn.

In Far Eastern traditions, such as Daoism, there are parallel understandings of the potential "special" role of people with disabilities but also philosophical and religious understandings that "uselessness" could have its own merits. The useless could outsmart the "useful," who tend to get used up (e.g., by being killed in wars). There are parallels here in Christian theology that reflect on the power of the "powerless." There are also Japanese traditions of guilds of professional musicians and storytellers who are all blind.

In every major faith tradition, there are stories of religious leaders with disabilities. We can legitimately ask whether that "holiness" is ascribed to them because of their "difference," such as how they learned how to deal with their situation and/or whether it was a function of living on the boundary between ordinary, divine, and/or demonic worlds. There are also stories, with many different interpretations, about key religious leaders being challenged by a person with a disability, including the famous story of Muhammad being rebuffed for turning away a blind man, Jesus being called to task by people with disabilities, the young Buddha being profoundly changed by death and disease, and more. Yet in most traditions, disability is an impediment to pursuing religious vocation (e.g., admission to a monastic order, seminary, or Holy Orders). This, again, is an area of great change, as people with disabilities seek to break out of confining expectations and disabling environments. As religions seek more valued social roles and callings for everyone, perhaps we also will recover traditions from the past in which every person was expected or had to work simply because families and communities could not afford for anyone to be idle. Religions may now help individuals and societies to reevaluate the vocation or calling of a person with disability.

DISABILITY AND COMMUNITY RESPONSIBILITY

All of the major faith traditions call for people to practice faith in relationship with others, calling for people to be compassionate to others in pain, suffering, or want. In Christianity and Judaism, it is called the Golden Rule. In Islam, charitable acts were not to be done out of pity but as a gesture of seeking good will from Allah and, as noted, establishing justice by giving people their due. Like Judaism, most faith traditions have equivalent injunctions to the commands that others should not put stumbling blocks in the way of the blind, make gestures at them that they cannot see, or curse the deaf. One was not to mock or obstruct people with disabilities. Even if they did not know, God saw. These acts of charity, many of which formed the basis for social support agencies of all kinds throughout the centuries and certainly in modern times, are just as much a part of religious traditions as are the stories and examples of religious shunning of people with various forms of disability because of assumptions about sinfulness and punishment.

At another level, religious faiths have often used the treatment of people with disabilities, along with the treatment of the "weak," "poor," and "widows and orphans," as a measure of the righteousness and character of the society. Jewish prophets, Islamic scholars and leaders, and Christian ministers and leaders have all suggested that society is to be judged by, or will succeed only through, the ways it treats the "least of these." This has led in the past century to new forms of religious advocacy, service, and explorations of the ways that faith and religious communities have a responsibility not just to care for but to include people with disabilities and their families.

In many places in the world, the religious call to charity or service is the major foundation for social services and supports for people with disabilities. In others (sometimes the same places), modern understandings of the abilities and rights of people with disabilities are at odds with confining religious/social attitudes. And in others, people with disabilities and their families are challenging a system of services and supports based on a charity model, whether it comes from a "religious" or "secular" source. A major challenge exists in many Western countries, where governments may use charities auspiced by religious traditions to deliver welfare, sometimes requiring service practices that can marginalize clients.

A BRIEF HISTORICAL OVERVIEW

The examples cited in this discussion of four dimensions of religions and disability emerge from recent research into the historical intersections between religion and disability. Yet the narration and findings of that history depend in measure on what one looks for, in terms of both positive and negative outcomes for people with disabilities and their families. Researchers are beginning to uncover and reexamine old stories and long-held assumptions, and they are finding ways to overcome the fact that disability is not often a major theme in any religious creed, system, or scripture.

Recent scholarship points to ancient rulers in Eastern traditions whose religion and faith led them to develop disability supports and service. Early Islam was one of the first traditions to recognize the rights of people with disabilities, such as the deaf, and develop services for people with mental illness. Christian hostels formed early community services for people with disabilities and were often connected in medieval Europe to the village or town cathedral. Jewish scholars and traditions explored "functional" definitions of disability long before it became a modern practice.

In the past century and a half, in North America and Europe and elsewhere, religious communities have often been the impetus for new services and supports, even if they were gradually taken over by public or secular professions and services. Since the 1950s, there has been growing attention to the intersection of religion and disability, as religions developed special religious education programs for children with disabilities, formed "deaf ministries" networks, and began to work on making religious buildings more accessible and religious communities more inclusive. Leaders such as Helen Keller in the area of blindness, Dorothea Dix in mental illness, and Harold Wilke in physical disabilities, along with Jean Vanier and L'Arche communities in mental retardation and intellectual disabilities, have changed both religious understandings of disability and spawned countless new practices and services. Since the International Year of Disabled People in 1981, most major faith traditions have developed and disseminated position papers and statements on faith and disability, such as the Roman Catholics Bishop's Pastoral of 1979 or the World Council of Churches statement of 2003.

In more recent developments, there have been partnerships such as the Accessible Congregations Campaign in the United States, coordinated between secular and religious support organizations. Christian and Jewish groups have developed strategies for accommodating religious education, worship practices, and rites of passage to include children and adults with any form of disability. There has been an explosion of written resources for Christian and Jewish networks, as well as the beginnings of scientific research into the power and impact of spirituality and spiritual supports for people with disabilities and their families. One example is the national *Space to Listen* research project by the Foundation for Learning Disabilities in the United Kingdom, which explores the role of spirituality in the lives of people with intellectual disabilities. The *Journal of Religion in Disability and Rehabilitation* has developed into the *Journal of Religion, Disability, and Health.* Theologians and practitioners are exploring ways to include disability in theological education and to affirm the right of people with disabilities to be in training for religious roles.

While admittedly Western in focus, this brief overview points to the huge need for further cross-cultural understanding and research. Some positive developments highlighted are not meant to hide the ways in which faith traditions and practice still often oppress people with disabilities and their families. There are huge questions, such as why religious traditions and communities have often been at the forefront of leadership in civil and human rights in North America but not so connected to the disability rights movement.

It is clear that the intersection of religion and disability:

occurs at many different levels and dimensions, from scholar through the intense believer to the public stereotypes of both religion and disability;

includes many voices, backgrounds, and perspectives—disabled and nondisabled—and a huge diversity of religious understandings; and

affects many areas of "religious" life, such as worship, theology, ritual, ethics, understandings of tradition and history, and reexamination of sacred text, all with implications for individual and community responsibility and practice.

This complexity and diversity has vast room for research and dialogue, the potential for all kinds of misunderstanding and oversimplification, and the possibility of building new bridges of understanding between people with and without disabilities, theoreticians and practitioners from many disciplines, and followers of many different faiths.

—Bill Gaventa and
Christopher Newell

See also Developing World; Judaism; Middle East and the Rise of Islam; Representations of Disability, History of.

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REPETITIVE STRAIN INJURIES

Repetitive strain injuries (*RSIs*), *cumulative trauma disorders, repetitive motion injuries,* and *work-related musculoskeletal disorders* are synonymous terms describing a broad range of injuries resulting from excessive use of the spine, arm, hand, leg, or foot. In 1999, these injuries constituted 9 percent of the injuries in U.S. private industry that resulted in lost workdays. Wrist and hand problems accounted for the majority of the injuries and were the most costly and the most disabling. Some health care systems no longer accept a categorical diagnosis of RSI and insist on more specific diagnoses (e.g., tendonitis, neuritis, fascitis, myositis, carpal tunnel syndrome, thoracic outlet syndrome, cubital tunnel syndrome, degenerative arthritis, tendinosis, fibromyalgia, herniated disk, focal hand dystonia, neuropathic pain).

Healthy tissues constantly turn over, repair, and remodel, a maintenance function that requires good hydration, nutrition, and balanced loading and rest. Normally, structural tissue damage postinjury activates a cellular cascade to mediate the inflammation and initiate repair. However, in patients with chronic repetitive strain injuries, cumulative loading can lead to reduced perfusion (blood supply), poor axonal transport of peripheral nerves and excessive tissue inflammation, scarring, cell compression, matrix degeneration, muscle fiber loss, and cell death. This can lead to tissue discontinuity, biomechanical irritation, pain, and change in the type and organization of the collagen in tendons and ligaments that alters strength, compliance, and flexibility. Thus, some individuals with RSIs can develop severe pain (with or without inflammation), others lose strength and endurance, and still others experience excessive fatigue, poor sensorimotor feedback, and painless loss of fine motor control, specifically at the work task (focal hand dystonia).

Repetitive microtrauma is usually classified by stage:

> Stage 1 = injury, probably inflammatory without pathological alterations
>
> Stage 2 = injury associated with pathological alterations
>
> Stage 3 = injury associated with structural failure (rupture)
>
> Stage 4 = injury meets criteria for stages 2 and 3 plus other changes, such as osseous calcification

This classification system focuses on the soft tissue response to injury without consideration of secondary, aberrant central nervous system degradation. Risk factors for RSI include occupation (e.g., heavy, stressful schedules of repetitive hand use that demand high levels of accuracy and progressive task difficulty), biomechanics (e.g., end range, forceful movements), patterns of use (e.g., rapid, stereotypical, near simultaneous, alternating movements), personal health (e.g., prior injury, disease status, hydration, fitness), psychosocial issues (e.g., emotional state, personality, perfectionism, anxiety, family support), and administrative factors (health care coverage, disability benefits, legal issues). These factors can affect the incidence of injury, the extent of the impairment, the potential for recovery, and the magnitude of disability.

Treatment initially includes rest from work, rest of the part, and anti-inflammatory medications. Ideally, intervention should also address prevention, including ergonomic modifications, decreased forceful repetition, aerobic and postural exercises, good hydration, and nutrition. If disabling signs and symptoms persist, intervention must factor in the stage of tissue pathology, the extent of tissue damage, the status of change in cortical function, and whether surgery, medications, therapeutic modalities, assistive devices, and/or therapeutic exercises, including learning-based sensorimotor training, are essential to recovery.

—Nancy Byl

See also Fibromyalgia; Spinal Cord Injury.

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REPRESENTATIONS OF DISABILITY, HISTORY OF

Patterns of the historical representation of disability in literary, artistic, and visual media cannot be generalized. This is due to the fact that while all cultures have wrestled with the meaning and nature of disability, social responses themselves vary greatly across time, region, cultures, and situations. Nevertheless, a survey of disability representations demonstrates the degree to which human differences pose substantial conflicts for all communities. Thus, representational art has always grappled with such conflicts, and these documented efforts create a significant historical discourse about disabled people.

Here, we define representation as the efforts of cultural workers to speak on behalf of an individual or group in artistic arenas. While one may argue that images of disability in any textual or visual arena are equally imaginative, we are primarily interested in the specific productions of disability in genres identified as "creative." Representation suggests an effort to imagine perspectives difficult to come by in our everyday lives. In part, this places an ethical demand on art to conjure the lives of those significantly distant from a reader's own experience. The historical sequestration of disabled persons makes them a common representational objective in that artists employ the uniqueness of such perspectives as an impetus for generating audience interest. For instance, in the Greek play *Philoctetes,* the abandonment of the disabled title character on an island because he is inconvenient and "un-useful" ultimately makes it necessary for his fellow warriers to return to retrieve him. Besides recognizing that Philoctetes holds Heracles's bow as a weapon, which could ensure victory in war, his literal absence also causes significant interest as to how he has lived and what wreckage on his psyche the impairment (a painful, festering wound) has caused. His abandonment results in the necessity of a return to the society that originally rejected his body, as if his removal ultimately comes full circle back to our interest in what has become of him. Since representation produces one thing that stands for another, the drama of Philoctetes's rejection ultimately becomes an opportunity to contemplate social tolerance toward difference. Therefore, disability's common ouster from social contexts ironically results in ritualistic returns in imaginative texts. One is tempted to draw a mathematical formula of inverse relations: the degree to which an experience appears absent from social life determines the degree of interest lavished on that object in artistic discourses.

Consequently, while many minority groups have argued that social marginalization occurs, in part, as a result of the absence of their images in artistic discourses, images of disabled people suggest a different representational fate. Their social marginality has occurred despite widespread circulation. In fact, the presence of disability, as allegory, motif, and social cause, can be said to serve as a critical component of a further silencing by representation that disabled persons may experience. In contemporary life, this circulation may be due to the mysteries that attend to bodies that have been hidden away for their lack of propriety. Whether for the sake of charitable act, freak show shock, indication of mysteries, evidence of suffering, or body difficulty that requires social attention to research and prevent it, representations of disability have remained central to acts of cultural production. Until recently, with the generation of a collective discourse concerning disability representation, this circulation of disability imagery has been little discussed by critics, historians, and cultural commentators. Recently, open interpretation of the disability implications of artistic discourses has occurred as an educational and research priority that accompanies deinstitutionalization and human rights initiatives on behalf of disabled persons. Still, representational critique refers us back to a lack of social consensus as to whether access and inclusion, as opposed to cure or sequestration, are the best goals to be held out for disabled persons.

Disability persists as a perpetual topic of commentary (particularly in representational mediums) due to a variety of historical developments:

1. Disability has largely been consigned to the domain of medicine as a matter of individual dysfunction or insufficiency.
2. Stories about disability often conclude with solutions that result in the erasure of impairments either through death or cure.
3. The alleviation of disability in our cultural narratives ultimately asks nothing of the wider society in terms of accommodation, political action, or social recognition.
4. Stories about disability have often featured a single individual existing without reference to a larger population of like-minded/embodied individuals.

While exceptions to these four general patterns of plot certainly exist, as narrative winds its way toward surprise, suspense, and satisfactions for the recipient, the list helps to explain the reasons why disability may be overlooked as a significant mode of characterization or metaphor in literary critical history.

Throughout the scant written records of ancient civilizations such as those from the regions of ancient Mesopotamia and Greece, one encounters the mark of disability as commonly relating to a metaphysical predicament. This fact alone suggests that the appearance of characteristics deemed highly distinctive, while presumed largely detrimental by other social residents, occurs with some frequency. Within the texts of these ancient societies, disability is often treated either as a punishment visited upon individuals and communities for the sins of the past or, at least, in a purely symbolic way as a message from the gods that must be interpreted. In either situation, disability references the mysterious ways of divinities and their unpredictable plans for human communities. At the epistemological level, ancient civilizations often treated disability as if it represented an encoded missive from a vaguely discernible extraterrestrial order—one that demands recognition of its symbolic significance and an appropriate response from the community at large.

Thus, we witness the existence of early prophetic texts, such as cuneiform tablets or oracles that predict future outcomes as encoded by the bodies of aborted fetuses and babies with birth disabilities. For instance, ancient Mesopotamian texts interpret human and animal "deviancies," disabled fetuses and demarcations in sacrificial herd animals, as a sign that something serious is in store for the recipient culture. These references by anatomical difference do not necessarily predict negative events—in some cases, predications about organic differences remark on lengthy regimes for a ruler or a favorable harvest. Yet, more often than not, metaphysical readings prompt visions of cultural catastrophe. Characteristics considered deviations from societal norms rarely refer to individual fates in these early texts. Instead, an entire community or society will be implicated by the meaning derived from a single anatomy. Thus, the arrival of visibly disabled offspring must have precipitated significant anxieties among leaders and citizens alike. Reported practices of the infanticide of "deformed" or "unhearty" children help to solidify this interpretation.

In classical Greek literature, perhaps the first extensive repertoire of disability texts available for scrutiny, we meet up with well-known characters such as the blind and hermaphroditic prophet Tiresias, the ensnared and cane-walking hero Oedipus, the untimely wounded Philoctetes, and the one-eyed gigantic Cyclops representing wholly other physical castes of tribes—among many others—whose bodily differences signify the need for their location on the periphery of various communities. Yet, whereas prophetic texts contended a direct correspondence between disability and social fate, these texts offer up reflexive contemplations of the question. While many narratives eventually justify exclusion based on human differences or presume a naturalized segregation of communities, there are numerous instances where social exile is shown up as an insufficient solution.

In much Greek literature, disabilities function as a sign of a character's "tragic flaw" or "compensatory insight." Tiresias's blindness provides him with an uncanny ability to predict the future and provide sagely commentary on a range of social conflicts; Oedipus's limp (a result of his father, Laius's, efforts to pin his ankles and leave him to die of exposure on a hillside) allows him to draw from his experiences of disability to solve the riddle of the sphinx (an anomalous hybrid figure in her own right); as discussed earlier, Philoctetes's agony from an untreatable wound prompts his fellow soldiers to abandon him on an island; and Cyclops's monstrosity is emphasized by physical characteristics that mark him both as racially foreign and less intellectually agile than his wily captives. Each of these stories turns on revelations drawn directly from the specific disability of each character. Thus, it can be said that Greek literature helps to initiate the long-standing historical reliance of literary characterizations upon disability as a means to differentiate heroes or villains from their less distinguishable (and thus often less storied) literary peers. For instance, the cycle of plays about Oedipus (translated from the Greek as "swollen foot") seems to hurdle toward the revelation that his limp marks him as an ill-fated agent. In other words, the meaning-laden significance of disability must be recognized for its social layering, its predictive consequences, and its psychological, albeit angst-ridden, complexity.

Whereas one finds key literary characters accompanied by disabilities in ancient literature, early Christian and Islamic sources adopt disability as either a strict marker of exclusion or as a generic characteristic of denigrated populations. The Hebrew Bible, for instance, tells the story of Jacob's struggle with his faith (represented as a "stranger" at the river) that results in a permanent disability from severe hip dislocation; Leviticus defines priestly purity primarily through the absence of disability as a source of potential contamination; Tobit's blindness allows him to be duped and then is "cured" by God as a reward for his daughter's loyalty; and Mephiboseth's childhood accident leaves him with a mobility impairment that both disqualifies him from his rightful claim to the kingship and provides him with an all-purpose excuse for his various shortcomings. There is little questioning or interrogation in the Old Testament regarding the way disabled persons should be addressed. Commentators struggle over translations that only continue to certify a naturalized derogatory meaning such as that King David is said to hate the blind and lame and therefore desired their eradication en route to conquering Jerusalem.

In contrast to this narrative tradition, the New Testament seems to offer a more rewarding series of scenarios. Cripples, deaf-mutes, the blind, and epileptic individuals show up with some regularity in these stories—particularly at key moments when the prophetic powers of Christ or his disciples prove in need of exhibition. Still a largely mass phenomenon, disabilities arrive as the characteristics of hordes of unfortunates, as if human vulnerability equates with the imperfection of an earth-bound existence. One finds some of the first lineups of disabled people as supplicants in these stories as an opportunity to demonstrate divine capacities exercised upon human imperfections. This foregrounding of misery through suffering embodiment situates early religious texts at the origins of a lengthy tradition of disability representation. Many biblical scholars have championed the cure of cripples in the New Testament as a historical transition of acceptance toward destitute populations. Furthermore, some scholars have argued that the flayed and broken body of Christ indicates an early form of social integration toward imperfection and suffering on Earth.

However, a paradox of the cure scenario, so often repeated in New Testament writings, turns upon the erasure of disabilities. An alternative tradition of argumentation has begun to take shape around interpretations of miracle cures as the obliteration of human differences rather than as justification for integration or social acceptance. At the very least, the parallel of divinity with the remedy of dysfunction, incapacity, or aesthetic deviation makes little demand on action at the level of wider social networks. Short of existing in a moment populated by a magical healer (the figure of Jesus Christ as one of the first rehabilitation specialists), disabled people (one might suppose) whose differences cannot be erased would find their integration hardpressed at best. Later Christian works, such as those contained in St. Augustine's *City of God* or the stories of St. Francis of Assisi kissing a leper, provide examples of piety demonstrated by the efforts of religious figures to eschew their worldly possessions and live among the downtrodden. A conspicuously promulgated morality exists in decisions to take up an intimacy with those excluded on the basis of fears of contagion, aberrancy, and social transgression.

Meaningful alternatives to these Western traditions of disability representation can be identified among traditions in the Middle East, Asia, and Africa, where disabled people can be found performing important social functions. Such productive representations of disabled people's contributions can be found in works such as "The Meadows of Gold" by Al-Ma'sudi (c. 896–956 CE), which tells a tale of a deaf person thought most worthy to represent the inhabitants of Kufa to the Caliph and also includes discussions about Abu al-Ayna, a blind person of great wit. In addition, the biographies of several prominent deaf, blind, and physically disabled people are detailed by the thirteenth-century Muslim writer Ibn Khallikhan in his biographical dictionary. Such biographies of exceptional persons include a learned blind man in Basra named Katada Ibn Di`ama As-Sadusi (679–735/6); Abu'l-Aswad ad-Duwali, who limped in public and experienced seizures from "palsy" (d. 688/9); renowned deaf teacher Abu'l-Abbas Muhammad Ibn Yakub al-Asamm (d. 957); Muhammed Ibn Sirin (653/4–729), the deaf law lecturer who also wrote one of the early translations of the life of the prophet Muhammed; poet Dibil Ibn Ali-l-Khuzai, who was reportedly deaf and hunchbacked from a "scrofulous swelling on the back"; and Abu 'l-Abbas Ahmad Ibn Yahya Ibn Zaid Ibn Saiyar (also known as Thalab the Grammarian), who became deaf but continued as an influential scholar in Baghdad. In addition, we might also look to the *Semimaru* (Plays of the No Theater) in Japan, written by Zeami during the twelfth century. These plays feature the exploits of a blind *biwa* player who lived on Mt. Osaka and was sentenced to death because of his visual impairment by his father, Emperor Daigo. Zeami's renown as a musician caused the son of prince Minamoto Hakuga to make a long, difficult trip just to hear him play.

In various Asian locales, there exists a long tradition of cultivating the talents of people with sensory disabilities in one particular skill such as music or massage. Far fewer examples of similar investments in those with cognitive or physical disabilities exist. However, a few examples of recuperated meanings around historical individuals with physical disabilities may be found. If we research back to ancient Egypt, King Amenemope, the fourth ruler of the twenty-first dynasty who ruled a substantial kingdom from 993 to 984 BCE, is reported to have had a series of visible physical differences identified in the many statues of him left behind such as an elongated head, large ears, distended stomach, and wide hips. Similarly, we might also reference the later example of the African Oba of Benin (1500–1597), who, upon experiencing lower limb paralysis, claimed that his legs had been transformed into the sacred mudfish. Since mudfish can navigate land on their legs and swim in water, they served as a symbol of the king's capacity to move between earthly and spiritual realms. Such an inversion of the meaning of disability saved this oba from the fate of his predecessors, who were often executed after falling ill. While such examples suggest individuals with disabilities of exceptional talents, they may also gesture toward the possibility of a more inclusive cultural moment in which disability did not automatically disqualify one from participation.

Of course, as in any tradition, one can also find evidence of more dehumanizing treatments toward people with disabilities. For instance, in eleventh-century Persia, instructional manuals for princes published by Kai Kaus ibn Iskander ibn Quabus (1082/3) inaccurately argued the following: "all dumb (i.e., mute) people are deaf" because they lack access to oral speech. In the wake of such beliefs, reports exist that Emperor Akbar undertook some early experimentation on disability by raising groups of children with deaf-mute nurses in a locked house. In addition, there exist many reports from European travel writers that the Ottoman court employed dozens of deaf-mute individuals as reliable servants to various rulers. Their valued capacities included beliefs that the impairments of these individuals rendered them incapable of hearing or bearing witness to the behind-the-scenes escapades of those in power. In these instances, incapacity becomes an ironic "value" while also overlooking the fact that sign languages served as an equally powerful means of communication among presumably incommunicative subjects.

Other than these brief references to the role of disabled people in various rulers' dominions, disability in the Middle Ages becomes increasingly sidelined as an expression of human difference. One finds some early treatment texts on devastating plagues such as those on leprosy and compound fractures of the skull. The sudden diminishment of disability as a common representational device (if this can be said to be the case) may be interpreted in a number of ways. This noticeable dearth of representations signals a new and perhaps even more pronounced disregard of disabled people. One gets the feeling that late Christian texts in this period, such as St. Francis's devotion to communities of people with leprosy as well as the practice of other religious figures renouncing material goods while taking up residence with the poor and incapacitated, play out efforts to combat this widespread neglect. Likewise, we could look to *The Book of Margery Kempe* (1430) for an example of a medieval woman's guild of the Holy Trinity that devotes itself to the care of convalescing disabled women. Such examples, as some scholars have argued, may represent shifting values about human embodiment and a new devotion to those most vulnerable to the violence of social rejection. Disabled and poor people become enshrined during this period as a population that some refuse to reject as deviant or unworthy of human care.

Yet, we might also consider the degree to which devotions paid to socially marginalized peoples provide a moral opportunity in this period to ensure one's own right to salvation in an afterlife. In other words, devotion to the "less fortunate" becomes a powerful system of exchange in this period, wherein one commits oneself to support of these communities as a way of guaranteeing outward signs of divine "election." We could celebrate these examples of religiously derived support to those who are often violently excluded during this period, without having to relinquish analyses of the social benefits that accrue to those who practice benevolent devotions.

Another possibility is that we might comprehend the fading significance of representations of disability during this period as a product of rampant social crises in the transmission of diseases. If much of Europe, for instance, found itself exposed to the ravages of various plagues, then a deepening sense of human vulnerability might have developed. Disabled people have often held down the terms of a radical frailty that others find threatening. Efforts to distance ourselves from disability often expose the degree to which we fail to acknowledge our own potential exposure to various human-made and natural forces. Perhaps one could locate this period as an example of a time when many people felt as if their mortality and/or functionality could be easily compromised, and thus the ability to distance oneself from the vagaries of human embodiment undermined a more explicit division across bodies. Perhaps the degree to which one could afford to recognize disability as a chasm between ourselves and others collapsed during the period, resulting in a failure of common othering strategies determined by investments in bodies and minds as a reliable partition between the vulnerable and invulnerable. We might also look to later texts such as St. Augustine's *City of God* (1467) for its efforts to challenge common beliefs in "monstrosity" as somehow outside of a divine plan of the universe of human embodiment.

However, somewhere between the fourteenth and sixteenth centuries, one starts to witness a desacralization of disability. While various religious systems continued to recognize disabled bodies as an object of charitable investments (massive charity networks developed just prior to this period), a corresponding secularization of disability begins to develop. Although earlier examples of state- and community-sponsored supports exist—such as the monetary provisions to disabled persons identified in the Athenian Constitution of ancient Greece—European legislation of various kinds becomes increasingly numerous. Most of these policies served as early "diagnostic" efforts to divide the "deserving" from the "undeserving" poor. This division would prove key in most Western locations, in that productive capacity to labor became increasingly critical to the definitions of citizenship in the modern nation. Accompanying the rise of urban trading centers and the decline of feudalism as a dominant economic system, cities and towns passed numerous ordinances to punish idleness and the practice of alms seeking. In the English Statute of Laborers, approved in 1349, imprisonment was used as an incentive to compel most citizens into "labor[ing] for their necessary living." While this early legislation identifies a vague group of social misfits based on unwillingness to labor, later legislation deepens this division based on the status of "cripples" as a material inability to work. In addition, such legislation suggests at least the suspicion of an outbreak of crippled pretenders—those who would feign disability to pursue begging as a viable career option to other socially recognized forms of labor. Later, around the year 1697, these English laws were further amended to require that those who were legitimately "on relief" had to wear a badge or mark (such as a large "Roman P") visible to all on their clothing. Such badging efforts were portrayed in the pinning of fox tails on disabled beggars, as seen in Pieter Brueghel the Elder's famous painting of "The Cripples" (1568), now hanging in the Louvre in Paris. Similar badging practices were resuscitated in National Socialist Germany during the 1940s toward those targeted on the basis of disability, sexuality, ethnicity, and race. These two systems—charity and labor capacity—continue to compete for interpretive authority for several hundred years; in fact, we could say that they continue to struggle for cultural capital as two primary modes of modern disability response.

From 1500 to 1800, we witness an explosion of works about "fools" and "court jesters" that represent social struggles over the presumably decreased capacities of individuals with cognitive disabilities and deafmutes, as well as the power often bequeathed to these individuals by rulers and other prominent members of ruling regimes. The court fool was ridiculed and scoffed at for these idiosyncrasies and served as a source of entertainment for gatherings at various royal assemblies. Yet, in addition to these prurient practices of human exhibition, celebrated fools also managed to garner a significant degree of power for their roles. Some individuals with cognitive and physical disabilities were thought to communicate in more metaphysical realms such that their "babblings" proved alarmingly insightful. While most participants in a leader's entourage were expected to comply with and support the dictums of their ruler, fools often found some room for maneuver in these circles. They could openly critique and satirize the doings of those in power as if fools provided a mirror to the rulers under whom they served. Such characters proved relatively singular in these instances, but their mockery provided an effective antidote to the arrogance that often developed in ruling circles. The Spanish painter Velasquez captured the function of fools as agents of critique among hierarchies of power when he positioned his jester figure as the lone individual whose stare breaks the plane of the painting and meets the gaze of viewers directly. The figure poses as both amused and knowing—as if he holds secrets that might easily undermine the "pretense" of the aristocratic family in which he serves.

Texts by European travelers to modern-day territories such as Turkey, the Middle East, and northern Africa during the period between 1500 and 1800 all describe the multitudes of disabled populations in attendance at various ruling class ceremonies. Hordes of deaf-mutes, dwarves, dumb men, eunuchs and women of seraglios, and others provide evidence of the degree to which human differences did not exclude one from participation at the highest levels of culture (no matter how hierarchical and diminished such inclusion might prove). One inventory from 1594 of the royal court in Constantinople by the English traveler, John Sanderson, lists the employ of 300 "falconers, dwarfs, and dome [dumb] men" in a workforce of more than 1 million for Sultan Murad III. As in the earlier discussion of deaf-mutes employed as guards who would not expose secrets or private affairs at court, such figures also played a key role in the seraglios. If rulers and other top officials were allowed to practice their sexuality across populations of women, disabled individuals—particularly those rendered sexually impotent as eunuchs—were thought to be ideal sentries who could not fall prey to the enticements of the harem. At the same time, narratives from the 1550s about the reign of Suleiman in Istanbul suggest that a disabled son in line for the throne could be contested on the basis of his physical differences. In addition, the British historian Richard Knolles reported that a group of seven mutes participated in the brutal assassination of the heir-apparent Mustapha during 1553. All of these stories help to establish the expansive roles of disabled people in various court intrigues. Their differences are invested with various meanings in which their distinct capacities—and, most important, incapacities—situate them within unique proximity to antics of power. Yet, it is not until the sixteenth century that we witness the publication of texts that foreground disabled individuals' own designs on power within such settings.

Perhaps, ironically, the first truly "modern" protagonist, William Shakespeare's rendition of Richard III (1591–1592), develops out of the revelation that disabled people inevitably participate in the seductions of power. In what is widely recognized as the beginning of modern literature, Shakespeare's disabled usurper of the throne delves theatergoers into his conscious musings on his status as a disabled person. For instance, his much-performed opening monologue points out the fact that while his "deformities" allow him full participation in wartime scenarios—where, presumably, the ugliness of military clashes eclipse Richard's own physical "distastefulness"—the peacetime that follows provides no viable role for such a figure. Throughout the drama, Richard mobilizes his disability status to his advantage by simultaneously playing on perceptions of his incapacity while also pursuing a violent scheme of retribution toward those he believes have wronged him on the basis of his disabilities. Thus, Richard III inaugurates a cultivated depth of characterization by hosting a character that appears one way but unveils his interior musings as existing in contradiction to his cultivated public demeanor. Disability could be said to have inaugurated a split between public and personal presentation that would continue to characterize representational strategies from this point onward as an inaugural moment in modern literatures.

One also witnesses the rise of the empirical method during this period as the European Enlightenment gets under way. Sir Francis Bacon and others craft a relationship to natural and social worlds that promises to expose the logical underpinning of the universe without reference to an omnipotent consciousness. The system of analysis depends heavily on what Barbara Maria Stafford (1993) refers to as "technologies of the visible." New instruments and "reading" strategies allow investigators to get below the surface and arrive at the essence of an object made newly available for scrutiny. Various taxonomic systems get under way in this period, such as Carl Linnaeus's *Systema Naturae* (1735) cataloguing of plants and animal life into various classifications of belonging—genus and species, flora and fauna. Likewise, human forms came under similar efforts to sort kinds of humanity into their appropriate columns. For instance, Linnaeus also put his efforts to sorting racial types—Americanus, Europeus, Asiaticus, and Afer—into a hierarchy of values based on his own privileging of northern European civilizations as superior to the denizens of more tropical locales. Disabled people's differences prove particularly critical to this venture in that an increasing premium was placed on the meaning of visible differences as a referencing system for otherwise intangible traits of character. In his essay "Of Deformity" (1601), Bacon—perhaps using Shakespeare's Richard III as his universal model—wrote about the unacknowledged "advantage" of deformity among participants in royal courts. Whereas previous literature had largely emptied out the subjectivity of disabled people from designs of power, Bacon invests "deformed persons" with aspirations of their own. As in the Shakespearian drama, Bacon cultivates an early psychological model of disabled subjectivity by arguing that deformity is a spur to individuals who seek to remove themselves from social ridicule. Rather than divest deformed persons of awareness, Bacon turns the tables and argues that their conditions give them an even greater degree of motivation for climbing the royal hierarchy.

By deploying deformity as an external sign of internal (albeit largely malignant) motivation, Bacon help to set off an entire tradition of sciences of the surface—those fields of investigation that rely on surface phenomena (such as facial countenance or bumps on the skull or visible deformities) to interpret otherwise difficult to detect moral qualities. While this practice was not new—some researchers trace the practice of interpreting questions of moral character in facial expressions back to ancient Greece—physiognomic systems came to be increasingly legitimated as "scientific." For instance, in 1778–1779, Johann Kasper Lavater published a highly influential system for reading the truth of one's character in the slope of the forehead, shape of the ears, line of the nose, and lips. Disabled people faired rather poorly in these interpretive systems, in that their "insufficient" bodies were immediately suspect—as if there existed an automatic shorthand available to locating deficiencies of personal integrity in the "obvious" deficiencies of the body, mind, or senses. Such efforts provide us the opportunity to trace out a history of the rise of normalcy, where the identification of the "deviant" body becomes the grounding for an imaginary normative body—one that is symmetrical, fully functional, independent, racialized, gendered, and economically mobile. Significantly, this idealized normal body came to be increasingly identified as a representative of the "healthy" nation.

Ironically, the rise of literary Romanticism positioned itself in contrast to this burgeoning bodily ideal. Rather than tout the efforts of empiricists and states to analyze, govern, and control the unwieldy nature of the body, Romantic writers took scientific efforts at dominion over nature as their antagonists. Wordsworth's "idiot boy" (1798), Coleridge's chronically depressed mariner (1798), Shelley's Frankenstein monster (1818), Hawthorne's blemished femininity (1843), Poe's obsessive narrators and claustrophobic interiors such as "The Fall of the House of Usher" (1839), Byron's hunchbacked protagonist, and Arnold, in his unfinished drama "The Deformed Transformed" (1824), all point to an era of literary production where disability came to be more synonymous with—rather than divergent from—conditions indicative of human vulnerability. Within these works—perhaps one of the richest in Euro-American representational traditions of disability—the nonidealized body becomes a vehicle of resistance and social critique. Thus, we follow Wordsworth's and Coleridge's entrance into sublime experiences of Nature with disabled characters as our guides; the Frankenstein monster's interrogation of his creator's rejection on the basis of his nonnormative appearance and functionality; the exposure of the alchemist, Aylmer, whose efforts to achieve perfection in his spouse through pursuit of a cure erases a birthmark on her face while also killing her; Poe's shifting mental states as undermining investments in static rationality; and Byron's social critique of disability as engendering violent responses from family and neighbors on the basis of solidifying normative expectation to which he cannot conform. All of these texts establish Romanticism as a key critic of normalcy's violent social scheme—that which the African American writer, Toni Morrison (1970:97), calls the most destructive concept in Western traditions—against which literature must resist. It also inaugurates a period where literature imagines science as a primary opposition in its promotion of schemes that often prove socially inflexible.

In fact, in many ways, we might read the alarm registered in Romantic literature toward empirically backed efforts of dominion over Nature as quite prescient. As the eighteenth century gives way to the nineteenth, one finds disability increasingly targeted by various efforts at "training" and institutionalization. In European locales such as France, Britain, the Netherlands, and Germany, as well as in Canada and the United States, the science of eugenics takes shape. Coined by the British statistician, Sir Francis Galton, in 1889 from the Greek word for "good seed," eugenics recognized certain cognitive, physical, and sensory disabilities as a threat to the progress of the nation. Eugenicists argued that, as in the sciences of horticulture and animal husbandry, human communities had the responsibility to oversee and protect their "hereditary stock" through active breeding practices. Such arguments began to establish a lethal cultural atmosphere toward "inferior" peoples of maligned ethnicities, races, sexualities, and particularly people with disabilities who cross all these identity groups. British social commentator Anna Laeticia Barbauld (1825), for instance, would apply rising sentiments of intolerance when she excoriated writers of her day to avoid defacing their work by populating plots with unsavory characters "suffering" from various bodily ailments. Others, such as entrepreneur Phineas Taylor Barnum (1810–1891), sought to capitalize on the prurience of public sentiments of the time through the exhibition of human "oddities" as a form of specular entertainment. His exhibits explicitly sought to exploit people with disabilities in their marketing as extraordinary anomalies, such as individuals of short stature (e.g., Tom Thumb and Lavinia Warren), those of exceptional height or congenitally truncated limbs, and people of color showcased as evidence of Darwin's evolutionary "missing links." In all cases, individuals with and without bodily anomalies performed for viewers through enhancements that emphasized their differences so as to achieve the desired effect—exceptions so extraordinary that they could command large audiences in the context of the freak show.

Freak shows played upon a fascination with human anomalies as their state-sponsored suppression increased. With the advent and later adoption of theories developed by researchers such as the Dutch botanist, Gregor Mendel, regarding the workings of regressive and dominant genes, eugenics sought to apply forms of reproductive control on human communities as well. Edouard Séguin in France, Samuel Howe in the United States, and Arthur Tredgold in Britain all worked to segregate those diagnosed as "idiots" in the mid-nineteenth century. In many respects, these figures participated as social reformers who identified familial and community neglect of people with disabilities as their primary nemesis. Yet, their arguments increasingly culminated in the proliferation of rabid fears in North American and European nations (as well as among various colonial outposts) that the wealth of the country was directly tied to its ability to promote the reproductive participation of those with good heredity while restricting such liberties for individuals recognized as "defective." Thus, as the nineteenth century draws to a close and the twentieth century begins, we find the proliferation of laws intended to actively police bodies. Marriage restriction laws for those who have experience bouts of "insanity," coerced institutional policies that could imprison "feebleminded" individuals against their will, sterilization laws that required those seeking to avoid institutionalization to exchange reproductive rights for their liberty, and, ultimately, Nazi extermination practices developed on the bodies of disabled people in psychiatric institutions all serve to expose the degree to which Romanticism proved accurate in its association of scientifically backed intolerance toward human variation with an upsurge in violent social practices.

Often in contradistinction to eugenic ideologies, leftist literature of the period sometimes held a close identification with disabled people in that their bodies could provide the material proof of inhumane work conditions as industrialization sped on and capitalist-based economic orders proliferated. In *Uncle Tom's Cabin* (1857), Harriet Beecher Stowe would use disability to metaphorize the wreckage of slave labor on the bodies of her African American characters; Karl Marx (1867) would argue that capitalism sought to make bodies expendable through the creation of surplus labor pools, thus exhausting the capacities of those who labored and then discarding "used up" bodies in favor of fresh, able ones; and in the novella, *Life in the Iron Mills* (1872), Rebecca Harding Davis would present her female hunchbacked narrator as evidence of an industry that mangles its employees with regular frequency. In a parallel spirit, many women writers such as Elisabeth Stuart Phelps (1877), Mary Wilkins Freeman (1890), Charlotte Perkins Gilman (1899), and others provided a "mute" or "hysterical" female body as evidence that patriarchal institutions sought to stifle women's ability to participate meaningfully in public domains gendered as exclusively masculine. Furthermore, one might turn to influential African American sociologist W. E. B. Du Bois (1903), who theorized racial feeblemindedness as a product of inadequate access to education and insufficient diet due to impoverished conditions that prevailed after the Civil War.

Disability allows one the opportunity to reconstruct a rich cultural fabric that weaves all identities into a shared project largely imposed from without. The rise in pathologizing designations during this period oversaw a proliferation of ways in which one could become "inferior." During the European and American nineteenth and early twentieth centuries, one can find racial, sexual, economic, ethnic, and gendered classifications of human deviance all dovetailing beneath the banner of defect—one that depended on a biologically encoded idea of embedded inferiority that could not be transcended to any significant degree by acculturation, training, or rehabilitation. Developments such as Native American reservations, segregated systems of racial apartheid, and widespread institutionalization efforts all shared an interest in sequestration practices as a response to reproductive fears of contamination. Each marginalized group was believed to share a similar capacity in the midst of multiple incapacities: an unnaturally high fertility rate. For instance, eugenicists claimed that those diagnosed as feebleminded of all races reproduced at 6 to 10 times the rate of "normals." As the famed Supreme Court justice Oliver Wendell Holmes stated in *Buck v. Bell* (1927), "Three generations of imbeciles are enough."

This period also witnessed a further tightening of immigration requirements, such as the passage of the Chinese Immigration Act (1885) and an increasingly expanding definition of which disability categories could be barred from entry. Eugenicists who had been instrumental in obtaining restrictive legislation against an array of conditions believed abnormal—feeblemindedness, epilepsy, homosexuality, a variety of psychiatric conditions, and various congenital physical disabilities—played a key role in associating various ethnicities with a greater prevalence of such variations. In fact, in 1913, noted U.S. eugenicist Henry Goddard was invited by the U.S. government to bring his staff from the institution at Vineland, New Jersey, to immigration headquarters at Ellis Island; the purpose was to demonstrate their greater proficiency at "spotting" feebleminded and other defective individuals as immigrant hordes passed by the surveillance station. Eugenics ideology deepened an already growing suspicion of difference across Europe and the United States based on biological rather than cultural principles of inferiority. Entire populations could be placed under suspicion as a result.

The impact of such a sanctioned national ideology would inevitably surface in representational works of the era. Many modernist writers, for instance, would use disabled characters to signify varieties of cultural collapse. If the "rough beast" of Yeats's celebrated poem came "slouching towards Bethlehem" (1919), then that monster often proved disabled in some manner. William Carlos Williams would represent the pure products of America in the figure of a "broken-brained" maid named Elsie (1923); T. S. Eliot would resuscitate the blind prophet, Tiresias, from ancient Greek mythology as a hermaphroditic figure who exposes the cultural wasteland that rolled out before dulled modern sensibilities (1922); Virginia Woolf would explore the promise of incapacitating illness for a woman writer while also espousing eugenic-like scorn for her own mentally disabled sister (1930); Sherwood Anderson would use physically and mentally "grotesque" figures to symbolize the stultifying lives of rural, midwestern existence (1919); the lethal German medical and legal team, Binding and Hoche, would forward an idea of "useless eaters" and "lives unworthy of life" as the central thesis of their tracts on euthanasia (1920); D. H. Lawrence would metaphorize a war-torn, beleaguered masculinity as the impotent, wheelchair-using Clifford Chatterley (1928); and William Faulkner would emblematize the era's chaos as a tale told by a 33-year-old "idiot" named Benjy in his experimental novel *The Sound and the Fury* (1929). All of these literary portraits deploy disability as an indicator of the extent to which nineteenth-century ideals had come crashing down around the moderns.

One can find a similar sensibility extant in graphic arts of the period. German expressionist painter Otto Dix's (1891–1969) paintings teem with disabled figures, as if the imperiled body saturated social landscapes indifferent to their losses. His experience with multiple wounds as a German soldier in World War I fueled his allegorical visions of an amputated civilization going about its business as if nothing had changed. Picasso and other cubist experiments with multiple perspectives sought to destabilize investments in singular, integrated vantage points on well-worn artistic subjects such the female nude, still lifes, and socially marginal individuals, such as his portrait titled *Blind Man's Meal* (1903). Paul Strand's photograph of a blind woman wearing a sign announcing her diagnosis (1916) and Giorgio de Chirico's abstract painting of disabled female muses (1918) also signal artistic efforts to use disability as a device to upstage long-naturalized sites of male investment in feminine "beauty." Whereas Francisco de Goya (Spanish, 1746–1828), Vincent Van Gogh (Dutch, 1853–1890), and Frida Kahlo (Mexican, 1907–1957) explored the rich territory of their own experiences with disability, most artists sought out disability as a metaphorical path to more paranoid visions. Whereas Romanticism would premise a desirable, yet vulnerable and even tragic, humanity through various human incarnations of imperfection, most modernist artists refused this stance as overtly sentimental—thus, disability came to be transformed in this period as evidence of one's willingness to peer, unwaveringly, into the cultural wreckage. In fact, one might be tempted to analyze much of modernist art as a reactionary movement to the artistic efforts about disability that preceded it by approximately one hundred years.

One can worry over the dehumanizing tendencies that so often crop up in the art of this period or marvel at the centrality of disability (even as it references other social conditions beyond itself) to this cultural moment's concerns. With the flood of disabled veterans in the aftermath of two world wars, disability must have been on the minds of many—particularly after effective treatments for bladder infections decreased the mortality of wheelchair users significantly. The rise of key institutions such as vocational rehabilitation, special education, and the various therapies (physical, occupational, speech) that all began—to one degree or another—in eugenics-based training programs of socially segregated populations began to compete with many of the institutions in which they originally appeared. At least in the United States, eugenics began to fracture amid a sea of institutions all vying for the management of disabled populations; rather than full-time segregation in institutions, for instance, special educators argued that a significant cost-saving measure could be achieved by educating handicapped and subnormal students in ungraded classrooms while sending them home each night to receive care in their homes. In Canada, vocational rehabilitation facilities and disabled veterans organizations would press for the provision of technologies—such as hand controls in automobiles or white cane travel training—to reintegrate institutionally static populations into their local communities. This call for disability-specific technologies proved necessary not only on behalf of the restoration of dysfunctional bodies but also largely on the basis of the inaccessibility of mass public transit systems in urbanizing economies. This "reintroduction" of a narrow array of technologized, cyborgian disabled citizens—particularly paraplegic, visually impaired, and postpolio populations—required a historical realignment on the part of societies that had avoided the necessity of more meaningful contact. Thus, just as the female protagonist Scout in Harper Lee's novel, *To Kill a Mockingbird* (1962), has to recognize the humanity of her cognitively disabled neighbor, Boo Radley, so did many Western countries start the difficult process of reintroducing disability perspectives—along with other minority constituencies—to their representational repertoires.

To the extent that early twentieth-century representational arts recognized disability as an encounter with cultural disintegration, many late twentieth-century artists recognized opportunities for unheard stories in the experiences of disabled persons. Andrew Wyeth's celebrated painting, *Christina's World* (1948), appears as a typical pastoral landscape on a farm until one realizes that her vantage point on the ground is that of a woman with a neuromuscular disorder. In photography, American documentary artist Dorothea Lange used her perspective as a woman with post–polio syndrome to identify with and create stirring images of people in the grips of rampant poverty during the U.S. Depression era. In the late 1950s, she also took a series of photos of her atrophied right foot as an object of contemplation and personal difference. In literature of the African diaspora, one witnesses a counterrepresentational effort to distance portrayals of racialized disability from earlier efforts, such as W. E. B. Du Bois's eugenics-era formulation of the "talented tenth" (1903). Rather than adopt this hierarchical model of exceptional racial genius created to combat associations of race with biological models of inferiority, contemporary writers of color began to explore disability as a meaningful part of the mosaic within their own communities. Mrs. Hedges's corpulent and scarred figure in Ann Petry's *The Street* (1946), Ralph Ellison's analyses of social invisibility in *The Invisible Man* (1952), Toni Morrison's multiple examples of disabled characters (Polly and Pecola Breedlove in *The Bluest Eye* [1970], Shadrack and Eva Peace in *Sula* [1973], Sethe in *Beloved* [1987], etc.), Alice Walker's Meridian and Wild Child (1976), Maxine Hong Kingston's "wild man of the Green Swamp" in *China Men* (1980) and Whitman Ah Sing in *Tripmaster Monkey: His Fake Book* (1989), and Louise Erdrich's (1984) and Leslie Marmon Silko's (1977) disabled Native American veterans provide a glimpse into new artistic efforts to revivify disability as part of—rather than a slander upon—racialized communities of color. In the United States alone, such influential minority authors precipitated a representational renaissance of minority viewpoints that often included disability as integral to the burgeoning of nonmainstream narratives.

As literary and cultural critic Leslie Fiedler ([1962] 1996:386) would announce, disability functioned as a "final frontier" of representational exploration. Whether this proclamation would prove true, developed disability perspectives helped to fuel social commitments to the portrayal of devalued lives during the final half of the twentieth century. As civil rights and women's movements gathered steam as vectors of political revision and social renewal, the disability rights movement galvanized its own successes for meaningful integration of bodies deemed formerly unproductive. Rather than late-nineteenth-century emphases on human difference as pathology, disability played a key role in representational efforts to reclaim rejected bodies and lives. Along with the passage of key disability legislation in a variety of global outposts, the stories of disabled people—particularly those produced by contemporary disabled visual, textual, and performance artists and their close allies—became one critical site for reimagining representational domains as critical sites of struggle over meaning. Given the debilitating depictions often associated with disability—those that largely overwhelmed various efforts to appropriate disability as a meaningful aspect of human diversity—media have become increasingly recognized as key to political interventions. Such efforts have not eclipsed the role of art in presenting less nuanced representations, but they have, at the least, charged the field of representation as one that is crucial to contemporary disability politics. Efforts to reimagine disabled people's critical relationship to a variety of social contexts often take place in representational domains—those imaginative landscapes that can provide meaningful blueprints for worlds where disability is treated as integral to human endeavor that have not yet been realized.

—David T. Mitchell and Sharon L. Snyder

See also History of Disability: Ancient West; History of Disability: Early Modern West; History of Disability: Korea; History of Disability: Medical Care in Renaissance Europe; History of Disability: Medieval West; History of Disability: Pleistocene Period.

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REPRESENTATIONS OF DISABILITY, SOCIAL

A phrase such as "representing disability" or "representing disabled people" bears many meanings. The most common refers to the act of (re)presenting disabled people in literature, the arts, and the media. An analysis of the evolution of these forms of representation through history, in particular in literature and the pictorial arts (including cartoons, cinema, and other media), informs us about the place that societies make for impairment in a given era. A second, more conceptual, meaning of representation, which encompasses the first, refers to a theory derived from social psychology. The concept of social representation takes into account the formation of bodies of knowledge originating from common sense and has been widely used in various disciplines of the social sciences.

A third meaning for the term *representation,* more distant and not discussed in this entry, refers to action in the name of another person or a group, that is, becoming a spokesperson or advocate on the political level. Disabled people thus have "representatives" and "representers" in a variety of instances.

REPRESENTATIONS OF DISABILITY IN ARTS AND MEDIA

Since the close of the 1970s and with the emergence of disability studies as an academic discipline, there has been a sharp increase in critical and historical works that address the ways in which disabled people are portrayed in culture, in particular in literature, cinema, and the media. Recurring stereotypes are associated with impairments: "There was the passively suffering angel of the house, the overcompensating supercrip, the tragically innocent disabled child, the malignant disabled avenger and the angry war veteran" (Mitchell and Snyder 2001:202). Some impairments are frequently depicted—epilepsy, restricted growth, the blind, the cripple, the leper—while others are ignored (Shakespeare 1994).

A Dominant Feature: The "Psychologization" of Disability

A first characteristic of works that bring disabled people onto the scene is a general tendency to pass over social conditions in the experience of disability, such as the inadaptation of the physical environment, in favor of individual factors. Thus, social isolation will not be attributed to the staircase that makes the outdoors inaccessible but to the paralysis that prevents walking. The process of "psychologization" that follows associates certain personality features with disabilities. Isolation is made into a tendency toward introversion, the presumed consequence of a necessarily tragic life experience.

Images Creating Ambivalence

A second characteristic of these representations is their bipolarity, which inspires such paradoxical feelings as fear, pity, and guilt but also admiration. The vulnerability and passivity of the innocent afflicted child are contrasted, now with the demonical and vengeful personality of the frustrated cripple, now with the heroism that permits another to "overcome" his or her disability. "In Victorian children's books, crippled young people teach messages of courage, forgiveness and generosity; witches are always ugly, and villains generally have had an impairment—Captain Hook, Long John Silver and all" (Shakespeare 1994:284).

The recurrence of such images and the plots into which they are introduced contribute to reinforcing cultural prejudice toward disabled people. As Barnes (1992:39) emphasized, "They form the bedrock on which the attitudes toward, assumptions about, and expectations of disabled people are based."

Disability as Metaphor

However, the simple distinction between negative and positive images of disability, acceptable or not, does not suffice to explain the metaphorical role that disability plays in culture. In addition, the criteria for what constitutes a negative or positive representation are not easy to define and vary according to the time and the culture.

A historical approach to this artistic reproduction points up the great complexity and richness of representations of disability and illuminates their symbolic and social functions in different periods. By representing the human body in all its diversity, its deficiencies, and its malformations, the artist goes beyond the visible that is apparent to everyone else "to reveal the hitherto concealed visible, to free our gaze from conventions and stereotypes, to imagine, fantasize, to open onto new scenes of human reality that are still unknown or ill known" (Blanc and Stiker 2003:10).

First, an observation: In all of this, the motif of disability is central in all eras, which leads to its recognition as a fundamental category of human experience, the rule rather than the exception (Mitchell and Snyder 2001). Another noteworthy fact is the use of disability as metaphor. By making reference to disability, the author most often seeks to represent, in figurative fashion, misery and depravity as one facet of the human condition. Thus, Clifford Chatterley, the impotent industrialist created by D. H. Lawrence, symbolizes "the decline of privilege and power in the British aristocracy" (Mitchell and Snyder 2001).

Stainton (2003) showed how the Renaissance marked a historical turning point in the ways in which madness and other forms of disability were represented. Until the close of the Middle Ages, representations of madness were purely allegorical. The famous painting *The Ship of Fools,* in which Hieronymus Bosch points up the folly of humans, is one illustration. Bosch stages a group of characters representing the whole of mankind, voyaging through the seas of time on a small ship gone adrift, eating, flirting, playing witless games, and pursuing unattainable objectives. With the exception of one "madman," recognizable by his cloak and hood, who is situated in the background and thus serves as a kind of cipher, none of the characters represented is stigmatized in one way or another. The *Ship of Fools* is not about other people; it is about "common individuals and common institutions, serving as the features of everyman"

(Stainton 2003:235). It is the group as a whole and its context, and not any one person in particular, that represents madness and folly.

Some years later, Brueghel, in *The Cripples,* portrays people voluntarily stigmatized with the help of prostheses. As in Bosch, their representation is metaphorical. The ridiculous headdresses worn by the characters symbolize organized social groups (the Church, peasantry, middle class, aristocracy). Given to our gaze is an inverted social space, "the disorder to be found in order, the mirror of a society that is always ill-formed" (Stiker 2003:128). However, where the rupture occurs, according to Stainton, is that starting with this period, representations of disability begin to be primarily representations of individual people. They are "increasingly associated with moral defects, and the study of physiognomic features as indicators of character was a pseudo-science popular in the sixteenth century" (Stainton 2003:237).

This observation may be juxtaposed with a more general evolution that characterizes the Renaissance: awareness of the existence of an internal self that determines conduct. Philosophers and poets became more and more interested in the workings of the mind. The idea that appearances are deceptive occurs frequently in the works of the period, in particular in the theater of Shakespeare. This cultural context favors the emergence of a belief in an association between physical appearance and character. Shakespeare's *Richard III* is doubtless one of the first illustrations of a natural correspondence between physical imperfection and villainy (Mitchell and Snyder 1997).

In their capacity as metaphors, representations of disability have a symbolic function. They are often hardly realistic and are remote from the experience of the people in question because they have another goal than to inform the public objectively. In a general way, they suggest significations, decoded with the help of the cultural tools available in every age (e.g., mythology, religion, psychology, biology, . . .), of what appears strange, unfamiliar, or even exceptional. These cultural interpretations make it possible to familiarize and domesticate what causes fear. Thus, medieval stories of fantastical children, such as changelings, attribute supernatural powers to children with congenital defects, which were inexplicable at the time. But at the same time as they supply meaning, representations of disability propose new categories of human variations and define, in ways that vary with the culture and the era, the characteristics that will make up the norm and those that will be excluded from it. "Disabilities exemplify that the ideal of the norm cannot exist without its 'deviant' contrast" (Mitchell and Snyder 2001). Here we have all the ambiguity of these representations, which, in a single interpretive act, seek both to domesticate the alien and keep it at a distance.

SOCIAL REPRESENTATIONS OF DISABILITY

The concept of social representations proposed by Mocovici (1984) provides a theoretical framework that allows the linking of representations of disability to the overall culture from which they emerge, and a better understanding of their dynamics, their functions and evolution.

Constructed at the juncture between the individual and the collective, between the subjective and the objective, agency and reproduction, social representations constitute a body of knowledge of common sense particular to a culture. They bring a sense of commonality and they organize social life. "Social representations live and die through the media, conversations, narratives, rituals, myths, patterns of work and art, among many other forms of social mediation" (Jovchelovitch 1996:127). Emerging into the public sphere, the space where intersubjective reality is constructed, they are at one and the same time descriptive, evaluative, and prescriptive. By determining both causes and consequences, they give sense to events, situations, and actions at the same time as they are the vehicle of a judgment, of an evaluation concerning them. These interpretations, socially connoted and shared by the members of a same group, orient future actions, at times serving as their justification. It should also be noted that this common knowledge, to which the dynamics of social representations contribute, is above all practical. It is elaborated at the very heart of daily actions and interactions, in a close relationship with current praxis.

Disability and Representations of the Person

Representations of disability in our cultures can be understood only in the context of the most general representation of the person. The increasingly central place that the rational individual is assuming in the modern age requires the formation of a common understanding—or "common knowledge"—of how the functioning of this individual, along with the reasons and meaning of his or her actions, is to be comprehended. The emergence, in the mid-eighteenth century, of physiognomy and phrenology, which sought to identify character on the basis of facial features or the shape of the skull, was a first manifestation of this need to understand.

Today it is "popular" as distinct from academic psychology that most often fills this same function. The modern individual is free and responsible for personal actions. Even if the individual is subject to the influences of the immediate environment, she or he has the power to control emotions in order to act rationally. The origin of behavior is, then, to be sought in the individual as defined by character or personality, which, once formed, displays a certain stability over time and through situations.

In this new cultural context, the metaphor of disability is transformed. It no longer evokes the human condition in general but an individual situation that nonetheless has a universal character. It becomes the symbol of personal tragedy, of brutal experience with unforeseen and irreversible consequences, experience that any person may encounter but that has victimized the disabled person. It is then the lived dimension of this experience, perceived as terrifying, and its consequences for the individual that social representations seek to articulate through artistic and media-related expressions. Reflective of the ambivalence generated by strangeness, the psychology of the disabled person oscillates between two poles: one marked by dependence, passivity, and frustration (general characteristics of social maladjustment) and the other by its heroic antithesis, driven by will power, coping, and perseverance. In both cases, to be carefree, spontaneous, and "comfortable in one's skin" are characteristics foreign to the dominant representations of disabled people.

Representations Inscribed in Social Practice

The psychological types associated with disability have their roots in a specific historical context. They correspond to the ideology of normalization through rehabilitation that dominated the introduction of medical and social care in the 1950s. The objective was to return people who had been wounded in war or injured in accidents to the multiple interactions of ordinary life, in particular, to the labor market, by acting as if there were no disability and one could become "normal" by trying harder. This pressure toward normalization has been costly in terms of energy and commitment on the part of those involved. The individualism that ignores social causes in favor of individual responsibility produces an effective reversal: Will power and self-control, consequences of great efforts to live up to social expectations, are considered causes of successful rehabilitation (Ville et al. 1994). Viewing as natural what is in fact a social response results in a reinforcement of representations and a legitimization of rehabilitation practices. In fact, such representation makes it possible to impute the failure of normalization to a weakness of character.

Social representations, in their capacity as cultural products rooted in praxis, also participate in the structuring of identities, which are in one sense self-representations. Thus, persons who contracted poliomyelitis (polio) in the 1950s and who responded to the demands of rehabilitation, in particular by assuming "normal" professional activities, exemplify a uniform representation of self, marked by the qualities of self-control, sense of duty, and meticulousness. "This post-polio identity overshadows all other social categories such as age and sex," unlike persons with paraplegia who acquired their impairments on average 25 years later (Ville et al. 1994:314).

New Representations and the Experience of Living with Disability

There has, in fact, been some evolution over the past three decades that offers alternative representations of the experience of disability. Through their collective mobilization and the emergence of disability studies as a discipline, disabled people refute these representations of themselves that are remote from their own experience. Instead, by means of their own production (artistic, scientific, media related), they propose realistic representations in which, neither victims nor heroes and heroines, they are seen above all as people confronting certain difficulties, difficulties most often related to the attitudes of others.

Beyond the variety of these representations, two great trends have today come to the fore, each playing on a different register. The first states its opposition to the individualist conception outlined above by shifting responsibility for the disability from the individual to the social environment. It is the social treatment of people who function differently from the norm that produces disability, that is, all the barriers to social participation (inaccessibility, exclusion, prejudice, and discrimination). The second would reverse the stigma by valorizing the experience of disability, the recognition of a specific culture, and the sense of achievement in contributing to it—disability pride.

While the first approach proposes new causes, located in the environment, the second assigns value to the positive consequences of experience of life with impairments. Although not mutually exclusive, each, by the specific sense that it conveys, seeks to initiate a certain kind of behavior. In the first case, the agenda is clearly political. It is a matter of engagement in actions whose aim is the overthrow of the physical and social barriers present in the environment. The second, on the other hand, stimulates cultural exchanges and cultural production. But they have the common feature of offering the opportunity for positive identifications for disabled people as political or cultural agents, and this can only contribute to anchoring these new representations in both the larger public and in themselves.

—Isabelle Ville and
Jean-François Ravaud

See also Disability Pride; Disability Studies; Film; Journalism; Novel, The.

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REPRODUCTIVE RIGHTS

Reproductive rights and disability issues intersect in two broad areas: whether people with disabilities can become parents and whether all prospective parents should be expected to use prenatal testing and abortion or embryo diagnosis to reduce the births of children who would have impairments.

PEOPLE WITH DISABILITIES AS PARENTS

Most disability does not prevent women and men from participating in creating or raising children, but many developed nations have placed informal and formal barriers to parenthood for people with a range of disabling conditions. A few impairments include female infertility and male sterility (Turner's syndrome and cystic fibrosis for women and men, respectively). Sometimes, women with certain impairments will be advised that a pregnancy will endanger their physical health and significantly increase the physical difficulties occasioned by such conditions as diabetes or multiple sclerosis. This entry concerns the nonmedical factors that influence the reproductive freedom of people with disabilities.

Opposition to parenthood for people with disabilities is especially surprising when it is remembered that most people whose disabling conditions occur after the births of their children simply carry on their parenting responsibilities. Yet for those who acquire impairments before the ages of typical family formation, parenthood is often discouraged. Regardless of impairment, people with disabilities have been assumed incompetent to keep their children safe or to give them the emotional and social guidance necessary for functioning successfully in society. It is believed that children of disabled parents would consequently need financial and social resources from the larger society to ensure their survival and growth. Yet another source of opposition links to social goals of reducing the numbers of people with disabilities in the population because it is feared that people with disabilities would transmit genetic conditions to future children. As a result of these views, many developed nations have encouraged the sterilization of people with a wide range of impairments late into the twentieth century, and prospective disabled parents report hostility from medical professionals, adoption agencies, and social welfare agencies, which have been known to remove children from their rearing parents simply because of a parent's disability. Notwithstanding these professional practices, people with disabilities are becoming parents through ordinary sexual relations, adoption, and assisted reproduction; at least one major national organization exists to provide services and assistance to parents with disabilities (Through the Looking Glass). Adult children of disabled parents have started to publish their reflections of being raised by people with disabilities, and a small body of research has started documenting the strategies that people use to raise their children successfully.

PRENATAL TESTING AND SELECTIVE ABORTION

Worldwide, disability organizations, disability rights activists, and theorists have taken up the question of how the increasing use of prenatal testing and selective abortion affects the place of people with disabilities in the world. Bioethicists, civil libertarians, health professionals, and the public generally argue that prenatal testing, followed by pregnancy termination if an impairment is detected, promotes family well-being and the public health. Testing and termination is simply one more legitimate method of averting disability in the world.

Although sometimes prenatal testing occurs outside of a plan to abort based on results of the test, most people who seek testing plan to abort the fetus if they learn of a disability. Standard justifications include the following.

Attitudes toward congenital disability per se have not changed markedly. Both premodern as well as contemporary societies have regarded disability as undesirable and to be avoided. Not only have parents recognized the birth of a disabled child as a potentially divisive, destructive force in the family unit, but also the larger society has seen disability as unfortunate.

In the absence of adequate justification, a child is morally wronged when he or she is knowingly, deliberately, or negligently brought into being with a health status likely to result in significantly greater disability or suffering or significantly reduced life options relative to the other children with whom he or she will grow up.

The parent's/parents' harms include emotional pain and suffering, loss of opportunities, loss of freedom, isolation, loneliness, fear, guilt, stigmatization, and financial expenses.

Parents of a child with unwanted disability have their interests impinged on by the efforts, time, emotional burdens, and expenses added by the disability that they would not have otherwise experienced with the birth of a healthy child.

Parens and Asch (1999) describe the disability rights critique of prenatal testing as follows.

Rather than improving the medical or social situation of today's or tomorrow's disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved. In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics might occasion.

When prospective parents select against a fetus because of predicted disability, they are making an unfortunate, often misinformed decision that a disabled child will not fulfill what most people seek in child rearing.

The disability critique argues that the practice and the rationales for it are misinformed about the nature of disability and morally problematic in the attitudes they connote about both disability and parenthood. The rationales for the practice are of three types. First, people with disabilities are more costly to society than others, and society should use its resources for children and adults who will not have impairments. Second, either the lives of disabled children are so miserable that they are not worth living at all, or they are more miserable than the lives of nondisabled children are expected to be. Third, the lives of parents and family members will be harmed by the psychological, social, and economic burdens of caring for the child, and these burdens will not be offset by the expected psychic and social rewards of raising a child without a disability.

Disability rights criticism of prenatal testing stems neither from general opposition to abortion nor from misgivings about technology. It is aimed at professional support for testing and abortion for some particular group of characteristics but not other characteristics, suggesting that health professionals, bioethicists, insurers, and policy makers believe that the births of people with some set of characteristics should be prevented. Pro-choice opposition to prenatal testing for disability shares much with those who oppose using the technology to avert the births of children of a particular sex. Suggesting that prospective parents select against an otherwise-wanted child because of its gender or disability implies that people who exist with these characteristics might be less desirable to others and less happy themselves than people with different characteristics. The critique is aimed at changing the way that testing technology is described to prospective parents, as well as at persuading professionals and parents that they have inaccurate ideas about disability and are using testing out of myth and stereotype rather than current information about how disability affects a child's or family's life.

Critics contend that this practice differs from other actions that prevent disability and should not be compared with prenatal care for women, vaccinations for children, or health promotion for everyone. Selective abortion and preimplantation embryo diagnosis both prevent disability not in an existing human being, or in a fetus likely to come to term, but rather prevent disability by preventing the embryo or fetus from becoming a person with a disability. The practices connote that if people do not meet a certain health standard, they should not be welcomed into the family or the world. Critics do not seek to ban the practice, but they believe that aborting a particular fetus differs from aborting any fetus because a woman does not want a child. They respond to each of the claims offered for prenatal testing by arguing the following.

Even if every disability diagnosed prenatally were followed by abortion, it would not materially reduce the prevalence of disability in the world or the need for society to change to better include those with impairments. As contrasted with the claims of Green (1997), who perceives a disability as an unacceptable infringement on a child's future, people with disabilities frequently enjoy their lives and do not generally perceive them as blighted by tragedy, even if their impairments impose some constraints on them. Furthermore, such constraints may be diminished or eliminated by societal changes to better include all citizens.

Most families raising children with disabilities are not ruined by the experience, and, on average, families including disabled children fare as well as other families on measures of well-being and family functioning.

Marsha Saxton (1998) expresses well the sense of offense experienced by many disability rights critics when she says,

> The message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are "too flawed" in our very DNA to exist; we are unworthy of being born . . . fighting for this issue, our right and worthiness to be born, is the fundamental challenge to disability oppression; it underpins our most basic claim to justice and

> equality—we are indeed worthy of being born, worth the help and expense, and we know it! (p. 391)

Most disability rights opponents of prenatal testing and selective abortion would not claim that the practice is "eugenic" because few governments compel it. However, the very offer of testing for some characteristics, but not all potentially diagnosable ones, connotes that only some characteristics are worth the expense and trouble to avoid. Thus, using embryo diagnosis and prenatal testing is a social decision, expressing societal views, and a direct challenge to the societal claims to include people with disabilities as full citizens and participants in the moral and human community.

The disability critique includes the idea that the sentiments behind offering and using embryo diagnosis and prenatal testing and abortion to avoid bringing children with impairments into the family and the world will ultimately undermine parental appreciation of any children they raise. Pro-choice disability critics agree that if a prospective parent makes a considered decision that the family or the child will have an unacceptable life based on parental hopes and values, embryo rejection or abortion should be available. They caution that such assessments may be misguided about both the nature of disability and the nature of parent-child relationships. Every life, every family, and every parent-child relationship contain disappointment as well as delight. Prospective parents may be misguided and misinformed about parenthood and may thus shortchange themselves and any children they raise by adopting a selective approach to parenthood.

—Adrienne Asch

See also Children of Disabled Parents; Citizenship and Civil Rights; Eugenics; Prenatal Testing; Sterilization; Values.

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RESEARCH

In industrial societies, demographic trends and advances in health care are swelling the ranks of individuals with disabilities. Plunging birthrates are increasing the numbers of elderly populations. Many individuals with catastrophic injuries and illness who previously might have died now survive and become candidates for rehabilitation. As a result, the incidence of chronic disease has accelerated. From both a personal and societal perspective, the incentive to find better solutions for the problems of disability is very high.

Scientific inquiry is a systematic way to solve problems and to have some assurance that the solutions are trustworthy. Disability research is a broad subject, encompassing a wide range of populations and research topics. This entry examines the way in which disability research is conducted, some of the major problems involved and their solutions, and what the future holds for the field.

How disability is defined determines the direction of inquiry. The book *Disability in America,* edited by Andrew M. Pope and Alvin R. Tarlov (1991), provides a traditional view. "A disability refers to limitations in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks and roles that individuals generally are expected to be able to do" (p. 35). Deficits are a characteristic of the individual in relation to societal expectations, and remediation comes from treatment by health professionals. Although there is recognition that there is an interaction between the individual and the social environment, there is no mention of changing that environment.

A second view of disability is that it is not an attribute of the individual but a social construction that is the product of society and attitudes about disability. Both the built environment and customs and attitudes limit opportunities. It is society's responsibility to make the necessary modifications so that individuals with disabilities can be integrated into society. Under the second perspective, disability becomes a political issue. These two views are not mutually exclusive; indeed, the World Health Organization's (WHO's) International Classification of Functioning, Disability, and Health incorporates both.

The headings that follow organize studies roughly on the basis of the numbers involved and the level of inquiry, which determine the goals of research and the methods by which to attain them. There are overlaps between sections. The classification is a rough scheme by which to organize a very large body of work.

THE SPECTRUM OF RESEARCH STUDIES

Population Studies

For governments to make informed decisions about allocating money, initiating new programs, or determining the effects of existing ones, it is necessary to have an estimate of the numbers of individuals with various disabilities and their status. The aim of epidemiology is to determine the incidence (the number of new cases per year), the prevalence (the number of existing cases at a particular time), or the health status of individuals with a particular condition. Population surveys devoted exclusively to disability are rare; most information comes from those that have other purposes. Census data, which attempt to reach the entire population, provide an estimate of the number of individuals with a disabling condition but have little detailed information. In the United States, the National Center for Health Statistics conducts an annual National Health Interview Survey on 48,000 households that includes questions on impairment or health problems that limit activity. The estimate is that more than 33 million individuals have some degree of activity limitation.

Mental illness is one of the most prevalent disabilities. It has also been one of the most difficult to identify because of changing definitions and methods of diagnosis. In the most recent research, individuals are identified as mentally ill if they have a cluster of signs and symptoms that result in impaired functioning. Most population surveys rely on telephone interviews in which strict sampling methods are used to ensure that the group contacted is representative of the population at large. Also, elaborate systems of questioning have been devised that maximize the potential for receiving truthful answers regarding various symptoms.

The 1999 report of the U.S. Surgeon General estimates that about 20 percent of the U.S. population is affected by mental disorders during a given year, the societal costs of which are enormous. The report found that direct costs of mental health services in 1996 were $69 billion. Indirect costs, estimated for 1990 at $78.6 billion, come from lost productivity at the workplace, school, and home. Additional estimates from surveys are also needed to determine the proportion of those identified with mental illness who need treatment. Most studies find large gaps between the numbers needing treatment and the facilities available.

Community Studies

Community-based studies focus on a sample of people living in one identified area, such as a city or region, with the assumption that the community is reasonably representative of other larger populations. A sample is drawn from the community, so it is possible to study individuals in considerable detail. The research can be a one-time study or repeated surveys that may extend over many years. Longitudinal studies are fairly rare because of the expense involved, but the information derived may be invaluable.

The Framingham Study is a well-known example of work that began in one city in Massachusetts in 1948 and has followed the fate of the study population ever since. The project, aimed at the effects of cardiovascular disease, selected 5,184 men and women between the ages of 28 and 62 at entry and followed them biannually with physical examinations, laboratory testing, and health history evaluation. It has been the source of some of the most important information available on risk factors for coronary heart disease. Because of the long time over which data have been collected, the Framingham Study has also been able to document the natural history of aging and what chronic diseases resulted in illness and functional limitations. Better information is needed on the major determinants of disability among those with chronic diseases to find ways to reduce and prevent physical disability in an aging population. During the 1983–1985 set of examinations, when the population had an average age of 72 years, more than 92 percent reported having no disabilities or functional limitations.

Another example of a community-based study, one that used a single time frame, is the Copenhagen Stroke Study. The question under investigation was whether a dedicated stroke unit resulted in better outcomes than other forms of traditional care. There has been considerable research devoted to this topic, but small numbers and selection bias made it difficult to draw definitive conclusions regarding the effectiveness of special stroke care. When one community in Greater Copenhagen set up a stroke unit that handled all the individuals in that area with strokes, it was possible to compare the results with a neighboring community without a special unit. The key to the research design was that a high proportion of all strokes in the two communities (88 percent) went either to the stroke unit or to medical or neurological units. Treatment on the stroke unit reduced the relative risk of death by 50 percent, reduced the relative risk of discharge to a nursing home by 40 percent, and almost doubled the chance of discharge home. The length of hospital stay was reduced by 30 percent. This was the first study to report on the effect of stroke unit treatment in unselected patients and demonstrated the effectiveness of stroke special units.

Community studies, either short term or longitudinal, are costly and require the mobilization of a team of investigators that may include clinicians, survey research specialists, biostatisticians, and interviewers. If done carefully, however, the yield can provide information that may not come from any other source.

Clinical and Educational Interventions

The largest proportion of disability research comes from a broad spectrum of work involving clinical or educational populations. Studies can range from large, multisite projects to much more modest research aimed at providing insights for the particular facility involved. Unfortunately, a high proportion of published work is not executed with enough attention to research design and methodology to provide useful answers. For several years, large-scale searches of the medical literature to determine the best treatments have found many studies wanting. The implication is that standards for both the execution and publication of research must be improved to ensure that the time and resources will be well spent.

Clinical Research

There are success stories in disability research, however. The example below illustrates several important principles of research. First, it investigates an important problem. Second, it has theoretical foundations that have evolved from several fields of investigation. And last, it took several years of work to develop the insights that were eventually established.

Edward Taub, a neuropsychologist at the University of Alabama at Birmingham, spent several years studying the behavior of monkeys with limb paralysis. He pursued this line of investigation because clinical work with humans with paralysis as a result of strokes or traumatic brain injury had shown limited success in improving functional recovery of upper extremities. Because patients valued the ability to use both limbs, they were frustrated at the lack of improvement.

When affected monkeys had their intact limb strapped down and went through graduated shaping procedures using the paretic limb, Taub found that there was considerable improvement in performance. When the animals had been free to use whatever limb they wanted, they naturally chose the intact one, resulting in a condition he called "learned disuse." Turning to individuals with hemiplegia as the result of stroke, Taub and his associates applied the techniques they had developed with monkeys. They found that immobilization of the good arm and an intense course of physical therapy resulted in impressive gains in ability (see Taub, Crago, and Uswatte 1998). Other research groups have begun to apply these techniques, termed *constraint-induced movement therapy,* and a body of evidence is accumulating regarding their effectiveness.

Educational Research

An essential tool of the research investigator is the ability to review past work. It not only provides a means for determining what has been done in a field of study but also identifies gaps in knowledge and the direction of future research. Easy access to electronic databases also makes the search much easier than in past times. There are large-scale collaborations among nations in the medical and educational literature to establish research evidence. The study below provides an example of a review in an area of study in which there are literately hundreds of pieces of work.

One of the most vexing issues in special education is the appropriate placement for children with disabilities. There is widespread agreement that, whenever possible, such children should be "mainstreamed," that is, included in classes of nondisabled children. The argument has been made on philosophical and legal grounds that children with special problems benefit educationally, socially, and in other ways from such exposure. The issue is a highly complex one, requiring different perspectives depending on age level, classroom objectives, and broader policy considerations.

Virginia Buysse and Donald B. Bailey Jr. of the Frank Porter Graham Child Development Center at the University of North Carolina at Chapel Hill were interested in comparing the outcomes of preschool children with disabilities in integrated and segregated settings. There are many benefits advanced for the integration of such young children, but there have been no reviews that compared these two settings. The authors set up a series of criteria by which to judge studies, particularly those related to the quality of research designs and methodology (Buysse and Bailey 1993). It is obviously important to identify those with strong designs and eliminate those for which conclusions cannot be drawn. Out of the dozens of studies examined, the authors found only 22 that matched the strict criteria they had set up.

The mean level of developmental outcomes, as assessed by standardized measures, did not vary in integrated as opposed to segregated placement. Integrated environments did provide a context that facilitated peer-related behavior; that is, children with disabilities had more social interactions in such settings. But there were questions about whether this led to more sophisticated levels of play and thus would have permanent effects. Integrated settings did show that children had more complex levels of play, with the opportunity to develop play-related skills. All in all, the review showed that there did seem to be some benefits for social-behavioral skills, although there were no advantages developmentally. Their work shows the complexities of trying to answer what seems on the surface a fairly simple question.

A second example of an educational intervention concerns the management of chronic disease. Medical care is limited in the ability to reverse disease processes or relieve symptoms. Individuals with chronic diseases then must learn to live with the disease and to manage their condition. There is a widespread need for health education methods that can assist with chronic disease management. A particularly promising effort is the Chronic Disease Self-Management Program, devised by Kate Lorig and colleagues (1996) at the Stanford University School of Medicine. This group had 12 years of experience with community-based educational programs for people with arthritis. In addition, the group conducted a series of focus groups of both well elderly and those with various chronic diseases. In these groups, they tape-recorded sessions in which the participants described their conditions, expressed their feelings about dealing with illness and disability, described the impact of the disease on the lives of the individuals and their families, and explained how they coped with such events. The records were then systematically analyzed. Finally, they incorporated a social psychology theory called self-efficacy into the program after finding that individuals with arthritis experienced pain reduction and enhanced capabilities when they felt they were in control of their symptoms. In the program that resulted from all this work, trained lay leaders conducted classes in community settings such as senior centers, libraries, hospitals, and recreation centers, teaching individuals how to develop exercise programs, problem solve, use communication skills, use medications, deal with emotion, and improve cognitive strategies for dealing with pain and disability. After training, individuals were better able to cope with chronic disease, experienced less pain, reported a better quality of life, and reduced their use of health care.

OUTCOMES RESEARCH AND QUALITY OF LIFE

The body of work reviewed above illustrates that disability research has many aims. A particularly prominent aim in an era of cost containment has to do with establishing the worth of program interventions. The usual objective of research is to test a hypothesis or establish some relationship, but outcomes research is management oriented. The applied research techniques that are employed still follow the tenets of scientific investigation, but there is relatively little control over what is studied. The goal is to monitor the effectiveness of interventions and to improve their quality.

Clinicians, counselors, and social service workers—all those who provide services—have always had an enduring interest in the success of their efforts. And, of course, clients have had similar concerns. It has only been in the era of accountability, rising costs, and the search for cost-effective care that the results of service have come to be called *outcomes.* The implication of the term is that results will meet some standard of acceptability and that the level of costs will also be acceptable. Programs of all types, from medical to educational, are charged with demonstrating that their outcomes meet expectations. Managers are to "manage" outcomes by improving services and by "risk adjustment," which simply means trying to select those who will benefit most. Unfortunately, this also has the effect of marginalizing many disabled people who are in greatest need.

Outcomes research must identify the principal results of programs and how to measure them. The usual list of outcomes includes improvement of physical and cognitive capabilities, greater independence, decreased need for assistance, decreased use of medical and personal care services, greater life satisfaction, and greater feelings of well-being. When programs are concerned with influencing physical and social environments and increasing opportunities for participation by those with disabilities, measurement of outcomes becomes more complicated. Indexes here include employment, financial support, access to transportation, access to health care, and other such evidence.

A view of service outcomes that is gaining greater acceptance is that the ultimate aim is to improve the day-to-day life of clients and patients. In health care, treatment populations increasingly are those with chronic disease for which there is no cure, but pain and discomfort can be relieved, the patient's functional ability may be improved, and outlook on life can be enhanced. *Quality of life* has been used as an umbrella term to include all the various aspects of health status, daily activities, economic circumstance, and perspective on life. A number of generic health status measures have been advanced as measures of quality of life related to health, but their applicability to disability is in doubt.

A major problem with health-related quality-of-life measures is in what constitutes health. In response to the question, "Does your health result in any limitations to activities?" a person with spinal cord injury might answer no. Likewise, someone with a severe disability that limited the ability to travel outside the house might still regard his or her quality of life as good, a perspective that might be puzzling to an outside observer. Quality-of-life conceptions, even though still not clearly defined or measured, will continue to be used. Whether funding agencies will pay for treatment aimed at improving quality of life could be a problem, although many such organizations recognize that individuals whose health, functional capacity, and life satisfaction improve may use health care services less.

DISABILITY RESEARCH AND EMPOWERMENT

Several forces have converged to force an examination of the role of those with disabilities in the research that affects them. In the 1960s, the civil rights movement resulted in social legislation aimed at improving the way society treated minorities. Although the movement initially concerned individuals of color, it soon spread to include anyone who was disadvantaged, including women and the disabled. A parallel phenomenon, although hardly distinctive enough to be called a movement, was the increasing attention given to the views of consumers. Initially concerned with commercial transactions, the consumer's perspective began to play an increasing role in various services, particularly health care and education. As health care became more competitive, the views of patients on the services they received and the results of services were solicited by means of satisfaction questionnaires. Other types of services have also begun to look at satisfaction. Because a high proportion of respondents indicate they are happy with what happened, satisfaction measurement is a blunt instrument that needs research on the underlying factors that determine satisfaction.

In the 1970s, a coalition of individuals with permanent disabilities began the independent living movement. It was a rebellion against what they saw as a paternalistic system that attempted to dictate how they should live and what services they should receive. This group has vigorously pursued the concept that those with disabilities should, wherever feasible, direct their own care and have a role in whatever studies are done about them. Funding agencies are increasingly requiring that whatever advisory groups grants create, there should be representation from those with disabilities.

To some extent, research investigators are caught between the two models of disability already mentioned. There has been far more research under the medical model, with the search for more effective treatment methods and other ways to improve performance deficiencies. For the most part, this body of work has been planned and executed by professionals with only occasional consultations with those whom it affects. The second model, which has been termed the *socioecological model,* involving the social and physical environments in which individuals with disabilities live, has been given increased standing by inclusion in the WHO International Classification of Functioning, Disability, and Health. In addition, the National Institute on Disability and Rehabilitation Research, the principal source of government-sponsored research funding in the United States, has made its "new paradigm" the centerpiece of planning. In this point of view, the aim is to reduce barriers, create access, and promote wellness and health. The individual with disability is regarded as a research participant and collaborator; decisions regarding research directions are to be made jointly with professionals.

This avenue of investigation produces considerable challenges, however. Ways to characterize and measure either social or physical environments are in early stages. It is not easy to do research in this area, particularly when a high proportion of such work is carried on by those trained in medical aspects of disability rather than in the social sciences. Greater interdisciplinary collaboration is obviously in order. Still another problem in research under the socioecological framework is that the ultimate aim of this work is to make social reforms of some kind. Researchers are not always comfortable in the role of social activist, however.

THE FUTURE

Although there have been impressive gains in the past 25 years in the status of individuals with disabilities and in the services they receive, there is still much to accomplish. Research is hardly the sole instrument in bringing improvements, but it contributes heavily to the development of new methods of treatment and education and in evaluating the effectiveness of those in use. Unfortunately, the priorities for research have come more from legislation and funding sources than from serious attempts at an integrated body of work founded on theory. With research spanning such a variety of problems, it is not surprising that findings are scattered without much organization. Several issues need to be addressed if disability research is to have an impact.

A Common Language. The lack of uniform concepts and a common language has plagued the field from its beginning. There is no consensus for even basic terms such as *disability* and *functional limitations,* which makes it difficult to compare measures and results. The addition of concepts such as *health status* and *quality of life,* even though they have important implications for outcomes, has brought additional confusion. Most studies do not define terms very well, so investigators often simply use an instrument and label it as measuring whatever they want. As a consequence, it is difficult to compare studies, and new knowledge accumulates slowly. In the end, however, it is up to researchers to better define terms and explain the procedures they use.

The Consumer Point of View. Although the views of the consumers of services for disability are sometimes sought, there has been little systematic effort to solicit priorities and preferences. Quite often, what an individual with a disability values as a contribution to his or her lifestyle is very different from the preoccupations of research professionals. The usual program outcomes that are measured are often the result of what can be measured rather than what is of special interest to the subjects studied. There needs to be a systematic method for determining client and patient goals at the beginning of a program and integrating such views into treatment plans and outcomes.

Outcome Measures for Disability. Many of the measures in use in social and medical programs are either of a utilitarian nature, reflecting a decreased burden to society or to caregivers, or enhancement of personal skills. Newer measures such as health status, quality of life, and health-related quality of life were developed without regard for applications with populations with disabilities. Although they are often used anyway or some modifications are made, their utility is less than if they were tailored to the needs and priorities of individuals with disabilities. Development of such measures may be costly, but the number of individuals with chronic diseases and injuries is easily sufficient to justify the effort. The shift in program goals to a socioecological perspective, in which better integration into society is important, will also require as yet undeveloped methods of determining outcomes.

The Subjective Experience of Disability. In the 1940s and 1950s, there were a number of observational studies of the mental hospital, some of which involved researchers being admitted as patients. They were then able to experience the often needless restrictions, the bureaucratic rules invoked primarily for the convenience of the staff, the lack of dignity with which patients were treated, the occasional physical abuse, and the pervasive boredom of routines with nothing to do. Such studies contributed to widespread questioning of the benefits of institutionalization and, ultimately, to the discharge of hundreds of patients from what was viewed as a noxious environment. Unfortunately, such patients were often turned out without adequate provisions of aftercare, and many drifted as homeless people.

Over the years, there have been occasional accounts of what life is like after a stroke, spinal cord injury, or other catastrophic condition. A few individuals have sufficiently recovered from autism to chronicle their experience. Unfortunately, most of these descriptions have been treated as idiosyncratic accounts that do not provide insights of general interest. All of this is in spite of the professed interest in the client/patient point of view. An array of qualitative research methods could provide a rich source of information about the disability experience.

The Challenge of Technology. There are accelerating advances in the miniaturization of circuits, new materials, and computerization of devices useful to those with disabilities. It is necessary, however, to determine the utility of such equipment for everyday life. The history of the use of lower leg braces, for example, has many accounts in which individuals have discarded braces, even though they provided physiological benefit, because they required great effort to use or were cosmetically unacceptable. The integration of special technology into routine life requires more than ever the collaboration of those for whom it is intended if use is to be successful.

Assessment procedures in which patients or clients must respond by computers are destined to become a much more frequent occurrence, even if these individuals have had no experience with this equipment. Touch screens or light pens can be used for multiple-choice answers and do not require keyboard use. Some aspects of personal and health history can be obtained this way, as can responses to a variety of health status questionnaires. Less staff time is required, and the responses can be instantly entered into a database, but respondents may need to be trained in the use of such devices.

Disability research holds great promise for improving the lives of those with disability, but such research is a product of the social and political context in which it occurs. The extent to which it is valued and understandable dictates whether it will be used. There are no shortcuts for creditable work. It must follow scientific principles, the individuals involved must be partners, and society must provide the resources.

—Robert Allen Keith

See also Disability Studies; Epidemiology; Models; Outcome Measures; Translating Theory and Research into Practice.

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RESJA

See Rehabilitation Engineering Society of Japan (RESJA)

RESNA

See Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)

RETT SYNDROME

Rett syndrome is a progressive developmental disorder associated with intellectual disability, growth retardation, loss of speech and motor skills, and emergence of stereotyped hand mannerisms. The condition is named after Andreas Rett, an Austrian pediatrician, who first described the disorder in 1966. His initial description of 22 patients remained largely unknown until 1983, when Bengt Hagberg of Sweden and his colleagues published an English-language account of an additional 35 cases. In 1999, mutations in the $MCEP_2$ gene were identified in almost one-third of a sample of 21 individuals with Rett syndrome. Further analyses suggest that mutations within this region may account for 50 to 75 percent of all cases of Rett syndrome.

The severity of Rett syndrome varies from mild to profound. Children with Rett syndrome appear to develop normally during the first 6 to 18 months of life, although subtle problems in muscle tone, posture, and movement may be evident from birth. The major clinical signs of Rett syndrome are usually pronounced by 2 years of age, and by 5 to 7 years of age, most children will have progressed to the fourth and final stage of the disorder. Clinical features that emerge over this period include loss of muscle tone, deceleration of head growth, seizure disorder, loss of acquired speech, and deterioration of motor skills, with mobility and functional hand use being significantly impaired. One of the more distinctive features of Rett syndrome is the nearly constant stereotyped hand mannerisms, which typically involve rubbing, wringing, and washing-like movements.

The condition primarily affects females, but similar symptoms have been described in males. Overall prevalence is estimated at 1 in 10,000 to 1 in 15,000 female births, making it the single most common cause of severe developmental and physical disability in females. As the identification of Rett syndrome improves through refined laboratory tests, estimates of prevalence are likely to change and become more accurate.

There is no cure for Rett syndrome, and the prognosis for significant improvement in the cognitive, social, and motor domains is poor. Still, quality of life can be improved by providing opportunities for participation in meaningful and preferred activities. A multidisciplinary treatment approach is recommended, with treatment focused on maintaining health and including provision of physical, occupational, music, and speech therapy. Communication is a major area of need. Even when some speech is preserved, individuals with Rett syndrome generally rely on informal body movements and facial expressions to communicate. Some can be taught to use augmentative communication devices to indicate basic wants and needs. There has been some success in reducing stereotyped hand movements through behavior modification. Individuals with Rett syndrome are often aware of and responsive to others and will therefore benefit from integration experiences in typical classroom and community settings. With regular and sound multidisciplinary management, many individuals with Rett syndrome can be expected to survive into adulthood, although death from malnourishment is not uncommon, and some otherwise healthy individuals may die suddenly from cardiorespiratory problems.

—Vanessa A. Green and Jeff Sigafoos

See also Developmental Disabilities.

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RIGHT TO WORK

At the beginning of the twenty-first century, for the first time in history, international social, economic, and political forces are acting in concert to promote widespread labor force participation of people with disabilities. The United Nations (UN) has acknowledged the right of individuals with disabilities to work, in order to promote equal opportunity and protection from poverty. The economic contributions of workers with disabilities can no longer be ignored in a constantly changing global economy, interlinking notions of work and citizenship. At the same time, an international movement of political activism among people with disabilities promotes a social theory of disability in which employment is seen as one route to community inclusion and protection of civil rights, albeit not the only route.

INTERNATIONAL AFFIRMATION OF THE RIGHT TO WORK

The UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities has proposed a series of fundamental principles for member nations. Article 22 of the convention is titled "Right to Work" and affirms that the opportunity to make a living doing work that is "freely chosen" in the "open labour market" is a basic human right. The need to protect workers with disabilities against discrimination in hiring, working conditions, pay, and advancement is affirmed in the article. Perhaps most important, recognizing that people with disabilities are "the poorest of the poor," an explicit connection is made between employment and "protection from poverty."

THE INTERNATIONAL EMPLOYMENT STATUS OF PEOPLE WITH DISABILITIES

Around the globe, people with disabilities live on lower incomes, receive less education, and have fewer job opportunities than their nondisabled counterparts, as revealed by international research statistics, as well as discussions among participants at the UN convention. In Latin America, for example, 75 percent of people with disabilities are not employed. More than two-thirds of British citizens with disabilities are out of the labor force or underemployed. Legislation in many countries forbids citizens with disabilities from entering certain professions. In countries with high unemployment, the labor market exploitation of disabled workers is often greater, so that when they do have access to jobs, these positions are often poorly paid and concentrated in a limited number of stereotypical occupations. Women with disabilities face particularly severe consequences of unemployment and associated poverty. In countries with publicly funded disability income support programs, large numbers of individuals with disabilities are trapped in poverty by income support policies that act as disincentives to employment.

POLITICAL ACTIVISM IN THE DISABILITY COMMUNITY

At the same time, a new conceptualization of disability has emerged that emphasizes community inclusion, accommodation, and protection of civil rights over the traditional focus on assessing impairment and remediation of functional deficits through professional services. Called the new paradigm, the social model, or the sociopolitical model, this new way of thinking about disability has its roots in the many political movements that grew out of the social protest and civil rights era of the 1960s. For example, the international disabled people's movement in the 1960s and the independent living movement of the 1970s sought a better quality of life for people with physical disabilities through equal opportunity and dignified treatment.

By the 1980s, disability rights advocates endorsed shifting the definition of disability from a focus on functional impairments and limitations to a sociopolitical perspective by means of a civil rights–based, "minority group model" of disability. This new paradigm views disability as an interaction between characteristics of an individual and features of his or her cultural, social, natural, and built environments. In this framework, disability does not lie within individuals but in the interface between their characteristics (such as their functional status or personal or social qualities) and the nature of the environments in which they operate. Put simply, the old paradigm views a person with a disability as someone who cannot function because of an impairment, whereas the new paradigm views this person as someone who needs an accommodation to function.

Use of this new model shifts the focus away from being solely on the individual to one that equally encompasses the environment. It highlights how the environments of people with disabilities often are socially isolating, economically constraining, legally exclusionary, and emotionally unsupportive. It also directs the search for solutions and remedies away from the sole concentration on "fixing" individuals by correcting their deficits to removing barriers and creating access through accommodation and reorganization of "disabling environments." It acknowledges that the "employment problem" for people with disabilities is due to faults in national and global economies and not deficiencies of individual workers. Concomitantly, the source of potential interventions expands beyond health professionals and clinical/rehabilitation service providers to include peers, mainstream providers, and consumer advocacy and information services. Most important in the new paradigm, the role of the person with a disability shifts away from being an object of intervention or a patient toward one of a customer, empowered peer, decision maker, and agent of social and political change.

Because these new paradigms have not been universally embraced, both national and international disability policy continues to lack coherence and direction. Much disability policy around the world has remained rooted in economic paradigms that pit benefits for individuals with disabilities against costs to the rest of society, thus reinforcing the medical rehabilitation model. In other countries, no formal disability policies exist, or a laissez-faire, de facto policy of benign neglect characterizes the approach that is taken.

LABOR FORCE DYNAMICS VIEWED THROUGH THE NEW PARADIGM OF DISABILITY

Use of the new paradigm allows for a more comprehensive understanding of the place of people with disabilities in the labor market and, especially, labor force dynamics for people with disabilities. This involves acknowledging that people with disabilities are both similar to and different from those without disabilities in their labor force attachment, experiences, and decision making. In the United States, for example, studies have shown that, while people with disabilities experience proportionally larger gains in employment during periods of market expansion, they also evidence greater losses during times of market contraction than people without disabilities.

The vulnerability of those who return to work while on the public disability insurance rolls in the United States is evident from studies showing that most reenter the labor force because of financial need rather than medical improvement. Those who do return to work tend to be younger and better educated than those who do not. Their initial jobs after reentry are lower paying and for fewer hours than the job held prior to disability onset, and they tend not to return to their previous employers. Finally, while workplace accommodations may extend the average duration of employment, there is evidence that injured workers who receive job accommodations "pay" for these accommodations in the form of lower wages.

These findings support the notion that return to work following onset of disability is a complex phenomenon encompassing more than the individual's level of impairment and functional limitations. Other factors, such as employers' attitudes, labor market conditions, availability of workplace accommodations, and prior employment, all are part of the environmental context that is critical to understand.

Most recently, disability scholars have questioned the notion that workforce participation can be the sole or even the most important route to social inclusion and emancipation. They argue that oppression of people with disabilities reflects a devaluing of impaired modes of being, which can never be fully corrected by inclusion in productive activity. Since the very nature of disability is defined by the ways in which a society organizes its productive activity, significant advances in employment for people with disabilities can only occur through a "radical reformulation" of the meaning and organization of work. This requires changes in the fact that productive activity in much of the Western world reflects values such as profit maximization, competition among organizations and their workers, and waged labor. It is these values, as well as the practices that stem from them, that limit or "disable" people with perceived impairments, rather than the functional limitations themselves. As long as work is organized around these principles, the inclusion of people with disabilities in productive activity is unlikely to bring about large-scale improvement in their economic circumstances. Such skepticism regarding the role of employment in the emancipation of individuals with disabilities is tied to the call for governments to adopt more interventionist labor market policies to encourage full integration. Disability advocates remind us of the long tradition in Western government of labor market restructuring through tax breaks and funding for business and industry to stimulate economies and enhance national security. In line with this thinking, members of the UN committee discussed encouraging member nations to pursue active labor market policies as part of promoting employment opportunities.

TRENDS IN GLOBAL WORKFORCE GROWTH AND LABOR DEMAND

Current trends in the worldwide labor market indicate the occupational context within which job training and employment placement will be occurring over the coming decades. Increasing economic globalization and technological advances have shifted the economy from a focus on "primary production" to one of "postprimary production," in which human services are the primary source of employment and information technology has replaced material production. For example, U.S. labor market projections indicate that the occupations with the largest job growth are expected to be retail trade, business services (including computer-related jobs), health services, and public and private education (including health care providers, teacher aides, teachers, and professors). Also, self-employment is expected to increase by almost 15 percent.

Some have argued that these new forms of production and technological advances offer unprecedented employment opportunities for people with disabilities. Environmental changes in workplace technology, telecommunications, and transportation systems have made the workplace more accessible to people with all kinds of disabilities through expanded transportation options and Internet technology. For example, mobility-impaired individuals can have enhanced access to job opportunities through the World Wide Web, a setting that already has been the focus of rehabilitation efforts.

On the other hand, new technologies must be accessible to people with disabilities if these alterations in the organization of work are to be advantageous. Increased funding to enhance innovation and affordability of assistive technology and universal design are essential. Accessibility to advanced telecommunications and transportation systems remains a major advocacy issue, with primary influence on an individual's likelihood of employment. In developing countries, access to advanced technology is limited among both nondisabled and disabled populations, pointing to the need to bridge the international digital divide.

THE NEED FOR REHABILITATION

In its statement of Right to Work, the UN committee called for increased access to technical and vocational guidance programs, placement services, and employment training, along with vocational and professional rehabilitation and return-to-work programs. The latter point highlights the importance of carefully integrating people with disabilities into mainstream government-sponsored employment programs to eliminate poverty. Special mention was made of "self-employment and starting one's own business," acknowledging the importance of building entrepreneurial skills as part of the rehabilitation process. In public discussions, some UN participants felt that this model applied especially for women with disabilities. Others noted that entrepreneurship provides people with greater freedom to participate in the economic sector of their own countries since they can act as their own employers and provide their own accommodations. A trend toward services and supports delivered by peers with disabilities is growing in many countries. However, in many others, access to vocational rehabilitation is severely limited or nonexistent.

NEW ROLES FOR EMPLOYERS

With expansion of the global economy, businesses have changed through downsizing and outsourcing, resulting in such phenomena as the flattening of workplace hierarchies and the erosion of job security. These trends suggest the need to incorporate employers and their organizations into the vocational rehabilitation process. Employers have been characterized as the "forgotten partners" in vocational rehabilitation efforts. Especially relevant to the new paradigm of disability are models of collaboration with business communities, which view the employment of people with disabilities as a socioenvironmental issue that can be addressed by a "trilateral" approach involving employers, consumers, and service providers. The UN committee recognized the need to encourage employers to hire workers with disabilities through affirmative action programs, incentives, and quotas. Also acknowledged was the need to educate employers about disability-related job discrimination and reasonable accommodations in the workplace.

THE INTERACTION OF DISABILITY AND POVERTY

Poverty co-occurs with disability around the world. In Western countries, this persists despite a series of public disability benefits and entitlements, including cash payments, vouchers, and other income support mechanisms. In countries without nationalized health care, such as the United States, disability beneficiary status provides the only access to medical and mental health treatment, and the need to protect this benefit leads many citizens with disabilities to forgo or limit their labor force participation. Yet even in countries with universal health care access, individuals risk their economic safety net when they work.

Providers of vocational rehabilitation services must be cognizant of service consumers' individual situations regarding eligibility for disability income and how they are affected by employment. Financial planning involving the sharing of accurate information is required so that consumers can consider the relative advantages and disadvantages of different work options. This means that the alleviation of poverty is explicitly addressed as part of the vocational rehabilitation process.

SUMMARY AND CONCLUSIONS

In conclusion, guaranteeing the right to work of people with disabilities might best be characterized as necessary but not sufficient to promote social integration and full participation. Without a reorganization of the values underlying the concept and organization of social production, labor force participation alone will not combat oppression. In the meantime, however, as stated in the UN article on "Social Security and an Adequate Standard of Living," in today's economy, "the best guarantee for independence and social security is employment."

It is hoped that tomorrow's global economy can be restructured through international policies so that employment is only one of the tools of emancipation from oppression available to people with disabilities.

—Judith A. Cook, Jane K. Burke-Miller,
and Lisa A. Razzano

See also Citizenship and Civil Rights; Employability; Employment; Employment, International; Human Rights; Worksite Modification.

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RISK AND RISK SELECTION RELATED TO INSURANCE

In this entry, the concepts of risk and risk selection in the insurance industry are discussed in the context of the disabled community in the United States. Risk in the insurance industry is a condition in which there is a possibility of an adverse deviation from a desired outcome that is expected or hoped for. The undesirable event is the adverse deviation, and insurance coverage is an attempt to provide protection from the undesirable event. Illness and injury would be undesirable health insurance events.

Adverse selection is the tendency of persons with a higher than average probability of loss to seek or continue insurance to a greater extent than do persons with an average or below-average probability of loss.

While an insurer will provide health insurance coverage to policyholders, the company must protect itself from excessive financial losses and examine its spread of risk by line of business, thereby avoiding a concentration of risk. Health insurance coverage to the disabled community presents the insurer with a business challenge in providing coverage, and the insurer will consequently do so in a manner that limits its risk.

INSURANCE ACCESS

The initiatives to guarantee health care access have been incremental since the introduction of Medicare and Medicaid in 1965. While new delivery models were introduced to promote patient access to providers, the ability to pay for services ultimately guarantees access to providers. The number of people without health insurance increased by 2.4 million, the largest increase in a decade, raising the total to 43.6 million. The increase brought the proportion of people who were uninsured to 15.2 percent, from 14.6 percent in 2001 and 13.6 percent in 2000.

Estimating health insurance demand is difficult to do because of the way health insurance is purchased in the United States. Almost 90 percent of insured individuals younger than 65 years of age obtain coverage from their employer or as dependents of a family member with group-sponsored health insurance. Insurance for medical expenses and for loss of income due to disability is provided by three basic sources: individual insurance policies, employee benefit plans (including fully insured, partially insured, and self-insured programs), and social insurance, including the Old Age, Survivors, and Disability Insurance (OASDI); Medicaid; and Workers Compensation programs.

THE INSURANCE PERSPECTIVE ON RISK

Competing with the public's demand for insurance is the business interest of the insurance company itself. An insurance company is an enterprise in the business to make a profit through the sale of policies to prospective policyholders. Business profiles are developed on an insurance company by various rating services that drive current and future operating performance and can affect long-term financial strength and the company's ability to meet its obligations to policyholders. In analyzing a private insurance company's financial strength, a company's book of business is assessed by line in terms of its geographic, product, and distribution diversification.

Large companies usually write conservative lines of business and avoid a concentration of risk. It would follow that insurance companies will avoid writing insurance policies, be it life or health, to policyholders who presented an untoward risk of injury or death. A companion issue with that of insurance risk in writing a policy is the issue of adverse selection. Adverse selection occurs if those who elect to participate in the program are sicker than average, and program costs may exceed expectations and/or premiums to participants may have to increase.

Adverse selection may cause the insurer to include waiting periods for preexisting conditions and limited benefits (such as exclusion of mental health coverage) in an effort to control selection. In addition, insurance deductibles are used in property, liability, and health insurance. The purpose of the deductible mechanism is generally to reduce problems with moral hazard by requiring that the insured take some responsibility for loss payments. Coinsurance and maximum limits also arise as a result of adverse selection in a competitive insurance market. This is the rationale for the insurance questionnaire prior to a policy being written that requests information of a policyholder's education and drinking and driving habits, as well as access to medical records to verify various medical conditions that may or may not be covered in the policy. The company is prospectively attempting to determine the potential risk of writing a policy to the insured.

From the perspective of an insurance company, the key consideration is whether it can charge a premium rate that reflects the expected cost of a potential enrollment group. The primary purpose of insurance is a controlled spreading of risk across the entire insured population. For example, with experience rating, the insurer estimates the premium based on the past cost experience of the group and then offers a self-supporting premium rate to that group that covers expected medical costs, administrative expenses, other loadings, and a profit. Therefore, obtaining insurance coverage is not precluded just because a group is higher than average cost, but there must be an insurance market for persons/groups of that type, and insurance companies must be willing to offer coverage to those groups. If an insurer can make a reasonable profit (and accurately estimate the cost of the group), then it is likely that insurance is feasible. Risk adjustment methods are another way of estimating costs for groups that have varying levels of risk (in addition to experience rating).

Managed care is another relevant concept in the insurance market. For example, for mental health and substance abuse services, a managed care organization can provide care at a cost that is under a fee-for-service and unmanaged arrangement. In addition to cost containment, managed care organizations (MCOs) usually provide greater access to care (a higher percentage of users), although more care is outpatient, and inpatient care is substantially reduced (in the MCO). The same group of disabled persons may receive a number of different premium rates from different insurers (assuming there is a market), and at least part of the cost difference is a result of the level of cost containment that the insurer can achieve.

DISABILITY

There is no consensus definition of disability that suits all purposes. While the U.S. Social Security Administration defines disability in terms of functional limitations as they affect employability, the Americans with Disabilities Act (ADA) defines disability as a physical or mental impairment that limits one or more major life activities. The point to be made here is that disability includes a number of physical, psychological, and medical conditions from arthritis, congenital anomalies, depression, HIV, hearing and vision impairment, multiple sclerosis, and impairment following an accident or medical episode, among others.

The context of the disability condition and its corresponding disability time period, be it short or of a lengthy duration, will determine the type of insurance that is warranted. Ultimately, disabled people will have to be their own advocates to gain access to insurance and to monitor claims payment to the provider by their insurance.

DISABILITY INSURANCE SOURCES

Risk and adverse risk selection are managed differently based on insurance source. The Social Security Act established Medicare and Medicaid in 1965. Medicare extended health coverage to Americans age 65 or older, disabled persons receiving cash benefits for 24 months under the Social Security program, and persons suffering from end-stage renal disease. Medicare provides health benefits to 41 million elderly and disabled Americans. Medicaid is a program that pays for medical assistance for certain individuals and families with low incomes and resources. The program is jointly funded by federal and state governments. Medicaid covers 47 million low-income people, including 24 million children, 11 million adults, and more than 13 million elderly and disabled people.

Workers' Compensation is insurance coverage, purchased by the employer, that covers occupational accidents and illnesses. Musculoskeletal disorders (MSDs) are the most prevalent and expensive work-related injuries in the United States. These MSDs are injuries and disorders of the muscles, tendons, ligaments, nerves, joints, cartilage, and supporting structures, such as spinal disks, which account for at least one-third of all work-related injuries. Around 1.8 million workers report work-related MSDs, and about 600,000 miss work due to MSDs each year. The final source for insurance is the individual nongovernmental market, developed to fill the gaps left by the employer market, including self-employed persons, graduate students, short-term and part-time workers, unemployed or soon-to-be displaced workers (pending layoff), the smallest of small business that cannot obtain group coverage, and persons before they are eligible for Medicare. The individual nongovernmental market served an estimated 16 million Americans in 2001.

THE DISABLED AND THEIR HEALTH NEEDS

Twenty-eight percent of insured people with disabilities reported that they needed particular therapies, equipment, or medications that were not covered by their health plans, compared to 7 percent of those without disabilities. Nineteen percent of disabled persons reported that they needed medical care within the previous year but did not get it, compared to 6 percent of nondisabled persons. Persons with disabilities attributed these failures to a variety of factors, including lack of insurance coverage (35 percent), high costs (31 percent), difficulties or disagreements with doctors (8 percent), problems getting to doctor offices or clinics (7 percent), and inadequate transportation (4 percent) (Reis et al. 2004). Reis et al. (2004) report that people with disabilities typically have a "thinner margin of health" due to their impairments and functional limitations, fewer opportunities for health maintenance and preventive health care, earlier onset of chronic health conditions, susceptibility to secondary functional losses, and, not uncommonly, a need for complicated and prolonged treatments.

The insurance needs of the disabled community are varied and diverse. Clearly, one insurance source will not satisfy all needs. A person who becomes disabled for a temporary or protracted time period will have to investigate his or her insurance needs and act as an advocate to make sure his or her needs are met.

CONCLUSION

Insurance risk examines the probability of illness, disease, and injury along with the duration of each. Adverse selection is the prospect that an insurer will enroll those who are sicker than average, thereby increasing their medical and administrative costs. Market forces in the private health insurance market dictate that an insurer enroll those who are healthy and who will make limited demand of the insurer. A prospective insured with an excessive need for health care services would not be a financially viable group for a private insurer. Workers' Compensation, Medicare, and Medicaid have provisions for those who become incapacitated for short and permanent time periods.

—Diane M. Howard and
Charles William Wrightson

See also Health Management Systems; Political Economy.

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ROARTY, JOHN JOSEPH (1921–1996)

Author and disability rights activist

John Roarty was born on February 10, 1921, in Merewether, New South Wales, the youngest of three boys, to Cyril and Margaret Roarty. He was born with cerebral palsy and, as a result, was severely disabled. As well as severe spasticity in all limbs, he had a speech impediment. Roarty never had the advantage of a formal education. His father abandoned the family when John was very young, and his mother got a job as a housekeeper on a property so she could keep the children with her. He eventually became too heavy for his mother to lift and carry around.

On July 11, 1937, at the age of 16, he moved to Weemala Nursing Home, where he resided until his death. In 1971, he was instrumental in forming the Residents' Committee. The lack of access to electric wheelchairs and the curfew on residents were the driving issues of the day. This was one of the first pieces of direct action by residents in an institution for disabled people in Australia.

Roarty's dream of writing his life story was realized when he published *Captives of Care* in 1981, during the International Year of Disabled People (IYDP). He wrote, "That is what this story is about: domination and the power of authority, and our struggles to curb that power and assert our independence and our rights as human beings" (p. 12).

A video of the same title was produced and aired on the ABC in 1982 and went on to win 11 International Awards. This led to a stage production produced by John L. Simpson, a long-time friend of Roarty.

Roarty, who was baptized Roman Catholic, had great commitment and dedication to his Christian spiritual beliefs.

The ultimate accolade to Roarty's commitment to the disability sector came in the form of the Order of Australia in 1988.

—Jan Daisley

See also Activism.

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ROBERTS, ED (1939–1995)

Founder of the independent living movement

Ed Roberts, a John D. and Catherine T. MacArthur Fellow in 1984, was one of the most recognized and admired leaders of the independent living movement of persons with disabilities, which began in the late 1960s. He was a founder of the independent living center concept, served as executive director of the Center for Independent Living (CIL) in 1972–1975 and director of the California Department of Rehabilitation from 1975–1983, and was cofounder and president of the World Institute on Disability (WID) from 1983 until his death in 1995. Roberts contracted polio at age 14. It left him paralyzed from the neck down. Relying on an iron lung or a respirator, Ed became the first severely disabled student at the University of California, Berkeley. While there, he worked with the university to develop a program run by and for disabled students to provide wheelchair repair, attendant referral, peer counseling, and other services that would enable them to live in the community. Due to coverage by *60 Minutes* (CBS News) and other media, Roberts's work to promote the concept of independent living became known throughout the world. In 1996, disability and community leaders created the Ed Roberts Campus, an international center and a service facility in Berkeley, California, in his memory.

—Joan Leon

See also Independent Living; Polio.

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ROOSEVELT, FRANKLIN DELANO (1882–1945)

32nd president of the United States

The central human characteristic that marked Franklin D. Roosevelt (FDR) the person—his severe physical disability—was concealed during his lifetime. From August 21, 1921, to April 12, 1945, every day had to be planned and structured to adapt to his disability. At first, he was confined to his bed at Campobello Island in New Brunswick, Canada, while his wife ministered to his physical and emotional needs. After he was transported back to his home in New York City, he learned to adapt to his disability by working with a nurse therapist who came to his home. After two years, he could stand and ambulate with minimal assistance by means of braces and crutches. After seven years, he was ready to plunge back into the rough-and-tumble world of politics. In his day, many men and women who held high responsibility would have broken under such intense strain. Not one in a thousand returned to combative political life. None except Roosevelt became a world figure.

THE POLIO ATTACK

In July 1921, FDR testified before a congressional committee investigating homosexual acts at a Newport, Rhode Island, naval training station. He had been the assistant secretary of the Navy in the administration of President Woodrow Wilson. On the way back to his summer home in Campobello, he stopped briefly at a Boy Scout camp in New York. Whether he contracted poliomyelitis in Washington or in New York is not known. The incubation period ranges from 3 to 35 days, with the average period lasting between 4 and 10 days. On August 10, he spent a strenuous day with his family swimming and fighting a forest fire. The next morning, he awoke with weakness in his left leg and pain in his back and both legs; by nightfall, he registered a temperature of 102° Fahrenheit. His illness was misdiagnosed by a local physician and by a Philadelphia surgeon, Dr. W. Keen, who was vacationing nearby. Keen's diagnosis was a spinal cord infarct resulting from bladder congestion. FDR's uncle, Fred Delano, contacted the Harvard Infantile Paralysis Commission, whose specialist, Dr. Robert Lovett, was called to Campobello, and he confirmed the diagnosis of infantile paralysis, the term for poliomyelitis used in the early decades of the twentieth century.

Legend has clothed FDR's recovery from the acute phase and his rehabilitation in myth and half-truth. In reality, he was by all accounts deeply depressed during the initial period of the fall of 1921 and the winter of 1922. After a brief stay at Presbyterian Hospital in New York under the care of Dr. George Draper, he was sent home to work with his nurse therapists, Kathleen Lake and Edna Rockey, who observed him daily in his struggle to sit and regain muscle strength. In an effort to spare him the knowledge that his back muscles were impaired, Draper devised a back support. Gradually, the paralysis in his upper extremities receded and was left in his legs. By October 15, he had worked through a severe reactive depression, carefully masked by a facade of cheerfulness. His nurse therapists and his physician observed an extraordinary sensitivity to the psychological aspects of his illness and maintained constant emotional support. His knees were contracted and very painful; although he regained power in his hip muscles, he could not walk. Despite considerable stress, his therapists observed that he was a compliant patient.

FDR's illness placed an enormous burden on his family. His wife, Eleanor, and their five children adapted to a husband and father who had previously been active in state and national politics and who now was confined to home and a limited existence. His mother, Sara Delano Roosevelt, wanted him to return to their country estate at Hyde Park, New York, and assume the role of a country gentleman. His political adviser, Louis Howe, kept up a constant stream of political correspondence to feign an active political life. FDR became the center of a titanic struggle for his soul and his future career, as was observed in the correspondence from Draper to Lovett: "I was able to see with a better perspective the intense and devastating influence of the interplay of these high voltage personalities one upon another." In June 1922, he went to Phillips House at the Massachusetts General Hospital in Boston to be fitted for a new set of braces. His departure for Boston broke the tension in the Roosevelt household. As long as he remained in New York, he assumed the sick role. When he returned, he had made his adjustment, and in the words of Albert Brewster, a young doctor who knew him in Boston, he was always smiling and seemed to have a charming personality undisturbed by all of the attention around him.

Two years after the poliomyelitis attack, Roosevelt had learned to manage with braces and crutches, but there was no restoration of permanently atrophied muscles. His last visit to Lovett showed only a trace of motion in the quadriceps on the right side and none on the left side, hip flexion was poor bilaterally, and bowel, bladder, and sexual functions were left undiminished. Although he vowed to walk independently, he never walked again without the assistance of a strong person holding his weak left side.

POLITICAL IMPACT OF HIS DISABILITY

Prior to 1921, FDR was perceived as a highly ambitious, rather supercilious young man whose social contacts were composed entirely of people in the higher political and diplomatic circles in Washington. Although he had successfully run for the New York state senate in 1910 and was familiar with the conditions of city slums at the turn of the twentieth century, he had little contact with the working classes and no contact with the problems of rural poverty in the Deep South. Those who knew him at Groton, a private preparatory school, and Harvard College remembered him as extremely ambitious to be popular but also as a snob who seemed ill at ease with people outside of his social group. One Harvard classmate who worked with him on the college newspaper said he did not have the common touch at all and that all of his humanitarianism came much later after he had had the polio attack. Frances Perkins, FDR's secretary of labor, who knew him before and after the polio, said he changed enormously, that he broadened his sympathies for the underdog and the underprivileged. During his long rehabilitation, he came into contact with ordinary citizens who had suffered polio, and he maintained correspondence with people disabled from polio throughout the United States and Canada.

Polio taught him to be patient and to bide his time for an appropriate reentry into politics. He was moving toward progressive positions in state and national politics before the polio, but he was no flaming liberal. The 1920s was a period of conservatism and isolation from foreign affairs. Although he nominated Al Smith for the presidency in 1924, he did not take an active role in politics until 1928, when he ran for governor of New York. When the stock market crashed in 1929, leading to the Great Depression, he was ready to assume the leadership of the Democratic Party. Polio gave him the chance to gain greater knowledge of the problems of poverty, to enlarge and broaden his circle of friends, and to concentrate on his political goals. In 1932, the nation and the world needed a leader who was as strong and clever as the European dictators. The nation was paralyzed by fear and economic depression. Roosevelt's triumph over his personal disability became a metaphor for national regeneration. During his 12-year presidency, there was increased attention paid to people with disabilities, through congressional legislation and through periodic charitable drives for people with polio, most significantly the March of Dimes. Perhaps the greatest contribution to the awareness of disability was Roosevelt himself, transferring from a chair to a standing position with the help of an aide, ambulating awkwardly to the podium, and gripping the lectern while deflecting the crowd's attention with his magnificent smile.

POST–POLIO SYNDROME

Since FDR's death, new information has been discovered about the late effects of poliomyelitis. Whereas polio was considered in his era to be a viral illness that had marked effects on breathing, movement, and sensation up to 2 years following the initial attack, it was not expected to progress or cause weakening of muscles that had not been initially affected. Patients often regained strength in some muscles and learned to sit, stand, and ambulate by a regimen of exercises and physiotherapy, such as FDR had undertaken. Studies in rehabilitation over the past 20 years, reviewed by Halstead (2004), have demonstrated a wide variety of symptoms experienced by former polio patients, ranging from 20 to 70 years after the polio infection. These symptoms are summarized as fatigue, decreased muscle endurance, muscle pain, joint pain, weakness in previously affected muscles and in unaffected muscles due to disuse, and atrophy. The problem of differential diagnosis is especially difficult with patients who are aging and have complex medical disorders that may simulate symptoms caused by polio. For example, many neurological and orthopedic disorders have similar symptoms of joint pain, muscle weakness, and fatigue. Therefore, a comprehensive medical examination, including an electromyogram, is necessary to confirm the existence of changes in muscle strength and sensation.

Did Roosevelt have post–polio syndrome? The medical evidence is limited by the absence of any continuous medical history from 1928 to 1944. These 16 years witnessed FDR in the governorship and the presidency. Apart from intermittent examinations to document his health for the electorate and to treat chronic sinusitis by his White House physician, Ross McIntyre, there is no record of his various illnesses. The laboratory reports during his presidency were stored under a pseudonym at the U.S. Naval Hospital in Bethesda, Maryland, and could not be found after his death. The most comprehensive and authoritative report was made by Howard Bruenn, a young cardiologist who treated him from March 27, 1944, to April 12, 1945. Bruenn diagnosed him with hypertension, hypertensive heart disease, left ventricular cardiac failure, and acute bronchitis. He recommended bed rest, limited work up to four hours per day, digitalis, a light and easily digestible diet, restricted salt, codeine for cough, sedation at night for sleep, and gradual weight reduction. The gaunt, haggard facial appearance of his last days was due to the loss of weight. Bruenn treated him for 12 months with no significant reduction in blood pressures, which fluctuated widely, from 170/88 to 240/130. Despite occasional chest pain, with one notable episode of substernal pain, FDR avoided an acute myocardial infarct or stroke until April 12, when he died from a massive cerebral hemorrhage. He was 63.

The confirmation of post–polio syndrome (PPS) cannot be made from Bruenn's clinical notes. The only evidence we have is completely anecdotal. Members of his family and of his inner circle of White House aides reported that he had lost muscle strength and endurance as early as 1941. The evidence is consistent with current criteria for diagnosing PPS after 15 years of neurological and functional stability. Moreover, he had less time for aerobic exercise such as swimming and for periodic rest such as frequent vacations due to the unprecedented stress of the world war. He was intolerant to cold, requiring extra warm blankets at home and while traveling to distant lands. After April 1944, Bruenn stopped his swimming in the White House pool because of hypertension. Although some of these symptoms may be caused by vascular disease, they are also indicative of PPS.

Did the late effects of polio contribute to his hypertension and hypertensive heart disease? In my conversations with Bruenn, he said that FDR's blood pressures were essentially normal during his first two terms. He was very active, swimming almost daily in the White House pool, traveling to Warm Springs, and going on frequent fishing trips for relaxation. The muscles in his legs were atrophied, so he used only his arms for moving his wheelchair and for swimming. During the war years, polio prevented him from managing muscle weakness and getting proper rest. Other causes of hypertension, such as renal disease, were absent. Hypertension and arteriosclerosis developed in an aging man, and polio did not have a specific effect on the elevation of blood pressure.

IMPACT ON THE DISABLED COMMUNITY

FDR's impact on people with disabilities came from many contributions: first, he established in 1926 a center for the treatment of polio patients at Warm Springs, Georgia. He spent four years there in an attempt to restore his atrophied muscles. Although he did not learn to walk unassisted, he did learn to use canes and benefited from the psychological support of other patients. He invested two-thirds of his inherited wealth, $201,667, to acquire the property of an old resort, including cottages, springs, and 1,200 acres of land, and established a modern hospital for the treatment of the aftereffects of polio. Some of the methods used to exercise weakened muscles, including physiotherapy, were adopted in a therapeutic environment shared by patients, nursing assistants, and "push boys" who maintained a spirit of equality and teamwork. Second, he established the Warm Springs Foundation, which hired medical specialists from Atlanta to direct orthopedics, build new pools, and expand the facilities. Third, in 1937, he became the prime mover behind the National Foundation for Infantile Paralysis Research, which raised funds for basic research to isolate the polio virus and develop a vaccine. The National Foundation's efforts led to the cultivation of the polio virus in a laboratory by John Enders, Thomas Weller, and Frederick Robbins, as well as the development of the Salk and Sabin vaccines. The announcement of the Salk vaccine was made on the 10th anniversary of FDR's death.

The voluntary campaign for the treatment of polio was the first widespread attempt to raise funds for a major disability. In an era when people with disabilities were either hidden or kept at home, pretty poster children with polio became models for acceptance. Roosevelt was used as a model who overcame his handicaps. It was thought that FDR had learned to stand, walk, and grasp the lectern as he made his political speeches. When a visitor entered his White House office or the State dining room, he was already seated. On the campaign trail, he held the railing of the rear train car while he flashed his magnificent smile and waved to the crowd. "If Roosevelt can do it, I can do it." In his era, he concealed the full extent of his disability in public, where his paralysis was shielded from the eyes of onlookers. Photographers had an unwritten agreement to avoid showing his atrophied legs. He was never seen in public in a wheelchair until March 1945, when he addressed Congress after making a strenuous trip overseas to Yalta in the Crimea.

Fifty-two years later, when the Roosevelt Memorial was opening in Washington, D.C., some disabled citizens criticized FDR for being a poor model since he concealed his disability during his lifetime. After public debate and controversy, a sculpture of him in a wheelchair now graces the memorial. The symbolism of Roosevelt triumphant over disability does not depend on the visible signs of braces and wheelchair but on the inspiration he provided for millions of disabled and able-bodied individuals throughout the world.

—Richard Thayer Goldberg

See also Depression; Polio; Representations of Disability, Social; Stigma.

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ROUSSEAU, JEAN-JACQUES

(1712–1778)

Philosopher and writer

Jean-Jacques Rousseau was one of the most influential thinkers of the eighteenth century, and his work continues to inform debates on education, the state, social welfare and morals. Rousseau spent most of his life residing in his native Switzerland and in Paris. In the novel, *Emile* (1762), he addressed critical issues in education, proposing a pragmatic approach to learning that focused on developing the natural proclivities of the individual and on learning through experience. He thought that teachers should not invest much energy in trying to educate "weak and sick" children because they would essentially end up being caretakers and guardians. He advocated that teachers ought to devote most of their efforts to the more "promising" students. In *The Social Contract* (1762), he argued that individuals could be more successful in facing threats in their lives by belonging to a society, a state, rather than by acting as individuals. The resulting "compact" between individuals about rules of behavior and sanctions for unwanted behavior sets the conditions for membership in society, including both rights and responsibilities. This work laid the foundations for discussions of the state, welfare, and care systems for the aged and disabled. Rousseau made a further contribution to disability discourse in his work on politics and morality. He stated that politics and morality cannot be separated and that the state is obligated to act in moral fashion or it will cease to exercise authority over its citizens. He also argued that the state is created to provide freedom for individuals. Thus, on individual and societal levels, Rousseau provoked discussion and took positions on issues critical to the place of disabled people in society.

—Henri-Jacques Stiker

See also Citizenship and Civil Rights; Education, International; Ethics.

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RUSH, BENJAMIN (1745–1813)

Physician and father of American psychiatry

Rush is known equally for his political and medical activities during the early years of the United States. He was a signer of the Declaration of Independence and served during the subsequent war as the physician general of the Medical Department of the Army. After the Revolutionary War, he actively pursued the still-new medical specialty of mental health and, in 1787, became supervisor of the section of the Pennsylvania Hospital devoted to those with psychiatric or intellectual disabilities (or "madness" and "fatuity," as Rush referred to these conditions in the writings). His textbook, *Medical Inquiries and Observations upon the Diseases of the Mind,* published near the end of Rush's life in 1812, served for many years as an influential summary of the knowledge base in the emerging field of psychology. In 1965, the American Psychiatric Association officially designated Rush as the "father of American psychiatry."

Rush wrote on occasion of the importance of humane treatment in terms that seem to foreshadow the "moral treatment" promoted by psychiatrists in the decades following Rush's death, describing how patients should "taste the blessings of air, and light, and motion, in pleasant and shaded walks in summer." However, many of his ideas and most of his practices were very traditional, punitive, and outdated even for their time, often relying on bloodletting, restraints, rapid spinning, and confinement to straw-covered cells in the basement of the hospital.

—Philip M. Ferguson

See also Psychiatry.

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RUSK, HOWARD (1901–1989)

Physiatrist

Conventionally considered the "father" of organized rehabilitation medicine in the United States, Rusk took his MD at the University of Pennsylvania, trained as an internist in St. Louis, and entered the Army Air Force's Medical Corps as a major during

World War II. Stationed near St. Louis, Rusk was exposed to the military's bimodal system of "rehabilitation." A patient was either "convalescent" and given few functional activities or deemed ready for duty and subjected to 10-mile hikes in full gear.

He designed a convalescent training program, incorporating psychological, physical, and vocational training to increase the functional state of the soldiers. The U.S. Army embraced this model and expanded it to military care facilities throughout its network. At the end of the war, Rusk took this model into civilian life. The military took the model into founding the Veteran's Administration hospital system.

Rusk's methodology invoked holism when reductionism in the medical model was particularly popular. An experimental demonstration while he was in the army, in which one barrack of disabled soldiers received intensive, holistic rehabilitation and another the standard "convalescent" care, dramatically showed the functional value of Rusk's methods to the military bureaucracy and to civilian observers. His genial style garnered him the nickname "Dr. Live-Again," also representing the prominence of the medical model in his early work.

In Manhattan, he founded the Institute of Rehabilitation Medicine at New York University, later named for him. He began a residency training program linking physical medicine with rehabilitation (a reason for his "father" status of the field). His public fund-raising efforts included privately lobbying the powerful, publicly persuading congressional budgeteers, and editing a column in the *New York Times.* Central to his unifying role was membership on the 1943–1952 Baruch Committee on Physical Medicine. He was preceded by figures such as John Coulter, George Albee, Henry Kessler, and Frank Krusen, who also played significant roles in establishing the twain fields of rehabilitation and physical medicine.

—Walton O. Schalick III

See also Physical Medicine and Rehabilitation; Veterans.

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RUSSELL, HAROLD (1914–2002)

Veteran and actor

A disabled veteran from World War II who, after 1945, briefly became a movie star and then a longtime advocate, in a variety of roles, for war veterans and people with disabilities, Harold Russell symbolized American disabled war veterans of the World War II era. Born in Nova Scotia, Canada, Russell immigrated to Boston with his family in 1933 and then worked as a butcher. He enlisted in the U.S. Army the day after the attack on Pearl Harbor. He trained as a paratrooper and then became a demolitions instructor, but he never saw action outside the United States. While working in the latter capacity, a defective fuse exploded a charge of TNT while he was holding it and led to the amputation of both his hands. Boyish charm and a positive attitude toward rehabilitation recommended him to the Army documentary makers, who sought a typical American soldier-amputee for a short training film intended to encourage amputees to achieve normalized lives. Though Russell had no speaking part in *Diary of a Sergeant* (1945), his natural grace before the camera recommended him to director William Wyler, who cast him as Homer Parrish in the Hollywood classic, *The Best Years of Our Lives* (1946). Russell won two Academy Awards: a Best Supporting Actor award for his performance and a humanitarian award for inspiring disabled veterans. Though he made brief appearances in other films and on television thereafter, his principal activities were as an advocate for both veterans and people with disabilities. He helped organize the World Veterans Foundation and served as vice president of the World Veterans Fund. He served three terms as national commander of the American Veterans of World War II (AMVETS). He maintained a consulting firm, which specialized in expanding job opportunities for the disabled. Following an appointment by President Lyndon Johnson in 1964, he served as chairman of the President's Committee on Employment of People with Disabilities, in which capacity he served until 1989. For many years, he also spoke widely on advances in the field of prosthetics. The Harold Russell Foundation continues his work through its

International Veterans Amputee Project, which assists disabled veterans to find and learn to use prosthetic limbs.

—David A. Gerber

See also Veterans.

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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.

Table 3 Resources for Finding Subject-Specialized Search Engines

Name	*URL*
CompletePlanet	www.completeplanet.com
Direct Search	www.freepint.com/gary/direct.htm
InfoMine	www.infomine.com
Invisible Web Directory	www.invisible-web.net
Librarians' Index to the Internet	www.lii.org
Search Engine Colossus	www.searchenginecolossus.com

Directories

Directories are hierarchically arranged subject guides composed of websites chosen by or recommended to editors of the directory (Table 4). Usually, directories follow a template in which major subject categories such as health, sciences, social sciences, or humanities are posted on the top-level page. Each of these links leads to lists of narrower subcategories. The links on the second level lead to narrower subcategories, and so on. A sample hierarchy from the directory created by Google (available at http://directory.google.com) lists the following subject breakdown: Society → Disabled → Disability studies.

Directories provide Web searchers with the ability to browse recommended resources in various subject areas without having to enter specific search terms. Other useful attributes of directories are that they often contain summaries and evaluations of websites.

Table 4 Selected Directories

Name	*URL*
eBlast	www.eblast.com
Google Directory[a]	http://directory.google.com
Internet Public Library	www.ipl.org
LookSmart	www.looksmart.com
Yahoo! Directory[a]	www.yahoo.com

a. These sites contain both directories and general search engines.

Article Indexes

Article indexes allow researchers to search by topic for published articles in magazines and scholarly journals. Researchers could certainly locate journal and magazine articles using a freely available search engine such as Google, but they would merely be skimming the surface of what has been published. While the Web provides access to *more* content, it does not provide comprehensive access to research published in journal articles. Article indexes are for the expressed purpose of finding journal articles. With a few exceptions (such as PubMed, an article index of health sciences journals developed and maintained by the National Library of Medicine), article indexes are not freely available on the Web. Libraries purchase subscriptions to multiple article indexes covering a wide spectrum of disciplines. The indexes available through a given library are often dictated by the curriculum of the college or university that the library serves. Thus, large research institutions offer a greater number of specialized article indexes than smaller institutions and public libraries. Due to licensing agreements between article index providers and libraries, off-site access to indexes is usually limited to faculty and students of a college or university. However, there are many libraries that allow members of the public to use their article indexes from within the library. A local public library would be a good starting place for those not connected with academic or commercial organizations.

Since article indexes are proprietary products developed by companies for sale to libraries, they tend to offer specialized search features that are not always available on freely available search engines. These features include subject headings, thesauri, abstracts (summaries of articles), and frequently the full text of articles. Researchers should familiarize themselves with online tutorials, "help" screens, and "about" pages to increase the effectiveness of their searching.

Freely available article indexes relevant to disability studies include the following:

- PubMed: A product of the National Library of Medicine, which includes more than 14 million citations for biomedical articles dating back to the 1950s. URL: http://www.ncbi.nlm.nih.gov/entrez

- CIRRIE: Center for International Rehabilitation Research Information and Exchange, a database containing more than 24,000 citations of international research published from 1990 to the present. URL: http://cirrie.buffalo.edu

Catalogs

While researchers can search indexes to find articles on specific topics, they can search online catalogs to find books. Some catalogs list the books available at individual libraries, while others contain the holdings of multiple libraries and institutions. The individual catalogs of public libraries and universities are usually freely available on the Web. The most comprehensive catalog is called WorldCat, developed by an organization called OCLC (Online Computer Library Center). WorldCat lists books available at public and academic libraries throughout the world. Like most article indexes, WorldCat is not freely available on the Web and must be accessed through a library.

Listservs

Listservs are mailing lists on the Internet that facilitate online discussions on various subjects. They allow researchers within a given field to communicate about scholarly issues via email. People customarily sign up for Listservs by sending an e-mail to the Listserv address stating that they wish to subscribe. Several Listservs related to disability studies are listed in Table 5. In addition, Web searchers can perform a search on a database called tile.net to search for Listservs by topic.

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.

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

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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