B

BABY BOLLINGER (1915–1915)

American victim of infanticide

"Baby Bollinger" (first name: Allen) was born to Anna and Allen Bollinger at the German-American Hospital in Chicago, Illinois. The seven-pound Baby Bollinger was diagnosed with multiple physical anomalies and became the first victim in a string of public infanticides of disabled babies committed by the head of staff at the hospital, Dr. Harry Haiselden. The doctor declared Baby Bollinger a "monster," a "pitiful bundle of semi-life." Anna Bollinger was encouraged to allow her baby to die by withholding life-saving surgery. "I want my baby. But the doctor has told me . . . I want him to live—but I couldn't bear to think of how he would suffer . . . how he would so often curse the day he was born. So I agreed with the doctor." On the day of Baby Bollinger's death, a Chicago newspaper printed the following description of him: "A pink bit of humanity lay upon the white cloth. Its blue eyes were wide open. Its hair was brown and silky, it dug at its face with little fists. It cried lustily as it drew up chubby legs and kicked out. It seemed quite vigorously informed with life."

—Sharon Lamp

See also Eugenics; Infanticide.

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BANK-MIKKELSEN, NEILS ERIK (1919–1990)

Danish reformer

Neils Erik Bank-Mikkelsen, an early champion of normalization, was born in Denmark in 1919 and received a degree in law in 1944 from the University of Copenhagen. During World War II, he joined the Danish resistance movement, was captured, and interned in a Nazi concentration camp. He developed the concept of normalization in response to his perception that institutionalized people with disabilities were treated only slightly better than concentration camp inmates. Following the war, he entered the Danish Ministry of Social Affairs. In 1950, he moved to the Danish Service for the Mentally Retarded, becoming departmental head in 1959.

He introduced the concept of normalization in a piece of Danish legislation called the 1959 Mental Retardation Act. He described normalization as a means to ensure people with this diagnosis the right to the same community-based existence as their peers without disabilities, including clothing, housing, education, work, and leisure. Normalization was seen as a way to ensure that this population received the same legal and human rights given to other citizens. In 1968, Bank-Mikkelsen received the Kennedy Foundation

Award in recognition of his work. In 1971, he became the Director of the Department of Care and Rehabilitation of the Handicapped, Danish National Board of Social Welfare, and was instrumental to the 1980 formation of Denmark's Central Committee on the Handicapped.

—Pamela Block

See also Bengt Nirje; Normalization.

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BARBELLION, W. N. P. (1889–1919)

English naturalist and author

The fledgling scientist and writer W. N. P. Barbellion, born Bruce Frederick Cummings, kept a journal from the age of 13 almost to his death. Earlier parts show the lad's abilities as a naturalist, a largely self-taught thinker, and voracious reader. When he learned in 1915 that the ailments long plaguing him arose from "disseminated sclerosis" (multiple sclerosis), the journal recorded a race against time to achieve some large ambitions before his body collapsed. He was by then married, had had scientific papers published, and held a minor post at the British Museum of Natural History. Barbellion (1984) continued "tinkering about in the Museum," though he found it "excoriating to be thus wasting the last few precious days of my life in such mummery merely to get bread to eat" (pp. 282–283), against a background of the Great War across Europe. A bowdlerized edition of his journal, published in 1919, impressed most of the critics with its freshness and lively acumen. Barbellion died knowing that he had made his mark in the world of human self-knowledge. Ironically, despite republication in the late twentieth century, his work remains practically unknown and unused by the disability movement.

—Kumur B. Selim

See also Autobiography; Multiple Sclerosis.

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BARKER, ROGER GARLOCK (1903–1990)

American scholar and author

Just after World War II, Roger Barker, while on the faculty in psychology at Stanford University, was asked by the Social Science Research Council to conduct a comprehensive review of the psychological literature on physical disability to help meet the needs of returning war veterans with injuries. Not content with an annotated bibliography of the literature, Barker, in collaboration with Beatrice A. Wright, Lee Meyerson, and Mollie Gonick, published an extensive theoretical and research monograph dealing with the social psychology of physique, disability, and illness. The monograph was revised in 1953.

In this work, Barker applied Kurt Lewin's field theoretical concepts of new and overlapping psychological situations to problems of physique, physical disability, and illness. He coined the term *somato-psychological relation* to refer to the question of how variations in physique affect the psychological situation of a person by influencing the effectiveness of the person's body as a tool for actions or by serving as a stimulus to the person or others. This pioneering monograph helped to establish the psychology of physical disability and rehabilitation as a research and professional discipline and to the launching of the division on Rehabilitation Psychology of the American Psychological Association.

—Phil Schoggen

See also Kurt Lewin; Psychology.

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BASHSHAR IBN BURD (714/715–783/784)

Arab poet and critic

The renowned blind poet Bashshar ibn Burd spent much of his life at Baghdad. He was probably born blind, though some writers argue that he lost his sight later. Efforts have been made to elucidate the question from his verses. Of the poetry of Al-A'sha and Bashshar, the celebrated critic Al-Jahiz wrote that these two blind men succeeded in catching truths that sighted people failed to discern, and Bashshar in particular excelled in doing so. Bashshar's self-reflexive wit gave rise to anecdotes, as when he broke wind in company and dismissed it as "merely a noise. Don't believe anything unless you see it!" Sometimes the joke turned against Bashshar. He publicly teased another savant, Said the Philologer, for academic fraud, by asking him the meaning of the word *jaranful* among the Bedouin. Said, who had himself invented this bogus word, was briefly silent, then came back, "The *jaranful* is one who has commerce with blind men's wives," causing hilarity among those present.

—Kumur B. Selim

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

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BEECHER, HENRY KNOWLES (1904–1976)

American anesthesiologist and researcher

Henry Knowles Beecher was an outspoken advocate of ethical standards in human subjects research and a pioneer in the study of pain, analgesia, and the placebo effect. He was also influential in the growth of anesthesiology as an independent medical specialty. Born in Kansas in 1904, Beecher earned his medical degree from Harvard Medical School in 1932. After early surgical training, Beecher was appointed Chief of Anesthesia at the Massachusetts General Hospital, despite having no formal education in anesthesia. In 1941, Beecher was named the Dorr Professor of Research in Anaesthesia at Harvard University, the first endowed chair of anesthesia in the world. Beecher's career was interrupted by service in World War II, when he observed pain responses of battle-wounded soldiers to be quantitatively different from those of surgical patients. Later, Beecher compared morphine and placebo to investigate psychological context in the physiology of pain control. This work has led to Beecher's appellation, "father of the prospective, double-blind, placebo-controlled clinical trial."

Beecher will be remembered most for his stance on human experimentation. He argued for informed consent by research subjects, and he condemned research that did not demonstrate potential benefit to patients as ethically unjustifiable. His landmark 1966 article in the *New England Journal of Medicine* chronicled 22 published studies with ethical infractions and consequently stimulated U.S. researchers to obtain informed consent prior to experiments.

In 1970, Beecher retired and received the Distinguished Service Award from the American Society of Anesthesiologists. Beecher died in 1976.

—Hugh M. Smith

See also Consent to Treatment; Ethics; Pain.

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BEERS, CLIFFORD WHITTINGHAM (1876–1943)

American advocate

Clifford Whittingham Beers developed the concept of mental hygiene, the precursor of our term *mental health* and the basis of much of prevention emphasis.

A Yale graduate who shared his struggles with mental illness openly in his autobiography, *A Mind That Found Itself* (1908), Beers garnered the support of mental health professionals and the public alike in an effort to advance the fledgling sciences of psychiatry and psychology. As founder of the Connecticut Society for Mental Hygiene (1908) and the National Committee for Mental Hygiene (1909), these groups picked up the term *mental hygiene* coined by Adolf Meyer, and developed an educational and reform movement for care of the mentally ill.

Beers's emphasis on prevention and his own example of recovery from a severe illness in his early adult life could be likened to the abolitionist efforts against slavery. As an articulate insider of Yale intelligentsia and some of the best-known private and public asylums of his day, Beers crafted a vision of recovery that engaged others and caught the attention of mental health professionals. His autobiography provided a balanced, substantive view into mental illness, allowing others to view compassionately and realistically the struggle of the human mind to come back from this loss. As a businessman and a communicator, he played a major role in formulating mental health policy by establishing a database on mental institutions, counting the number of individuals served by these institutions, and the psychiatrists serving there. Among the legacies of Beers's courage is the National Mental Health Association, formed in 1950. This organization's mission is to continue Beers's goals of "spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health."

—Patrick H. Tolan
and Karen Taylor-Crawford

See also Advocacy; Autobiography; Mental Illness.

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BEGGING

People with disabilities have begged throughout history and across the world. They have asked for money and other kinds of charity. Peddling, the selling of typically inexpensive items, can be similar to begging. Begging is done by individuals and in more organized ways. Societies have supported and opposed begging by those with disabilities. Begging by those with disabilities reflects their subordinate position in society.

People with disabilities have begged for thousands of years. In ancient Egyptian and Hebrew societies, blind people often begged. The Bible records that Jesus encountered blind people who begged. While individuals born with disabilities in ancient Greece were often killed, those who became disabled later in life were spared. Some who were spared turned to begging, often near well-traveled places such as temples. During the Middle Ages, begging by those with disabilities was widespread. Many works of art have associated disability with begging.

Begging continues today, though it may be more prevalent in developing countries. Most people with disabilities live in developing countries where opportunities for them to earn a living without begging are often few. Begging becomes a means for survival. It may be the most common employment worldwide for those with disabilities.

Similar to begging is peddling. For example, some deaf people sell cards printed with the manual alphabet and other small items at airports and other public places. They may ask the recipients to "spend" whatever they wish. The unskilled playing of a musical instrument by a blind person in order to receive donations from passers-by is comparable to begging.

Begging by those with disabilities has been an individual and an organized enterprise. Adults have enlisted disabled children to beg. They have even maimed children in order for them to beg more successfully. During the Middle Ages as competition among beggars occurred, guilds and brotherhoods were established, including ones for bind beggars. Pensions have been provided to beggars, as they were to elderly, blind beggars in Italy in the fourteenth century. Some deaf peddlers, at times illegal immigrants who do not know well the language of their host country and have little education, have been organized into peddling rings under the control of deaf or hearing bosses.

Communities have supported begging by those with disabilities. Disabled people have often been viewed as the deserving poor. They deserved the charity of those more fortunate. Religions such as Christianity,

Hinduism, and Islam teach their followers to show charity toward those in need, including those with disabilities. In the ancient world, blind people were assigned the role of beggar. Statutes in France from the mid-fourteenth century governed the begging by blind residents for the benefit of their entire community. During the Middle Ages, the church at times supported begging by those who were blind by allowing them to beg near their entrances or on church grounds. Laws restricting begging by nondisabled people sometimes made exceptions for those with disabilities, as did statutes in more than a dozen states in America in the early part of the twentieth century that made exceptions for blind people who begged.

Societies have also discouraged or prohibited begging by those with disabilities. Begging became so widespread during some eras that disabled beggars were viewed with contempt, as dangerous rascals, with suspicion and hate. Laws were enacted to limit begging.

As societies industrialized, begging may have become less accepted. Industrialization emphasized paid work as the way to contribute to society. Work increasingly became a measure of a person's worth. Begging was not paid work that contributed to society. Furthermore, with the development of the Enlightenment, the view spread that people with disabilities could be, should be, educated in order to be productive members of society. Begging was contrary to this understanding of those with disabilities.

Begging expresses a complex relation between people with and without disabilities. It relies on the sympathy, pity, perhaps relief, and maybe fear of the nondisabled donor. It enacts interpersonally the larger social relation of inequality between those with and without disabilities. Yet when people with disabilities beg, they also assert themselves. They make themselves visible instead of hidden and ask, even demand, to be compensated for the inferior position the nondisabled world puts them in. Begging may help reproduce the subordinate position of those with disabilities, but it is also a rational response to limited opportunities. Until societies enable all members to sustain themselves through paid work or other means, some people with disabilities will beg.

—Paul Higgins

See also Charity; Poverty.

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BEHAVIOR THERAPY

Behavior therapy refers to a broad range of theories (hypotheses about factors that contribute to the prediction and control of behavior) and a set of treatments that derive from these theories designed to change behavior that is disruptive to patients' lives and functioning. In 1919, John Watson published *Psychology from the Standpoint of a Behaviorist,* and in his preface he states:

> The present volume does some violence to the traditional classification of psychological topics and to their conventional treatment. For example, the reader will find no discussion of consciousness and no reference to such terms as sensation, perception, attention, will, image, and the like. These terms are in good repute, but I have found that I can get along without them. (p. viii)

Watson proposed that the aims of psychology were the prediction and control of behavior. It is reputed that a major newspaper of the day ran an article with the headline "Psychology Loses Its Mind." Other early contributors to the theory and practice of behavior therapy were Ivan Pavlov (respondent conditioning), B. F. Skinner (operant conditioning), Joseph Wolpe (desensitization), Albert Bandura (social learning theory), and Aron Beck's and Albert Ellis's independent development of cognitive behavior therapy. What characterized these diverse thinkers and their

paradigms was an adherence to the scientific method for establishing principles of learning and functioning that formed the basis of their theories and therapeutic methods.

There are three major disabling conditions from a psychiatric perspective: developmental disability, autism, and schizophrenia. Behavior therapy has developed effective treatment strategies for each of these conditions primarily using the operant paradigm, or contingency management, going back more than 40 years.

Before the 1960s, developmentally disabled people were largely warehoused in residential and hospital settings with very little hope for any other life. With the advent of behavior modification programs focusing on verbal behavior, social skills, and independent living skills, most of this population can live more normal lives working in lower-level jobs or sheltered workshops and living in independent or semi-independent (supervised) settings.

Similarly, Ivar Lovas's pioneering work, starting back in the 1960s, with autistic children using intensive operant conditioning procedures on acquisition of verbal behavior, communication skills, social skills, self-care, and independent living skills has increased substantially the proportion of this population able to live more normal lives (some entirely normal) outside of institutional settings.

Schizophrenia is another area in which major contributions have been made by behavior therapy since the 1960s. Gordon Paul's seminal research showed clear superiority for a token economy treatment program over milieu and standard state mental hospital care. Patients were more functional in terms of symptom reduction, social/communication skills, and independent living skills, as indicated by higher discharge rates and lower relapse rates (ability to function and maintain themselves in the community). Even more impressive is the fact that these results were achieved without the use of medication. More recently, cognitive therapy and behavioral systems therapy are being used effectively with patients and their families to further enhance the patient's ability to live in the community.

In addition to the above three conditions, the crippling effects of severe depression and anxiety can result in disability. Disorders such as major depressive disorder, bipolar disorder, panic disorder with agoraphobia, posttraumatic stress disorder, obsessive-compulsive disorder, as well as other anxiety disorders, have been the focus of a great deal of research resulting in the development of effective treatment protocols. For more than 30 years, Beck and his colleagues have been developing cognitive therapy as a treatment of choice for depression. During the same time frame, Peter Lewinsohn and more recently, Neil Jacobsen with his behavioral activation therapy, have effectively approached depression from an operant perspective. Exposure and response prevention (ERP), which was pioneered by Edna Foa with obsessive-compulsive disorder, and later by David Barlow with panic disorder with and without agoraphobia, has become the treatment of choice for anxiety disorders, producing significant improvement rates of between 70 and 80 percent.

Other potentially disabling conditions such as attention deficit disorder with or without hyperactivity (ADD and ADHD), substance abuse, and borderline personality disorder have also been the focus of attention from behavioral researchers and clinicians. ADD and ADHD have been treated for many years with incentive programs focusing on academic performance and prosocial behavior, as well as parent training programs. More recently, Joel Lubar pioneered the development of neurofeedback therapy, a form of conditioning therapy focusing on brain wave patterns as a promising treatment for, in particular, ADD. Sophisticated behavioral approaches to substance abuse using a wide variety of behavioral techniques to target the multifaceted problems of this population (e.g., functional analysis of drinking behavior, self-management strategies, social skills, self-soothing and emotional regulation skills training, cognitive therapy, couples' therapy, and relapse prevention strategies) have been developed. Marcia Linehan's dialectical behavior therapy (DBT) and Jeffrey Young's schema therapy are the only psychosocial treatments for borderline personality disorder that have demonstrated efficacy.

Over the past 80 years, major contributions to the treatment of diverse disabling conditions have come from the operant, respondent, social learning, and cognitive paradigms. And over those same years, as might be expected, controversies have arisen. An early controversy involved the symptom substitution hypothesis;

that is, behavior therapy targets superficial symptoms rather than deeply rooted causes, and thus new symptoms will emerge. Another controversy involved the coercive nature of behavior modification programs in hospital and prison settings. The movie *A Clockwork Orange* raised a controversy about the use of aversive conditioning. In actuality, however, the goal was to create a stable disability of sorts (inhibited libido and erectile dysfunction), but if Alec's demonic smile at the movie's end is any indication, the goal was not achieved. Many technologies can be abused (e.g., cars result in a high number of injuries, disabilities, and deaths, as do guns, industrial waste, nuclear energy, and even food). The key here is in ensuring the knowledgeable, compassionate, and ethical use of an effective technology through well-conceived and comprehensive research, training, and monitoring of practice.

—Michael B. Evans

See also Agoraphobia; Anxiety Disorders; Autism; Developmental Disabilities; Obsessive-Compulsive Disorder; Panic Disorder; Posttraumatic Stress Disorder; Schizophrenia; Psychiatric Disorders.

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BEHAVIORAL DISORDERS

Behavioral disorders can be defined as the state in which youths under age 18 behave persistently and repetitively in ways that violate the basic rights of others or major age-appropriate cultural, or ethnic norms. The person is more sick than wicked. When behavioral disorders occur after the age of 18, they are considered to be personality disorders.

There are four criteria to diagnose behavioral disorders. To make the diagnosis, at least three should be present during the past 12 months, and at least one should be present for six months:

1. *Physical aggression:* This includes physically cruel behavior toward people and animals, initiating physical fights, using dangerous weapons such as a knife or a gun against others, robbing, or forcing someone into sexual activity.

2. *Deliberate destruction of others' property,* with or without fire setting to cause serious damage.

3. *Deceitfulness or theft:* This includes breaking into another's home, building, or vehicle; lying; and stealing (including shoplifting).

4. *Serious violations of rules:* This includes often staying out at night despite parental prohibitions (before the age of 13); running away from home overnight at least twice; frequent truancy from school before the age of 13. In many Eastern countries, however, truancy at any age is considered as a behavioral disorder—an example of how differences in traditions lead to different diagnostic criteria.

To fit the diagnosis, these behaviors must also significantly affect performance (academic, social, vocational, or personal skills); hence behavioral disorders are considered to be disabilities. Patients who suffer from behavioral disabilities also are unable to learn or work, and these disabilities are not due to intellectual, sensory, or health factors. These patients also lack the ability to build or maintain satisfactory interpersonal relationships.

Because the diagnostic criteria of behavioral disorder vary widely, its manifestations at different stages differ, and because of differences in the adopted methodology, it is impossible to determine precisely its prevalence. However, it is considered to be a common problem in children and adolescents. In the United States, the condition is more prevalent among boys (6–10 percent) than among girls (2–9 percent). The prevalence is more in urban and suburban than rural settings, and even greater in overcrowded cities.

Behavioral disorders can be present with, or derive from, biopsychiatric disease (mood disorders, psychosis, attention-deficit hyperactivity disorder), organic impairment, and mental retardation. Although some of these children and adolescents have family history of behavioral disorders (which might indicate a genetic role), in most cases family, socio-economic, and environmental factors contribute heavily to the genesis of behavioral disorders. Conduct disorders can be complicated by drug abuse, alcoholism, AIDS, dropping out from school, and criminal behavior.

Only a fraction of children with this disorder are treated. Family and school intervention, psychotherapy, cognitive-behavioral therapy, and medications (psychostimulants, antidepressants, antipsychotic, anticonvulsants) have been successful.

The most important preventive measure is the establishment of a strong and cohesive family, with a clear policy of child-rearing practices, stressing the importance of religious and social factors.

—Marwan M. Al-Sharbati

See also Crime and Delinquency; Parenting and Disability.

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BELL, ALEXANDER GRAHAM (1847–1922)

American (Scottish-born) inventor and scientist

Alexander Graham Bell, inventor of the telephone, was one of the foremost proponents of a nineteenth-century oralist movement in Deaf education. Bell used his international fame to promote a philosophy that American deaf children should be taught to speak and taught only through articulation and speech-reading, with no use of sign language. The oralist ideology was very much a product of its times, riding the late-nineteenth-century wave of nativism and social Darwinism to promote a view that Deaf people should be linguistically and socially assimilated into a monolingual, auditory, speaking society.

Bell was one of a number of scientists interested in questions of heredity who would go on to found the American eugenics movement. Among his publications was the 1883 *Memoir on the Formation of a Deaf Variety of the Human Race* in which he claimed the intermarriage of Deaf people would invariably lead to a Deaf subset of humanity. This claim proved false, but would recur periodically among scientists and the general public over the next decades.

Bell was born to a Scottish elocutionist and his deaf wife in Edinburgh on March 3, 1847. His marriage to one of his first deaf pupils, Mabel Hubbard, was by all accounts a happy one, lasting 45 years. Both his mother and his wife did not use sign language. Bell died on August 2, 1922, in Nova Scotia, Canada.

—Joseph J. Murray

See also Audism; Deaf Culture; Eugenics; Sign Language; Speech and Language.

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BELL'S PALSY

Bell's palsy was named in honor of, but not by, the Scottish surgeon-anatomist (1774–1842) who discovered in 1821 the difference between the fifth cranial nerve that gives the face sensation (trigeminal nerve) and the seventh cranial nerve that gives the face expression (facial nerve).

Bell's palsy refers to a specific type of sudden, unexpected onset of facial paralysis on one side of the face and is the most common cause of facial paralysis in all age groups. It is a diagnosis of exclusion (idiopathic), meaning that all other causes of facial paralysis have been sought and excluded. This distinction is important because there are definable other causes of sudden facial paralysis that should be detected and treated differently, some may be quite dangerous, such as cancer, nonmalignant tumors, infections, and trauma.

Recently, herpes simplex virus, type 1, the common cause of fever blisters, has been implicated as a cause of some cases of Bell's palsy. Because of this, antiviral medications have begun to be used in conjunction with orally administered corticosteroids, such as prednisone, a commonly used treatment for Bell's palsy. However, there is little scientific evidence to prove these treatments are helpful.

The physical impairment from Bell's palsy falls in two time domains, immediate and late. Immediate impairment is the dysfunction of the facial nerve (seventh cranial nerve), resulting in complete paralysis or partial paralysis (also known as paresis). The resulting disability from this impairment is the inability to close the eyelids, thus failing to lubricate and protect the eye; the inability to express emotions or produce voluntary movements, such as smiling, on that side; and difficulty eating with the mouth fully closed. Because all cases of Bell's palsy recover to some degree, but not necessarily to normal, late impairments are common. Late impairments are permanent paresis, synkinesis, and contracture. Synkinesis is the concurrent movement of a portion of the face in a region other than the one voluntarily or emotionally moved, for example, winking when trying to smile. Contracture is the increased resting tone of the side of the face, which leaves the patient with an eye more closed than normal and a mouth with a permanent smirk. Disabilities from these late impairments are the inability to express oneself completely, especially smiling and softening of the eyes in the smiling process, and the inadvertent transmission of incorrect nonverbal facial messages, such as winking while eating or permanently smirking. Excessive tearing while eating, known as "crocodile" tears, may occur and impair or distort communication, such as tearing in one eye during a romantic dinner.

Facial expressions in human communications are important in both the receptive and the expressive modes. Because Bell's palsy is more common during the teenage and early adult years, times of important social development, the disabilities may be especially socially traumatic. Similarly, infants learn to detect facially expressed emotions and develop accordingly. Facial disfigurement may be distressing to the receptive infant and to the expressive sibling, parent, or grandparent who may look quite different with Bell's palsy.

—J. Gail Neely

See also Neurological Impairments and Nervous Disorders; Paralysis.

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BIESALSKI, KONRAD (1868–1930)

German pediatrician and reformer

Konrad Biesalski was a pediatrician, orthopedic specialist, and the founder of the rehabilitation policy for the physically disabled ("cripples' care") in Germany. He was born in Osterode/Prussia and studied medicine in Halle and Berlin. In 1894, he passed his Boards, after which he got his Ph.D. in medicine and became an assistant doctor in Berlin and Würzburg. Biesalski initiated the first census of physically disabled youths, or "cripples" as they were officially known, in 1906. Through cure, education, and employment of the affected persons, he wanted to prevent the economical harm caused by the social needs of the physically disabled. His motto was "Vom Almosenempfänger zum Steuerzahler" ("From alms recipient to taxpayer"). In addition, in 1906 Biesalski opened a small institution in Berlin. After he had founded the *Zeitschrift für Krüppelfürsorge* (*Journal for the Care of Cripples*) in 1908, the Deutsche Vereinigung für Krüppelfürsorge (German Organization for the Care of Cripples) was created on April 14, 1909, as an umbrella organization for the care of the physically disabled.

In 1911, with the *Leitfaden der Krüppelfürsorge* (*Manual for the Care of Cripples*), Biesalski published a standard work for this new field of social policy. On May 27, 1914, he opened the Oskar-Helene-Heim für Heilung und Erziehung gebrechlicher Kinder (Oskar-Helene-Home for the Cure and Education of Frail Children) in Berlin, which soon became internationally known as a model facility. With the Kriegskrüppelfürsorge (care of war cripples) initiated by him during World War I, Biesalski laid the foundation for establishing specialized medical treatment for the first time, along with special institutions, and the prospect of social and professional rehabilitation. The Preußische Krüppelfürsorgegesetz (Prussian Cripples' Care Law) of 1920 enacted, for the first time, a right to medical care, and scholarly and occupational education for the physically disabled. In 1928, the Museum der Deutschen Krüppelfürsorge (German Cripples' Care Museum) opened in the Oskar-Helene-Home. Biesalski died two years later on January 28, 1930, of a cardiac infarction.

—Petra Fuchs

See also Advocacy Movements: Germany; *Cripple*.

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BINET, ALFRED (1857–1911)

French psychologist

Universally known as the developer of the *quotient d'intelligence*, Alfred Binet was most of all an innovative psychologist. At first, he continued legal studies, while expressing interests for natural science and initiating himself with the experimentation. The birth of his two daughters provided him the opportunity to study child psychology, more particularly analysis of the individual differences in connection with the genetic inheritance and education. In 1892, he had his first contact with Theodore Simon, who solicited his counsel for the education of the abnormal children for whom he was in charge.

His question about the abnormal children is capital: What distinguishes them from the "normal" children; is it a difference of degree or nature? And how to define, in a general way, this concept of difference, and how evaluate it? In 1904, he caused, with Simon, the creation of a departmental committee, with objective

the examination of two problems: the diagnosis of the states of mental retardation and the education of the abnormal children.

Six months later, he presented at the International Congress Psychology (Rome, 1905) his test of diagnosis, first version of the future "metric scale of the intelligence." In a clinical approach of epistemology, Binet transformed the diagnosis into numbers representing the intellectual level to make measurement an effective instrument of the backwardness. The next few years were devoted mainly to the development of the famous test known as the Binet-Simon Test, whose centenary was celebrated during 2004. Binet died on October 28, 1911, at age 54.

—Henri-Jacques Stiker

See also IQ.

BIOETHICS

This entry reviews the major intersections of disability studies and bioethics, describing the principal issues that have sparked controversy between disability rights activists and scholars and mainstream bioethicists. The discussion lays out key arenas of struggle between those with a disability rights perspective and those within bioethics; it also comments on issues that have received less attention from within disability rights but that could benefit from a dialogue.

CONVERGENCE AND CONTRAST WITH DISABILITY RIGHTS

What characterizes the field of bioethics is its concern with fundamental questions of health and illness; life and death; autonomy, dignity, personhood, and humanity; the relationship of medicine to nature; the relationship of health to well-being. Both bioethics and the disability rights movement have appeared only in the past half-century, and each has emerged in reaction to a dominant paradigm in the medical and helping professions. Recognition of bioethical issues first arose when the public learned that physicians and scientists all over the world in the first half of the twentieth century engaged in widespread abuse of many classes of vulnerable citizens by failing to obtain their consent to serve as subjects in dangerous medical research. Prisoners, concentration camp inmates, residents of institutions for the psychiatrically and cognitively disabled, and African American sharecroppers had all been victims of government and professional research interests. Discovery of these abuses spurred demands for regulation, reform, and new oversight of governmental and professional behavior.

The early U.S. independent living and disability rights movements exemplified much the same challenge to professional domination and demands for self-determination and autonomy. Adults with disabilities and advocates for disabled children protested abuses by powerful government and philanthropic institutions that historically had usurped the decision-making authority of parents and guardians, using the same language as physicians, lawyers, philosophers, and theologians who questioned the power and paternalism of medicine in conducting medical research and using new life-sustaining technologies.

If disability and bioethics began with similar concerns, they have also broadened their focus in similar ways. As disability scholarship and activism have moved from demands for individual control and self-determination to calls for sweeping societal change, bioethics has recognized that the complex life-and-death decisions made by individuals and families cannot remain its only concern. Recent debate also focuses on the implications of life-creating and life-changing technologies, on questions of what constitutes a just distribution of resources for medical care, and on which life situations should properly come under the purview of medicine.

But if bioethics resembles the disability rights movement in its commitment to patient autonomy, it skepticism about professional authority and paternalism, and its support of consumer rights, it has never shared its understanding of disability or its valuation of lives with disabilities. The dominant bioethics voices have argued that human life has to be respected and valued, but not necessarily at any cost or in any state of impairment. Now that human mastery over nature permits lives to be sustained despite significant illnesses and disabilities, it is incumbent on individuals

and societies to set limits on which medicine and technology should be used for these purposes. Instead of the medical question, "Can this life be saved?" bioethics invites the question, "Should this life be saved?" Bioethics challenges the disability community by asking whether it is appropriate to use medical technology to sustain the life of someone who would be left with a severe disability.

For disability scholars, these very questions, and the haste with which bioethicists have answered them negatively, reveal a fundamental misunderstanding of the nature of disability. Bioethics has presumed that impaired mobility, physical deformity, sensory deficits, or atypical learning style or speed explain why people with disabilities are less likely than their fellow citizens to be educated or employed, and more likely to live in poverty and isolation. Most bioethicists uncritically adopt what Gliedman and Roth (1980) and Bickenbach (1998) termed the medical model of disability, as contrasted with the social or minority group models. Disability critics of standard bioethics reject the medical model, with its assumption that functional impairment is the sole or primary cause of what is presumed to be an unacceptable, unsatisfying life.

HEALTH, NORMALITY, DISABILITY, AND QUALITY OF LIFE

Those who embrace either the social or the minority group model of disability contend that prevailing bioethics understandings of impairment rest on two erroneous assumptions. First, the life of someone with a chronic illness or disability is permanently disrupted, in the way one's life can be temporarily disrupted by the flu or a back spasm. Second, if a disabled person experiences isolation, powerlessness, poverty, unemployment, or low social status, these are inevitable consequences of biological limitation. Many bioethicists generalize from the problems and disorientation that some people experience at the onset of a disability and assume the disruption is unchanged by rehabilitation, adaptation, mastery of new means to accomplish desired ends, or changes in the life plans one pursues. Many bioethicists also fail to recognize the extent to which disadvantages experienced by people with disabilities arise through society's lack of accommodation to the different methods of performing valued activities such as learning, communicating, moving, or taking in the world. Disability scholars counter, first, that life with disability is not the unremitting tragedy portrayed in medical and bioethics literature and, second, that the culprit is not biological, psychic, or cognitive equipment but the social, institutional, and physical environment in which people with impairments must function—a world designed with the characteristics and needs of the nondisabled majority in mind. For the past three decades, disability scholars and activists have argued that the main problem of disability is, indeed, the denial of civil, social, and economic rights, not the lack of health or functioning.

A substantial body of literature reveals that even before legal and political advances in the United States and other nations, but certainly since then, many people with disabilities have found satisfaction in their lives that was far greater than anything expected of them by members of the health and rehabilitation professions. When people with disabilities report unhappiness or dissatisfaction (a minority in every study), the sources resemble those in the lives of nondisabled people—inadequacies in financial security, work, or social and personal relationships. While impairment-related factors, such as pain or fatigue, sometimes contribute to unsatisfying relationships or employment difficulties, the greater frustrations come from barriers to incorporating the impairment into existing interpersonal and institutional life.

There are several plausible explanations for the gap in understanding between bioethicists and disability scholars. Few bioethicists identify as people with impairments or as members of the disability rights movement. The emphasis on self-sufficiency of many bioethicists leads them to doubt that anyone who cannot execute "normal" life tasks of eating, walking, or managing personal hygiene could live as well as someone who performs these tasks without human assistance. And their focus on individual cases, often to the exclusion of social and economic background conditions, reinforces the impression that even satisfied people with disabilities are a burden to their families and society.

In one area, cognitive impairment, disability scholarship often displays the same limitations of experience and understanding as bioethics. Like bioethicists, disability scholars are typically highly educated individuals who prize rationality and intellect, place a premium on "autonomy," and tend to denigrate, or ignore, the interests and rights of people deficient in those characteristics. But this bias and oversight have not gone unnoticed. From within the disability rights and bioethics communities, researchers have complained that the esteem given to intellect, rationality, and self-awareness leads some scholars to question the moral status or life quality of people with cognitive impairments.

The gap in understanding about life with disability has surfaced in two controversial areas of health care policy: (1) deciding whether to initiate, maintain, or withdraw life-sustaining treatment for impaired patients, particularly newborns, who cannot decide for themselves or communicate their preferences; and (2) deciding whether to test for impairments prenatally, and whether to abort, or decline to initiate pregnancy, if they are detected.

EXTENDING AND CREATING LIVES WITH DISABILITIES

Extending Lives: Newborns with Impairments

In the early and mid-1980s, U.S. disability rights adherents first challenged bioethics over decisions about standards of care for infants with significant disabling conditions who required immediate medical treatment. Should physicians counsel parents of children with Down syndrome who also had heart problems to let the infant die rather than treat the heart condition, leaving the infant with Down syndrome? Should parents of a child with spina bifida be permitted to refuse surgery to close the child's spine and reduce the risk of infection? Should parents of a child with bowel obstruction consent to surgery to remove a necrotic bowel to save the child's life, although long-term survival of a child with such obstruction is estimated at less than 1 in 10,000? Should a severely premature baby be placed on a respirator against the wishes of the baby's parents if chances of survival are negligible?

Rationales for withholding treatment focused on the suffering caused by potential treatments and the impairments themselves; on the suspicion that technology was being used to sustain children who would have short, painful, and miserable lives regardless of what was done for them; on the reluctance to impose further anguish on parents who might have to watch their child die slowly after fruitless medical procedures; on concern for the disappointment of parents who would not have the healthy child they expected and would instead have to raise one never free of disabling conditions; and on the conviction that the millions of dollars spent for such treatments could be better spent in other ways.

Disability critics rejected these rationales as both mistaken and unjust—mistaken in their assumptions about the quality of life possible for impaired infants and the burden they imposed on their families; unjust in denying treatment to one class of human beings. Concentrating on infants with treatable medical conditions, they maintained that denials of beneficial treatment represented discrimination against people with disabilities by the medical profession and frightened parents. If denying beneficial medical treatment to a nondisabled infant constitutes child neglect or abuse, so does denial of that same treatment to one with a disability. These discrimination claims appear to have changed prevailing practice. In 2000, most infants with Down syndrome and spina bifida born in the United States received medically indicated treatments, as did premature and low-birth-weight infants who—if they survived—became part of the disabled population. Most U.S. bioethics literature now concentrates on other topics, although there are no public retractions of the views that enraged the disability rights movement.

Creating Lives: Prenatal Testing and Selective Abortion

By the 1990s, bioethicists, health professionals, and the public generally accepted the claim that a live-born infant should get medical treatment to provide a chance at life. However, the vast majority of

theorists and health professionals still held that prenatal testing, followed by pregnancy termination if a potentially disabling condition was detected, promoted family well-being and public health—it was simply one more legitimate method of reducing disability in the world. Disability rights scholars and activists raised the question of how the increasing use of prenatal testing and selective abortion affected the place of people with disabilities in the world. Opposition to prenatal testing has led to no highly publicized court cases, but the themes in the prenatal testing debate echo those in the earlier debate about disabled newborns.

Standard justifications for prenatal testing and selective abortion invoke the suffering or hardships of both the disabled child and his or her parents, although most disabled children are manifestly happy to be alive, and the burdens on their parents appear to differ from those facing the parents of nondisabled children mainly in degree, if at all. Disability scholars have challenged the empirical and moral assumptions that lie behind such conventional views. Parens and Asch (1999) described the disability rights critique of prenatal testing as follows:

> Rather than improving the medical or social situation of today's or tomorrow's disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved. . . . In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics might occasion. (p. S12)

This disability critique, and the response from bioethicists, are discussed at greater length in the entry on reproductive rights. The debate illustrates the extent to which bioethics and disability scholars and activists continue to differ in their assessment of the quality of life with disability, a difference that recurs in two other contexts we will examine: life-and-death decision making by people with disabilities, and the relevance of disability to the allocation of scarce health care resources.

LIFE AND DEATH: DECISION MAKING

Most bioethicists oppose the medical treatment of patients against their expressed wishes, insisting on the right of competent adults to stop treatment, even if by doing so they ended their lives. The recognition of a right to self-determination concerning medical treatment has been partially extended to adults with cognitive impairments.

Most cognitive impairment leaves individuals with some means of understanding their situations and expressing preferences about how they are treated and who should decide for them when they cannot decide for themselves. It should be possible for people with nearly any disabling conditions to communicate about whether they find life and medical treatments worthwhile and acceptable to them. The bioethicists Buchanan and Brock (1989) recognized that persons unable to examine all long-range implications of a decision may nonetheless be able to provide valuable information to ultimate decision makers about their preferences and thus meaningfully participate in decisions about their lives and well-being. Several recent discussions by professionals familiar with people who have cognitive disabilities favor methods that would enable people who fall short of legal "competence" to reveal their decisional capacities, express their preferences, and, if possible, make choices about their medical treatment.

Many bioethicists, though, contend that difficulties in communicating preferences and making decisions can largely be preempted by using "advance directives" to express the prior choices of individuals who can no longer make their own wishes known. They also recommend the appointment of health care proxies to act on their behalf. Such legal devices might assist families and health professionals in dealing with treatment decisions for the millions of people who lose some of their cognitive and communicative abilities through stroke, Alzheimer's disease, or the like. However, they would be of no help to the lifelong disabled. Moreover, "living wills" or advance directives do not encourage people to think critically about which capacities and activities are essential components of an acceptable or good life.

From the standpoint of disability rights, the most serious flaw of advance directives is that noted by the bioethicists Dresser and Robertson (1989), who criticized the "orthodox" reliance on any advance statement of preferences. People who are not living with disabilities and cannot imagine that their lives as disabled would be satisfying make such statements in profound ignorance of relevant information and experience. Dresser and Robertson urged that nondisabled people evaluate treatment decision making from the perspective of the now-disabled individual. Their point is an important corrective to snap assessments that "Mom would hate living like this" or "my brother's advance directive was explicit about stopping life support if he could not hear or speak"—despite the fact that the mother or brother appears to take great pleasure in the activities and experiences that remain possible for them. Admittedly, as Buchanan and Brock and others argue, people care about more than their current experiences. Even an apparently content person with severe dementia might prefer that his or her wish not to live in a disoriented, demented state be honored by following a validly executed advance directive. In general, bioethicists are more inclined than disability scholars and activists to let clear, emphatic pre-impairment directives override post-impairments preferences, especially if the latter are uncertain or ambiguous.

Furthermore, most case law has concerned individuals very likely to die without treatment. More problematic, and more revealing of the continuing chasm of perception between bioethicists and disability scholars, are those cases where apparently competent patients with disabilities seek withdrawal of treatment or physician assistance in suicide for conditions that are not terminal in this sense; conditions with which they could live for decades with technological support, for example, with spinal cord injury or multiple sclerosis. Bioethicists often equate requests to die in such conditions as equivalent to the requests of imminently dying people who wanted to avoid prolonging their lives by a matter of days, weeks, or months.

Most disability theorists and activists, however, construe these decisions to stop treatment entirely differently. They agree that people with disabilities deserve to have their views respected. However, they argue that such decisions are often made because people with disabilities have experienced constant discrimination, denials of information about life possibilities, inability to obtain legally available services and supports, and abandonment by family and friends.

Key to the differing appraisal of these cases is the different understanding of concepts of dependence, independence, and interdependence. Like the newly disabled people themselves, professionals construe the inability to execute life tasks such as dressing, toileting, or moving from place to place as demeaning dependence and as leading to inevitable feelings of embarrassment and humiliation. Disability rights adherents contend that independence need not be viewed in physical terms; rather, self-direction, self-determination, and participation in decision making about one's life are more genuine, authentic measures of independence or, better, universal interdependence.

These themes play out in the broader physician-assisted suicide (PAS) debate of the past two decades. As the bioethics debate shifted from terminating life-prolonging treatment to PAS, the disability rights community sounded a cautionary note with some influence on the mainstream bioethics literature and the case law. But that community does not speak with one voice. Two ideological strands of the disability rights movement offer divergent responses to PAS. The strand of the disability rights movement that stresses self-determination argues that disabled people are no more vulnerable in general to coercion, pressure from family, or victimization by society than anyone else and may benefit from legalized assistance in dying. These theorists are offended by what they see as the paternalism that leads some prominent members of the disability rights community to oppose PAS.

In contrast, the ideological strand that stresses biased social arrangements for people with disabilities holds that the legalization of PAS in a world of harsh prejudice, inadequate health care, unreliable social services, and frequent familial rejection would inevitably lead to its widespread abuse to hasten the death of vulnerable patients seen by society, and often by their families, as burdens.

While recognizing the legitimacy of both perspectives within the disability community, the fact remains that support for PAS among bioethicists reflects

troubling assumptions about the quality of life with disability. As Bickenbach (1998) noted:

> It is telling that . . . there is never any suggestion that the right to physician-assisted suicide should extend to people who do not have a severe disability. Implicit in the judgments themselves . . . is precisely the prevailing prejudicial social attitude that having a disability is a sensible reason for committing suicide. (p. 130)

JUSTICE IN HEALTH CARE ALLOCATION

The sharpest conflicts between disability rights and bioethics have occurred in life-and-death situations. But the stigma and devaluation of lives with disability can take subtler, or less explicit, forms than the outright denial of treatment or "assisted" suicide, and these other forms need closer attention from bioethics. One historically freighted example is the recurrent medical abuse of people with cognitive impairments, who often become research subjects without informed consent. At present, however, people with disabilities are more likely to suffer from medical neglect than unwanted attention. This is apparent both in the provision of reproductive services and in the allocation of scarce health care resources more generally.

Bioethicists who consider reproductive liberty as a fundamental human right have largely neglected the obstacles facing people with disabilities in pursuing parenthood. Sterilization is still forced on people with many impairments, especially with cognitive or psychiatric impairments, in nations such as Australia, Spain, and Japan. But even in societies that have rejected involuntary sterilization, people who need assistance with household and daily activities face obstacles to parenthood if they cannot acquire any additional services for child care. Neither bioethics nor the disability rights movement has undertaken a sustained discussion of what social accommodations are owed to those people who can experience the rewards of parenthood only with some assistance or supervision. The lack of attention to reproductive and parenting support reflects a broader devaluation of the health care needs of people with disabilities.

A chief concern for the disability community arises in the context of access to health care itself and whether—if at all—an individual's existing impairments should influence the types of services he or she receives. Disability has sometimes been used invidiously to deny people available treatments from which they could benefit. For example, someone with Down syndrome may be denied a kidney transplant, based on the assumption that he or she could not comply with treatment requirements, or on an evaluation that rated life with Down syndrome as less worthy of scarce organs because of its presumptively low quality.

Several different methods have been proposed to allocate health care based on its presumed effect on the recipient's "quality of life," as Dan Brock argued in 1993. Should priority be given to those considered "worst off," or to those whose presumed quality of life after treatment would be high? Different allocation schemes would have vastly different results for the world's disabled population. If societies choose to provide care to improve the conditions of the worst off, people with disabilities could receive care based on being considered worst off. However, if they choose to provide care to those expected to derive the most benefit in terms of maximal quality of life, stereotypes about disability and life quality could severely limit the care received.

Even if experts or nations achieved consensus on the version of social justice that should guide allocation decisions, there would be conceptual and empirical difficulties in ascertaining quality of life. From whose perspective should life quality be judged? If people with disabilities consistently indicate that their lives—even with problems—are more satisfactory to them than nondisabled people or health professionals believe, should their judgments be used in measuring life quality? If, instead, health professionals and nondisabled people become the judges of future life quality with impairments, people with disabilities will fare badly in allocation decisions based on expected quality of life.

MEDICAL INTERVENTIONS AND "CORRECTION" OF IMPAIRMENT

What about possible efforts to "cure" disability by cochlear implants, spinal cord regeneration, fetal tissue transplants, or gene therapy? Such actual or potential medical interventions to reduce functional impairment or restore species-typical function raise the

issue of what makes something an "impairment" that one ought to correct, as opposed to a characteristic that one has no reason to change. Is being "short" a biological impairment or exclusively a socially constructed disability in a society that prizes height? The new paradigm of disability must play a role in deciding when growth hormone is a legitimate medical therapy and when it is an inappropriate enhancement. If individuals can gain hearing from cochlear implants, are they morally obliged to have them, and should they lose access to interpreter services if they decline, as Tucker (1998) asserted? Are people morally obliged to obtain any therapy that reduces impairment or restores species-typical functioning? If the disability rights movement would endorse surgery for an infant with spina bifida to increase mobility, is it equally acceptable to support parental interests in providing some hearing by virtue of a cochlear implant? Is deafness properly considered a culture, not an impairment? If somatic cell or germ-line therapy could safely correct detectable impairments in eggs, sperm, or embryos, should they become standard parts of medical care? Should people with disabilities support or oppose such measures, which do not exclude or select against individual lives but reduce the incidence of disabilities? Is having an impairment just one desirable or inconsequential form of human variation, or, even with just or optimal accommodation, is impairment always undesirable? Bioethics and disability studies must work together to understand the apparent importance of health and normal functioning and to explore the meaning of impairment and disability.

It seems fitting to close this discussion of the intersections of disability studies with bioethics by affirming what bioethics can learn from disability studies. Paul Longmore's (1995) description of the values needed for people to accept the disabled are values that, he says, would change orientations toward another regardless of disability. They would change bioethics and society in ways that could surely promote human rights for everyone: "not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community" (p. 9).

—Adrienne Asch and David Wasserman

See also Death; Ethics; Euthanasia; Family: Law and Policy; Health; Health Management Systems; Impairment; Normality; Physician-Assisted Suicide; Quality of Life; Reproductive Rights.

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BIOLOGICAL DETERMINISM

The term *biological determinism* refers to claims that most human characteristics—physical, mental, and personality based—are determined at conception by hereditary factors passed from parent to offspring during reproduction. Of course, all human traits are ultimately based in the material nature of our being organisms (e.g., memorizing a poem involves changing molecular configurations at synapses, where nerve cells interact), but the term *biological determinism* has come to imply a rigid causation largely unaffected by environmental factors. Prior to the turn of the twentieth century and the rediscovery of Gregor Mendel's work on heredity in 1900, a wide variety of hereditary causes were postulated (such as direct environmental effects acting on the mother's or father's germ cells or indirectly on the fetus via the mother during pregnancy). After the rediscovery of Mendel, theories of biological determinism came more and more to be formulated in terms of the new science of genetics, so that today *biological* and *genetic determinism* are virtually synonymous.

In the eighteenth and nineteenth centuries, theories of biological determinism were based on vague, often highly controversial ideas about of the nature of heredity. Since the concepts and tools were not available during that period to study heredity directly, biologists and anthropologists measured physical features of humans, trying to associate mental and personality traits with some anatomical (occasionally a physiological) feature, such as facial angle (angle of slope of the face from chin to forehead) or cranial index (ratio of lateral to vertical circumference of the head). Certain physical features, such as high cheekbones or a prominent eyebrow ridge, were often said to be indicative of criminal tendencies. With the growing acceptance of Mendelian genetics in the first half of the twentieth century, most theories of biological determinism came to locate the causal element in defective genes. With the revolution in molecular genetics during the second half of the century, defective genes became identified with altered sequences of the molecule of heredity, deoxyribonucleic acid (DNA).

Throughout its history, theories of biological determinism have been particularly applied to what were conceived of at the time as negative physical traits such as cleft palate, clubfoot, dwarfism, gigantism, foreshortened appendages, and social traits such as criminality, feeblemindedness, pauperism, shiftlessness, promiscuity, "feeble inhibition," manic depression, and hyperkinesis (hyperactivity). Many of these later conditions or traits we would refer to as disabilities today, and the claim that most or all of them are inherited was, and is, highly controversial. This is partly a result of the difficulty in obtaining rigorous data about the genetics of such traits, especially when there is no established definition on which all investigators can agree (what *is* criminality or alcoholism, or when does exuberance become hyperkinesis?) It is also a result of the fact that so many other factors

interact with whatever genetic elements are present that it is difficult to tease them apart. Thus, throughout recent history, attempts to show that certain disabilities were genetic have had little success.

One of the most prominent movements to apply genetics to understanding social and personality traits emerged early in the twentieth century as the eugenics movement. *Eugenics* was a term coined by British geographer, statistician, and general polymath Francis Galton (1822–1911), first cousin of Charles Darwin. By "eugenics," Galton meant "well" or "purely born," and he argued for planned breeding among the "best stock" of the human population, along with various methods to discourage or prevent breeding among the "worst stock." It was the belief of eugenicists such as Galton, his student Karl Pearson (1857–1936), and their American convert Charles B. Davenport (1866–1944) that most social problems were due to the accumulation of genetic defects, producing an increasingly disabled, or "degenerate" population. Society was deteriorating through the increased reproduction of the disabled—particularly the mentally disabled. Various forms of inherited mental disability were said to be the root cause of social problems as varied as crime, alcoholism, and pauperism (in all cases, it was claimed that low mental ability led to inability to cope in a complex society, and hence the turn to antisocial behaviors).

Using the newly developed IQ tests in the 1920s and 1930s, eugenicists proceeded to rank people into categories based on quantitative scores (normal = 90–110, high-grade moron = 70–90; idiot = > 50; imbecile = no ranking). In most cases, especially in the largest categories, those individuals with scores between 70 and 90, who were claimed to be genetically disabled were not disabled at all, simply disadvantaged (the poor, the uneducated, the immigrant who could not adequately interpret test questions). Nor was there much sound evidence that such cases were in any way genetically determined.

The eugenics movement in the United States, and especially Germany after the National Socialist takeover in 1933, carried through legislation specifically aimed at taking action against the disabled of all sorts, but again the mentally disabled in particular. In the United States, laws were passed in more than 30 states by 1935 allowing for the compulsory sterilization of those deemed to be genetically unfit in state and federal institutions such as mental hospitals, asylums, and prisons. Overall, in the United States more than 60,000 people had been sterilized under these laws by 1963. In Germany, similar laws (actually based on ones in existence in the United States) led to the sterilization of more than 400,000 people by the early 1940s. Sweden and Canada had similar laws allowing for sterilization of the supposedly genetically disabled.

One of the major consequences of widespread belief in biological (genetic) determinism is the underlying assumption that if a trait or condition is genetic, it cannot be changed: "Genes are destiny," genetic determinists have claimed. However, the relationship between what geneticists call the genotype (the actual genes an individual inherits) and phenotype (what traits they actually show) has turned out to be far more complex and unpredictable than previously thought. For example, cystic fibrosis (CF) is a multifaceted disease that is present in about 1:2500 Caucasians and can be severely debilitating. It is due to a recessive Mendelian gene (meaning that for it to show up phenotypically, the individual has to inherit the defective gene from both parents), and it has now been completely sequenced (meaning that every base-pair in the sequence of nucleotides that make up the DNA of the gene has been determined). Moreover, more than 1,000 mutation sites are known, and most have been related to different manifestations of the disease. However, one of the startling findings has been that even with the same mutated site within the gene, different individuals will show remarkably different phenotypes. Some will show early onset, others, later onset; in some, the kidney is most afflicted, while in others, it is the lungs. In some individuals even with the most common mutation, the effects are severe, while in others they are mild to nonexistent. Although the reasons for these differences are not understood, it is clear that both genetic background and environmental factors (such as diet) must play an important role. In other words, genes are not destiny even in cases where the genetic basis of a disability can be well understood. It is certainly not destiny when the genetic basis is unclear or circumstantial.

With modern genomics, the science of understanding complex genetic interactions at the molecular and

biochemical levels, the possibility exists of treating such genetically based disabilities, such as diabetes type I, cystic fibrosis, or sickle-cell anemia (a genetic defect in the hemoglobin molecule) either with gene therapy (much more difficult at present) or pharmacologically, prescribing drugs that can perform and carry out the normal biochemical function of the defective gene. Social attitudes about what constitutes a disability, and how economic and social resources are to be allocated to deal with disabilities, change over time. In hard economic times, the disabled tend to be written off as "too expensive," often justified on the basis of "genetic determinism" (whether scientifically valid or not). Throughout its history, arguments for biological determinism have been employed more to restrict than to expand human potential.

—Garland E. Allen

See also Eugenics; Eugenics: Germany; Feeblemindedness; Walter Fernald; Henry Goddard; IQ; Sterilization.

BIOMECHANICS

Biomechanics is the study of the structure and function of biological systems using the methods of mechanics. Although the ideas and investigations that can be classified as biomechanics go back to Giovanni Borelli (1608–1679), who first described the basis of muscular and skeletal dynamics, the term *biomechanics* and research performed in this field have became well known only in the past several decades.

Contemporary biomechanics is a multidisciplinary field of science that combines physical and engineering expertise with knowledge from the biological and medical sciences. Biomechanics includes several main directions of research, for example, cardiovascular biomechanics, cell biomechanics, human movement biomechanics, in particular orthopedic biomechanics, occupational biomechanics, and sport biomechanics. As an example, sport biomechanics deals with performance improvement and injury prevention in athletes. In occupational biomechanics, biomechanical analysis is used to understand and optimize mechanical interaction of workers with the environment. Development of the biomechanics of labor focused on increasing worker efficiency without sacrificing labor safety. It resulted in the design of new tools, furniture, and other elements of a working environment that minimize load on the worker's body. Another development was clinical biomechanics, which employs mechanical facts, methodologies, and mathematics to interpret and analyze typical and atypical human anatomy and physiology.

Beginning during and after World War I and especially World War II, the focus on development of prosthetic limbs for management of the many wartime amputations led to major progress in rehabilitation medicine as a result of the application of biomechanics. Work in this area focused on increasing the mechanical efficiency of orthopedic implants that, for example, allowed those undergoing hip or knee replacement surgery to walk again. A biomechanics-research-based approach generated a major step toward improving walking for individuals with lower-leg amputation and children with cerebral palsy. As an example, development of a new class of prosthetic feet that store and return mechanical energy during walking allowed for reduction of the metabolic expenditure in amputees and made it possible for individuals with amputation to participate in athletic activities. The biomechanically based design of assistive devices, such as wheelchairs, and the optimization of the elements of the environment allow individuals with disabilities to improve their lives.

Application of biomechanics is wide-ranging as its diverse topics include everything from human gait to blood-flow dynamics. During the past decade, growing public opinion favoring investment in medical and health care research contributed to opening of new avenues in biomechanics. Among these are the use of biomechanical analysis in artificial prosthesis design (e.g., artificial heart and small-diameter blood vessels), the engineering of living tissues and organs (e.g., heart valves and intervertebral discs), biomechanics of injury prevention related to labor safety and vehicle accidents (from low-speed collisions with minor soft-tissue injuries to high-speed collisions with severe and fatal injuries), and biomechanical aspects of disability with the ultimate goal of improving the lives of individuals with functional impairments.

—Alexander S. Aruin

See also Amputation; Veterans.

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BIPOLAR DISORDER

Bipolar disorder (BPD) is a chronic, recurrent, disabling illness characterized by mood instability and associated with significant morbidity and mortality. Both biological and environmental factors are critical to its development. BPD is frequently complicated by other comorbid conditions that can impede proper diagnosis and treatment. Optimal strategies to manage bipolar disorders require medication, psychotherapy, and attention to concurrent psychiatric disorders.

BPD includes symptoms of mania/hypomania, depression, or their combination (i.e., mixed states). While the defining characteristic of BPD is mania (i.e., elevated, expansive, or irritable mood state) or hypomania (a less severe form of full mania), depression is often the heralding symptom and patients usually experience more time depressed than manic over the course of their illness. More severe episodes can also present with psychotic features (e.g., delusions of grandiosity) and impulsive destructive behavior (e.g., suicide). The suicide rate for BPD is about 10 percent in untreated patients and about 25 percent will attempt suicide at some point in the course of their illness. The risk for suicide is greatest during a depressed or mixed episode. Lack of treatment is also a major risk factor, since mood stabilizers appear to protect against suicide.

Classic *bipolar I* patients experience *full mania* and depression, while *bipolar II* patients experience *hypomania* and full depression. Associated symptoms may include hyperactivity, pressured speech, flight of ideas, inflated self-esteem, decreased need for sleep, distractibility, and excessive involvement in activities that have a high potential for painful consequences. The course of illness can vary from only few episodes to a more virulent pattern characterized by multiple episodes over short periods of time. One example is *rapid cycling* (i.e., four or more episodes per year), which is more common in females with bipolar II disorder; has a higher suicide risk; and may be precipitated by antidepressant use or thyroid dysfunction. The US lifetime prevalence rate of bipolar I disorder is estimated to be 1.3 percent. When bipolar II and other more subtle forms of the illness (e.g., cyclothymic disorder) are also considered, the prevalence rate has been estimated to be about 3.7 percent. There is an equal distribution among ethnic groups and between men and women.

While BPD can occur at any time, the onset of this disorder is usually before the age of 20, with the peak period between 15 to 19 years. Initially, BPD may present as one or more depressed episodes, have psychosis as a prominent feature, or mimic disorders characterized by hyperactivity. As a result, it is often mistaken for other conditions (e.g., unipolar depression; schizophrenia; attention deficit hyperactivity disorder [ADHD]). This, in turn, can delay accurate diagnosis and implementation of appropriate treatment. In most individuals, BPD produces substantial disability and functional impairment in work, leisure and interpersonal activities, both during and between mood episodes.

Secondary mania is a condition separate from BPD that can be precipitated by a variety of medical conditions (e.g., hyperthyroidism, and complex partial seizure); medications (e.g., steroids, tricyclic antidepressants); or drug use or withdrawal (e.g., amphetamines, cocaine). Further, substance and alcohol abuse or dependence frequently co-occur in this population, make accurate diagnosis more difficult, worsen the long-term course and compromise otherwise effective treatments. Other comorbid conditions frequently associated with BPD include obsessive-compulsive disorder, panic disorder, bulimia nervosa, impulse control disorder, ADHD, conduct disorder and certain personality disorders. Recognition of the high rates of comorbidity in BPD is critical to

developing treatment strategies that will address all existing disorders. For example, unless alcohol-related complications are adequately managed, it is unlikely that adequate mood stabilization can be achieved or sustained.

ETIOLOGY

As with most complex major psychiatric disorders, the cause of this condition is thought to involve both biological predisposition and environmental influences. Several hypotheses have been proposed to help elucidate the biological basis for BPD. They include abnormalities in: relevant neurotransmitter activity (e.g., norepinephrine, serotonin); second messenger systems (e.g., phosphoinositide cycle); biological rhythms (e.g., sleep-wake cycle); neuroendocrine function (e.g., thyroid system); neuroanatomy; neurophysiological activity (e.g., kindling phenomenon); and the immune system. The support for a genetic basis comes from family studies that establish a pattern of aggregation, linkage studies that can identify specific genomic regions associated with the disorder, and twin studies that estimate concordance rates to be 14 percent for dizygotic twins and 57 percent for monozygotic twins (whether raised together or separately). The absence of 100 percent concordance rate in monozygotic twins, however, indicates a role for other factors. Thus, a genetic-environmental interaction has been proposed in which a number of small susceptibility genes establish a gradient of liability which may trigger BPD in the context of various stressors. Other important risk factors include a family history of mood disorders, females who are postpartum, or a history of cyclothymic disorder (symptoms similar to but less severe than full bipolar disorder). Of note, linkage studies report a number of genomic regions that may represent susceptibility loci for both BPD and schizophrenia. This is also consistent with a number of observed characteristics that these two disorders have in common. They include a similar lifetime prevalence; onset in early adulthood; tendency to run a chronic, episodic course; high suicide risk; substantial overlap in symptom presentations; and response to antipsychotics. Such data speak to the possibility of greater commonalities between these two disorders than our present diagnostic system would indicate.

TREATMENT

The management of BPD is complicated, must encompass effective treatments for acute episodes of mania and depression, appropriately manage comorbid disorders, and should ensure long-term mood stabilization. In addition, education of patients and their families is crucial to long-term success. Since there is no ideal therapy, BPD often requires complicated strategies to achieve the optimal outcome. While *medication* has been the primary approach, various *psychotherapeutic interventions* (e.g., cognitive behavioral therapy [CBT]; interpersonal therapy [IPT]) may substantially enhance the beneficial effects of drugs. Group, family, marital, and other forms of individual psychotherapy may also be useful. For example, psychosocial interventions combined with pharmacotherapy have been found to significantly reduce any episode recurrence, hypomanic relapse, and depressive relapse when compared to drug treatment alone. *Somatic treatments,* particularly electroconvulsive therapy (ECT), may also be effective for both the manic and depressed phases in patients who are in an acute crisis or who are poorly responsive to or intolerant of medications.

Several classes of medications have been used, including mood stabilizers, antipsychotics, antidepressants, anticonvulsants, and anti-anxiety/sedative hypnotics. The exact definition of a mood stabilizer is still a matter of debate. However, most experts agree that such a drug should be effective for acute mania and depression, stabilize mood over the long term, decrease the impulsive suicidal propensity of bipolar patients, not cause a switch from one mood state to the other, and not worsen the course of BPD (e.g., induce rapid cycling). Mood stabilizers include lithium; divalproex sodium and lamotrigine, which are anticonvulsants; and second-generation antipsychotics (SGAs) such as olanzapine and risperidone. Until recently, most trials with these agents have involved treatment of the manic phase of bipolar disorder.

The ideal approach is to manage BPD with a single agent usually combined with some form of psychotherapy. Unfortunately, this is rarely possible. Thus, if adequate trials for *bipolar mania* with one of the two most commonly prescribed mood stabilizers (i.e., lithium *or* divalproex sodium) are insufficient, then various drug combinations are usually required.

This may include combining the primary mood stabilizer with an anti-anxiety sedative-hypnotic agent; an antipsychotic; or another mood stabilizer (e.g., lithium *plus* divalproex sodium). More recently, the newer generation antipsychotics (i.e., olanzapine, clozapine, risperidone, quetiapine, ziprasidone, and aripiprazole) have demonstrated antimanic properties separate from their antipsychotic effects. Thus, they may represent another strategy when used in combination with other agents or as a monotherapy for acute mania.

Unfortunately, much less data is available to guide treatment of *bipolar depression.* Antidepressant monotherapy is not recommended due to the high risk of mood destabilization. The best evidence to date supports monotherapy with lithium, lamotrigine or carbamazepine. Other approaches include combining mood stabilizers (e.g., lithium plus lamotrigine); a traditional mood stabilizer plus antidepressant; or an SGA plus antidepressant (e.g., olanzapine plus fluoxetine). Potential biological, nonpharmacological alternatives for bipolar depression include ECT, bright light therapy, and possibly such investigational therapies as vagal nerve stimulation and transcranial magnetic stimulation.

Given the recurrent nature of BPD, *relapse* prevention and *prophylaxis* to prevent future episodes are critical. In this context, the best data supports lithium, divalproex sodium and lamotrigine. Other strategies include combining mood stabilizers; a mood stabilizer plus SGA; or combining a mood stabilizer with cognitive therapy.

—Philip G. Janicak

See also Depression; Psychiatric Disorders.

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BLACK REPORT

The Black report is the popular title given to the *Report of the Working Group on Inequalities in Health*, published in 1980 in the United Kingdom. The working group had been appointed by the Labour government in 1977 under the chairmanship of Sir Douglas Black.

The report brought together information about difference in health status between different social classes and examined the causal factors. It also suggested implications for policy and made recommendations for further research. The 30 recommendations for action, which can be summarized under the following four broad themes:

- Development of a comprehensive antipoverty strategy
- Development of policies aimed at giving children a better start in life
- Encouragement of good health among a larger proportion of the population
- Reduction of the risk of early death among disabled people in order to improve their quality of life, and to reduce the need for institutions as far as possible

This entry examines the link between social inequality and individual health, as outlined by the Black report.

BACKGROUND TO THE HEALTH AND DEPRIVATION DEBATE

Much previous research has sought to identify the links between social class and ill health. Social class

[QU: Please complete the reference for the 1980 Black report in the Further Readings section]

has long been seen as a determinant of health and ill health. Indeed, differences in health and economic status have been noted as far back as the twelfth century. Prior to the Black report (1980), there had been a long tradition of health inequalities research in the United Kingdom, one of the earlier examples of which is Frederick Engels's *The Condition of the Working Class in England* published in 1845.

In this text, Engels presented evidence for widespread inequalities in health based on social class. He argued that the industrialized urban poor suffered much higher mortality rates than the wealthy. Engels attributed this inequality to, among other things, poor housing, ventilation, sanitation, environmental pollution, clothing, and working conditions. Contemporaneously with Engels, the early "modern" public health movement was emerging in Britain, with Edwin Chadwick as its leader. Unlike Engels, capitalism was the driving philosophy behind Chadwick and his followers: It was feared that ill health and premature death led to loss of worker productivity and lower profits. The public health movement argued that tackling social causes of ill health, such as poverty, poor sanitation, and poor housing, would eventually pay for itself. Public support for public health measures soon followed, and Britain embarked on a range of measures aimed at improving the living conditions of the urban poor.

These arguments around improvement of the public health resurfaced in Beveridge's 1942 *Report on Social Insurance and Allied Service.* This laid the foundations for the British Welfare State and the National Health Service, the first socialized health care system in the world. The Beveridge report claimed that "want" could be eliminated via the provision of a state-run insurance scheme to guard against interruption or loss of earning power and the provision of child benefits. Coupled with a new Health Service, this would eventually lead to an improvement in the public health and a reduction in expenditure. Inequalities in health would also be eradicated.

Conventional wisdom was that the establishment of the welfare state, despite soaring costs of healthcare, had at least gone some way to removing health inequalities. These beliefs started to be called into question in the mid-1970s: Britain was slipping behind some other countries in health improvement, despite 30 years of the welfare state. There were differences in mortality rates across social classes, and speculation that these persisting health inequalities were to blame for the lack of improvement in mortality rates. This led to the setting up by the government of the Research Working Group on Inequalities in Health in 1977, chaired by Sir Douglas Black.

THE BLACK REPORT AND ITS FINDINGS

The resulting Black report was the first time any government had attempted to explain trends in inequalities in health and relate these to policies intended to promote as well as restore health. The main findings of the report were as follows:

1. Men and women in social class V had a two and a half times greater chance of dying before retirement age than class 1.
2. Inequalities existed throughout life and at all stages of the life course.
3. Risk of death for men was twice that of for woman.
4. There were major regional differences, both on a macro and a micro scale.
5. Mortality varied by housing tenure, owner occupiers having a lower mortality rate than local authority tenants.

The report noted the following trends:

1. Morbidity follows same general pattern as mortality.
2. Pre-1950s there was a long-term decline in death rate for males in all occupations.
3. Post-1960 social class V's health declined both relatively, when compared to social class 1, and absolutely.
4. A long-term decline in infant mortality.

EXPLAINING INEQUALITIES

The Black report identified four possible explanations for inequalities in health: that the findings were an artifact, that they arose because of natural or social

selection, that cultural/behavioral reasons were to blame, or that they were due to materialist explanations.

Artifact

This explanation implies that there are no actual inequalities: The observed effect is the result of the way in which class and health are measured. It suggests that changes in social class and classification of occupations over time make such comparisons impossible. This explanation is confounded by work that found difference in mortality dependent on salary.

Natural or Social Selection

This explanation suggests that it is not class that determines health but health that determines class: the healthy experience upward mobility and the ill slip down the social scale. There is some evidence to support this explanation, particularly for disabled people. Disabled people are more likely to be living on or below the poverty line. The Black report recognized this and argued for the implementation of a comprehensive disability allowance to pull disabled people out of poverty. More recent work has also highlighted this cause of inequality. However, the extent of social mobility in Britain is not sufficient to account for the large variations in health.

Cultural or Behavioral Explanations

This approach argues that people in lower social classes adopt a more risky lifestyle. These people adopt what are seen as reckless, irresponsible, or unthinking behaviors and place themselves at greater risk of ill health. Lifestyle explanations have considerable appeal to governments that may want to reduce public expenditure. If individuals are seen as responsible for their own health, then government inactivity is legitimized. It adopts what is termed a "victim blaming" approach in which individuals are seen as being responsible for factors that disadvantage them but over which they have little or no control. Victim blaming is applied both to individuals and to whole groups.

Material Disadvantage

In this explanation, inequalities reflect unequal distribution of resources in society. Those who experience ill health are those who have the least money, are lower in social hierarchy, are the least educated, and experience the most unemployment. These social factors make it difficult for them to implement what they know to be healthy choices. Social and health care provision also varies inversely with the need for it in the population served—known as the inverse care law.

The material disadvantage explanation was the one favored by the Black report. However, it did not find favor with the Conservative government of Prime Minister Margaret Thatcher, to which the committee reported in 1980, and for that reason the whole report was largely ignored. However, with the election of a Labour government in 1997, it could be argued that the agenda of the Black report finally began to be implemented in the United Kingdom.

THE BLACK REPORT AND DISABILITY

The Black report recommended that the government must take into account the material conditions of poorer groups, and it called for a reorientation of health and personal social services. Disabled people were one of the target groups identified by the authors. In addition to calling for the funding of a comprehensive allowance for disabled people, the report examined the inequalities in health and social care experienced by disabled people. It argued that class differences existed in the provision of care to disabled people. Disabled people who had been non-manual workers often lived in different accommodations than did manual workers. More often than not, non-manual workers who were disabled lived in their own homes while manual workers who were disabled were found in institutions. Those living in their own homes had better care and better rehabilitation. They were also more likely to be employed and have better social relations and experience greater privacy. The report argued strongly for a reduction of the number of people in residential care and called for the implementation of what is now termed *community care*. To enable this policy, the report also urged the government to increase home help services and expand the number of accessible homes for disabled people.

Although there is little evidence that the recommendations of this report influenced government policy in Britain throughout the 1980s and early 1990s, its wider impact was widespread through public health debates

in many countries. The report played a central role in the shaping of the Common Health Strategy of European Region of the World Health Organization; in particular, it located equity as a central theme in that document and a reduction in inequalities was the first of the 38 targets set as part of Health for All 2000.

—Nick Watson

See also Disability Rights: United Kingdom; Health; Poverty.

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BLADDER CONTROL

Urinary incontinence (UI) refers to a loss of bladder control. UI is considered a symptom rather than a disease. Causes are many and include infections of the urinary tract or vagina, weak or overactive bladder muscles, enlarged prostate, neurological diseases, pelvic or spinal injuries, aging-related degenerative changes, and problems resulting from pregnancy or childbirth. UI is categorized into the following types:

- *Stress* (damage to the sphincter or pelvic muscles results in leaking when the bladder is under pressure)
- *Urge* (sudden and uncontrollable bladder contractions due to illness or neurological damage result in an urgent need to pass urine)
- *Overflow* (blockages or injuries produce a situation where the quantity of urine exceeds the holding capacity of the bladder, causing leakage)
- *Functional* (bladder control is normal but medical disorders or disabilities, such as restricted mobility, make it difficult to get to an appropriate place for urination prior to loss of control)
- *Mixed* (two or more types)

UI is a dynamic condition, with continence status fluctuating throughout the life course. Treatments include behavior therapy (bladder control training, pelvic muscle exercises, biofeedback, and timed and prompted voiding); pharmacological therapy; and surgery. In addition, management techniques may be used such as implants, urethral plugs, and various absorbent devices.

UI appears to be highly prevalent worldwide, especially among women, with stress incontinence predominating and incidence increasing with age. Across cultures, quality of life has been found to decrease as UI becomes more severe. In the United States, up to 25 million people are estimated to be affected, including approximately 1 in 10 of those 65 years of age or older. In addition, 10 percent of children over age 5 have problems with bedwetting.

The meaning and significance of UI is linked to that of urination in general; these meanings vary by culture. Very little scientific or scholarly literature exists on how urination and UI are understood cross-culturally. That which does exist focuses primarily on urination, for example, practices related to urinary hygiene (such as where it is appropriate to urinate in a particular culture), attitudes toward urination (which range from nonchalance to humor to extreme shame), and painful/difficult urination and traditional treatments for these conditions. Discussions of incontinence in the ethnographic literature concentrate on its management among infants and young children, its role as a symptom of culturally specific illnesses, and ideas about behaviors that may cause or prevent the problem. As examples of the latter, the Iroquois traditionally believed that the use of clamshells as spoons could cause UI, while the Yakutat Tlingit reportedly thought that rotten wood under the toilet in the menstrual house would protect a teenager from incontinence in old age.

Despite variation in beliefs and knowledge about UI, in many cultures it remains underreported and undertreated, in part because affected individuals do not seek help. Hesitation with respect to seeking professional attention may be related to embarrassment,

lack of resources, and doubts about the effectiveness of available treatments.

—Lori L. Jervis

See also Aging; Bowel Control.

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National Association for Continence, http://www.nafc.org/about_incontinence/

BLIND, HISTORY OF THE

The history of the blind is difficult to chart. There are few examples before the nineteenth century of sustained, organized efforts by the blind to act in concert to achieve collective goals. Rather what is left to the historian is a collection of biographies of "extraordinary" individuals, from Homer to Helen Keller, Louis Braille to Jorge Luis Borges, which provides little in the way of a narrative thread that one can pull together to create a tapestry of blind history. Prior to the eighteenth century, the history of the blind is atomistic, a collection of biographies, protagonists in religious and secular stories, weaving in and out of popular consciousness, serving as object lessons, or providing inspiration to the sighted. The negative historical assumption is of the blind as objects of charity rather than active agents in history. Occasionally, the blind could be found clustered in certain state- or church-sanctioned professions or guilds such as massage, minstrelism, and mendicancy, but in large part blindness is assumed to be a ticket to misery, a curse, a sentence to second-class status.

The blind, in truth, occupy no greater or lesser a place in history commensurate to their numbers in the general population. There are historical examples of blind teachers, soldiers, religious and secular leaders, scientists, philosophers, mathematicians, historians, and a variety of other professions. There are, as with the sighted, countless blind who lived out their lives in quiet obscurity. Thus, it can be said that while history offers a pantheon of blind characters, there exists nothing unique to blind people that is unknown to the sighted. Even so, the past 200 years have seen efforts by the blind to come together to improve their situation, share strategies of success, and have a voice in society, rather than to be objects of curiosity and speculation.

THE BLIND IN THE ANCIENT WORLD

In the preindustrialized world, it has long been assumed that the blind enjoyed few opportunities and lived out their days in penury as beggars, or wards of their families in the absence of any systematic state or government assistance. Historical knowledge of the lives of blind people in the premodern Western world is extremely limited, and it is strongly influenced by literary or religious texts. Traditional interpretations of classical literary representations hold that blindness is a punishment for social or religious transgressions or, alternatively, is the price one pays to gain spiritual vision and insight. Oedipus is often cited as an example of the former, while Tiresias may be seen as an example of the latter. There are 79 references to blind persons in classical Greek literature, all of which describe blindness as occurring through accident, through warfare, or as punishment for social or religious transgressions. Today, 2.9 percent of cases of blindness result from accidents, and there is no evidence to support the idea that the situation would be any different for those living in Greece or Rome. With so few examples to draw on, most of which falsely portray blindness as occurring from accident, literary sources do not provide good evidence on which to base broad assumptions about either how the blind lived or how the blind were popularly perceived as a class by their contemporaries.

Religious texts similarly provide little knowledge of actual blind people in the early centuries prior and subsequent to the Christian era. Biblical scholars debate whether blindness is to be interpreted in either spiritual or corporeal terms. Some New Testament scholars, for

example, believed that depictions of Jesus healing the blind is meant to be seen as curing spiritual blindness, not physical blindness. Nonetheless, ancient and medieval depictions of the blind as either sinners or saints persisted into the modern era and continued to be the subjects of religious and philosophical inquiry.

While the Greek poet Homer is often assumed to be blind, there is no evidence of whether or not he could see, although Homer's odyssey features the blind poet Demodocus. The names of a handful of other blind storytellers survive, such as Ossian, blinded warrior and son of the third-century BCE Caledonian King Fingal; and Torlogh O'Carolan, Gaelic poet (b. 1607). More known are the blind scholars of the premodern era. Best known of these in the early Christian era is Didymus, born in 308 CE in Alexandria. Didymus used carved wooden letters and was the teacher of St. Jerome. St. Herve (b. 539) established a monastery in Brittany, which today is a shrine for blind musicians. In Japan, Prince Hitoyasu (b. 853), son of the emperor of Japan, established music and massage as designated professions for the blind and established the role of court historians as the purview of the blind. Abdul al Moiré (b. 973 CE near Aleppo) became a preeminent poet. His poetry transcended the mundane topics of love and war and reflected a skeptical view of the world. Prospero Faghani (ca. 1590 CE–1671) was a canonical scholar who refuted the medieval Catholic Church's dispensation to the blind as outside the obligations of the church. Fagnani asserted that the New Testament was more concerned with blindness of spirit rather than the body, and he brought the blind into the fold of the church. John Milton (b. 1608) is perhaps the best-known blind author of the late Renaissance/early Enlightenment. He was a well-known poet before going blind at age 44, although he wrote his masterpiece of epic poetry, *Paradise Lost,* after losing his sight.

THE BLIND IN THE AGE OF PHILOSOPHERS

The Enlightenment-era philosophers introduced new questions about blindness and the nature of the blind, moving the conversation away from strictly spiritual questions toward rational interpretations of understanding and knowledge. Enlightenment scholars debated whether or not the blind were more likely to be atheists due to their presumed bitterness against God over their condition. Others argued that the blind were closer to God, as they were spared the burden of earthly distractions owing to their blindness. John Locke, in *Concerning Human Understanding* (1690), considered the question of whether a person born blind who became sighted would be able to recognize objects previously known only by touch. Locke asserted that newly sighted people would not be able to understand the world using their new vision. Bishop Berkeley in 1709 disagreed with Locke, arguing that what one saw with the eye was merely the inference, not the essence, of a thing. The question was a favorite among philosophers long after Locke, as the rhetorical scenario allowed speculation as to the nature of learning and understanding.

The debate was not merely rhetorical to the blind, however, as there were direct implications as to whether or not the blind could or should be educated in reading and writing and the classics. If sight was required to understand the essence of a thing, as Locke argued, then educating the blind was a futile enterprise. If understanding was generated from within, as Berkeley argued, then there was no reason a blind person could not learn as well as the sighted.

Nicholas Saunderson (1682–1739) lost his sight at the age of one from smallpox. Saunderson went to Cambridge University to study mathematics, but he was not allowed to matriculate as a student. He was given access to the library, where he used a tactile ciphering board to work out mathematical formula. Saunderson's advanced mathematical acumen gained him the attention of Sir Isaac Newton, then at the height of his fame. Newton personally lobbied to have Saunderson given a chair at Cambridge, despite the lack of formal credentials, as he was one of the few who Newton felt truly understood the ideas expressed in *Principia Mathematica.* Saunderson became one of the Enlightenment's foremost mathematicians and philosophers.

EDUCATION AND THE BLIND

Denis Diderot penned one of the most influential treatises on the blind and education in 1749 with his *Letter on the Blind,* which he revised in the course of

his lifetime. Diderot met and was deeply impressed by the Parisian music sensation, Melanie de Salignac, who had devised a tactile form of print to both read music and correspond with friends. Diderot saw de Salignac as an example of what was possible, and he argued that the blind could be educated so long as the educator focused on what skills the blind person possessed and not on the lack of sight. As one of the most influential philosophers of the French Enlightenment, Diderot provided a philosophical foundation for the education of the blind.

It was Valentin Haüy (1745–1822), however, who opened the first school for the blind in Paris in 1784. Haüy had been influenced by the Abbé de l'Épée, who had opened the first school for the deaf in the 1770s. Haüy, like Diderot, was inspired by a talented blind pianist, Maria Theresa von Paradis (b. 1759). Von Paradis showed Haüy the tactile alphabet she had developed, which she used to read and write. Von Paradis had been corresponding with a German man, George Weissenbourg, who in turn had taught other blind students the finger alphabet the two used to write one another. Haüy appreciated that the blind could learn by reading with their fingers. The school for the blind in Paris soon had more than 50 students. Haüy developed a raised alphabet system to teach his students. Haüy's methods would become the standard and the model adopted by educators of the blind for the next half century. Unfortunately, reading raised roman letters was a very inefficient system of reading. Haüy wanted a system that looked attractive to the sighted as much as he was interested in what actually worked for the blind.

This conflict between what the sighted educators asserted the blind needed and what the blind themselves insisted really worked became the central organizing force of blind people in the coming two centuries. By the early nineteenth century, several schools appeared in Britain: Liverpool (1791), Edinburgh and Bristol (1793), among others. These schools were developed along English trade school models, where students were taught a trade rather than to read and write. Johann Wilhelm Klein founded a school in Vienna in 1804. Klein believed that blind students should be integrated into the classroom with their sighted peers. These three models—Haüy, English trade schools, and Klein in Vienna—drove the debate for the next century about what blind children should learn. Some educators believed it was better to teach a trade in order that the blind could support themselves as adults, while others asserted that a classical education would propel the blind into more esteemed professions, as well as provide examples of the potential of the human capacity for learning.

Just as the blind sparked a debate among Enlightenment philosophers over the nature of understanding in the seventeenth and eighteenth centuries, social reformers of the nineteenth century argued over the degree to which the blind could be "rehabilitated" or trained to take their place in the broader community as contributing citizens. Samuel Gridley Howe (1801–1876), who opened the Perkins School for the Blind in Boston in 1831 (the second school of its kind in the United States), argued that the blind could be educated and trained to become independent members of society, earning their own way in the world. The education of the blind for these reformers was akin to an experiment in human engineering to prove broader philosophical points about the redemptive powers of social programs.

Howe's School for the Blind in Massachusetts became a model for schools all around the United States. In part, Howe's success derived from his famous pupils. Laura Bridgman, a deaf-blind girl, arrived at the Perkins school in 1832 and would become one of the most famous women in the world by the 1840s. Howe wanted to prove that anyone could learn to read and write, and he set out to teach Bridgman language through finger spelling and raised type. Bridgman would live her life out at the school and would in 1876 meet the next century's most famous deaf-blind girl, Helen Keller, who would also go to Perkins to study.

In 1837, Ohio established the first state-sponsored school for the blind. By the time of Howe's death in 1876, there were 23 schools for the blind, most of which were state funded, marking a change from the education of the blind as a charitable enterprise to an entitlement paid for with tax dollars. Blind children would continue to be educated at residential schools, apart from sighted children, until well into the twentieth century. By the 1920s, educators and blind advocates began to argue forcibly that the blind ought to attend school with their sighted peers. By 1970, this idea

would become a movement known as mainstreaming. With the passage of the Education of All Handicapped Children Act in 1975 (now known as the Individuals with Disabilities Education Act [IDEA]), the mainstreaming of blind children became a right, not a trend. Schools for the blind diminished in importance in favor of integration of the blind with the sighted.

THE BLIND ORGANIZE

Much of the debate about the abilities of the blind in the years from Diderot to Howe occurred among the sighted. The actual voices of the blind were not part of this debate. However, the advent of schools and institutes for the blind afforded the blind an opportunity to organize as a group for their own interests. The blind were able to talk to one another and learn strategies of success for living as a blind person. Schools and institutes served as hothouses for the development of and experimentation with new devices and systems of writing.

Louis Braille (1809–1852), a student at the Royal Institute for the Blind in Paris in the 1820s, took a raised-dot system of code brought to the school in 1821 and turned it into the most important advancement in blind education. Charles Barbier, a sighted military officer, had invented a raised-dot system intended to allow officers to communicate with one another in the dark. The French army never adopted the system, nor did the Paris School for the Blind at first. However, Louis Braille took the eight-dot system proposed by Barbier, reduced it to six dots, which was easier to read with the fingertips, and created a system of abbreviations and shorthand symbols that would allow the blind to read at a much faster rate. The dots looked nothing like the roman letters they replaced, but the system was much easier for the blind to read. The school rejected Braille's system, in part because school administrators were reluctant to replace all the raised-alphabet volumes created at great expense under Haüy and his successors. Braille was a teacher at the school, however, and taught his system to his blind students. By the time of Braille's death in 1852, the school finally accepted the superior Braille method of transcription.

Braille's system also made it possible for the blind to be teachers of the blind, further strengthening resistance to the raised-dot system by sighted teachers. The introduction of Braille not only revolutionized education for the blind, it allowed the blind to communicate with one another without sighted intervention, creating a community of blind alumni. In addition, the blind began to publish their own stories in the form of memoirs intended to capture the interest of a sighted readership. Such narratives were a combination of religious inspiration and titillating details about the life of blind people.

By the end of the nineteenth century, the blind were organizing into professional associations, such as the American Association of Workers for the Blind (AAWB), and began to agitate for more overtly political objectives in such publications as *The Problem* and *The Outlook for the Blind*. Advocacy groups organized by blind activists flowered in the 1920s and 1930s in a number of states. Blind activists in Wisconsin, Pennsylvania, Colorado, and California were successful in agitating for pensions for the blind and public awareness efforts to inform their communities about the needs and interests of the blind. These state affiliates came together in 1940 to charter the National Federation of the Blind (NFB). The NFB would organize affiliates across the United States to become the largest advocacy group of blind people. The NFB began publishing the *Braille Monitor* in 1957, and it is still in print today. The NFB produced a number of leaders in what would be called the "blind movement" by those who advanced the objectives of the NFB and its supporters. Jacobus ten-Broek, president of the NFB from 1940 to 1960, and Kenneth Jernigan, president of the NFB from 1968 to 1986, were galvanizing figures in the blind movement. Ten-Broek was a constitutional law professor, who agitated on behalf of a blind pension divorced from the social security system, and Jernigan was a teacher, who transformed rehabilitation services for the blind as the director of the Iowa Department for the Blind from 1958 to 1978. In 1960, the American Council of the Blind (ACB) was established by former members of the NFB who disagreed with the direction and leadership of that organization. The ACB publishes the *Braille Forum.*

World War I prompted the rise of national efforts to provide services to blinded veterans, which would eventually morph into the dense network of state

rehabilitation and private welfare programs for the blind in the twentieth century. The Smith Act of 1920 expanded the range and scope of rehabilitation services available through the states to the blind. In 1948, the Hines Training Center was opened outside of Chicago. Named after Frank Hines, Secretary of Veterans Affairs, the Hines Center was an innovative program that sought to train blinded vets to transition back into their communities. Students at the center were given long white canes, known as Hoover canes—named for their inventor, Richard Hoover in 1944. The Blinded Veterans Association (BVA)—founded in 1945—was active at Hines, and was active in progressive politics for many decades. Rehabilitation programs became increasingly important to all blind Americans and would become the focus of advocacy groups such as the NFB, BVA, and ACB agitated for better services from the agencies that were charged with providing help to the nation's blind.

—Brian R. Miller

See also Advocacy; Blindness and Visual Impairment; Louis Braille; Laura Dewey Bridgman; Denis Diderot; Valentin Haüy; History of Disability: Ancient West; History of Disability: Early Modern West; Visibility and Invisibility.

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BLINDNESS AND VISUAL IMPAIRMENT

Throughout recorded history, the eyes—the sense of sight, of looking and seeing, of vision and blindness—have been a fascination for artists and scientists alike. Writings about blindness as symbolic of human traits and action or as a sign of divine intervention are found across many cultures and societies, and they date back to ancient times. Science and medicine developed specializations in eye diseases as far back as the Ebers papyrus, an Egyptian medical textbook dating from the Eighteenth Dynasty (ca. 1500 BCE), which has an entire chapter devoted to eye diseases (Monbeck 1973). Blindness and visual impairment have important socioeconomic implications for blind people and for the societal structures in which they live. Blind people are treated differently because of their blindness—they face environmental, economic, social, attitudinal, and educational barriers. Nowadays, blindness is thought to be a major public health problem, which is being addressed by governments, health, economic, and charitable organizations at international, national, state, and local levels. The costs of rehabilitation and care may be the most apparent with indirect costs resulting from loss of productivity. Modern medicine has developed specific definitions of blindness and visual impairment within which they frame data collection, research findings, and public policy.

DEFINITIONS OF BLINDNESS AND VISUAL IMPAIRMENT

The World Health Organization's (WHO) International Statistical Classification of Diseases and Related Health Problems (ICD-10), defines blindness as visual acuity of "less than 3/60 (0.05) or corresponding visual field loss in the better eye with best possible correction" (visual impairment categories 3, 4, and 5 in ICD-10). This corresponds to loss of walkabout vision. "Low vision is classified as visual acuity of less than 6/18 (0.3) but equal to or better than 3/60 (0.05) in the better eye with the best possible correction" (visual impairment categories 1 and 2 in ICD-10). The international medical community generally accepts the ICD definitions of disease and uses it to describe and diagnose medical conditions, diseases, and disabilities.

Almost all U.S. government agencies have adopted medical measurements broken down into three categories of visual impairment, which are used to determine eligibility for services and financial compensation:

1. Totally blind
2. Legally blind (20/200 or less visual acuity in the best corrected eye [20/200 visual acuity means that what a fully sighted person sees from 200 feet away, a person with 20/200 vision sees from 20 feet away], and/or 20 degrees or less in the visual field)
3. Partially sighted (20/70 visual acuity in the best-corrected eye or 20 degrees or less in the visual field); the U.S. Bureau of the Census simplifies its definition into lay terms (unable to see regular-size newsprint)

All of these definitions of blindness and visual impairment determine eligibility for financial support, social services, and government-funded medical services, including research studies, treatment, cure, ocular prosthetics, rehabilitation training, and job placement. Given these governmental definitions of blindness, it is commonly assumed (particularly by sighted people) that someone would only identify as "blind" if they had no vision at all. However, many people categorized as "legally blind" actually identify as blind. These people challenge traditional notions of blindness because they retain some usable vision, demonstrating that blindness, like sight, is a continuum. Many people identified as "legally blind" or "partially sighted" greatly benefit from standard accommodations for blindness, such as audio description of environments, access devices and technology, books on audiotape or compact disk, and universal design.

Even though the degree of blindness is calculated in a very functional way by government agencies and many other institutions, it cannot be assumed that there is a simple relationship between the difficulties individuals face in their lives and their level of blindness. Many other factors intervene in this process, such as the accessibility of their environment, the degree of support they have, and their financial resources. While magnifiers; monoculars; talking watches, personal digital assistants (PDAs), and portable global positioning systems; and large-print and speech output software can significantly facilitate blind people's inclusion into everyday activities of living, costs are often prohibitive, even for those who are working. In addition, many technological and optical devices are largely unheard of, and certainly unaffordable, in developing nations where 90 percent of all blindness and visual impairment occur.

COMMON CAUSES OF BLINDNESS

The most common causes of blindness vary according to geographic location, socioeconomic status, and age. Largely preventable and treatable, bacterial diseases such as onchocerciasis, otherwise known as river blindness, and trachoma are leading causes of blindness in the developing world. Many international health-promoting organizations have blindness prevention programs. They work in rural, poverty-ridden communities to improve hygiene education, sanitation conditions, and access to health care.

The U.S. Centers for Disease Control and Prevention (CDC) reports that many causes of blindness occur before birth although some conditions clear up over time. Older children (between 3 and 10 years old) have more vision impairments than do children younger than 3 years old. Nearly two-thirds of visually impaired children also have at least one other impairment. This may, in part, be due to the fact that some diseases have visual impairment as

secondary effects. Diabetes, glaucoma, and cataracts are the most common causes of blindness among adults in Western nations. Because more people are living longer than did earlier generations, age-related macular degeneration is becoming more prevalent.

PREVALENCE OF BLINDNESS

The World Health Organization estimates that there are about 148 million blind or visually impaired people around the world, with 9 of 10 cases occurring in developing nations. There is a strong link between poverty and blindness. Of the more than 100 million blind children around the world, more than 80 percent live in underdeveloped countries. The majority of cases are preventable, but adequate financial commitment to prevention and treatment programs, healthier agricultural practices, and more attention paid to nutritional deficits is needed (World Bank 2003b). Current available studies estimate that there are, at minimum, 1.5 million blind children in the world; 72,000 of them live in Europe, the United States, and Japan (Kocur and Resnikoff 2002). The level of ophthalmic health care is shaped by each country's political system. For example, countries that were part of the USSR are currently grappling with shifting their socialist (free) health care to non-government-subsidized health care systems, for example, private health insurance; hence, health care including ophthalmic care is in transition and so is not always adequate (Kocur and Resnikoff 2002). In North America, there are between 10 and 11 million blind or visually impaired people (American Foundation for the Blind [AFB] 2001; U.S. Bureau of the Census 1996) with the large majority having some residual vision.

The Royal National Institute for the Blind (RNIB) in the United Kingdom reports that it is difficult to know exactly how many blind and visually impaired people there are in European Union countries, but the most widely used estimate is 7.4 million out of a general population of 385 million. In the United States, approximately 1 million people over age 40 are blind (National Eye Institute & Prevent Blindness America [NEI] 2001; Prevent Blindness America). One problem gathering accurate data is that people who begin to lose their vision as part of the aging process often do not register for social or rehabilitation services (RNIB 2003). In addition, different countries have different data collection methods, which makes it difficult to estimate total numbers of blind and visually impaired people.

EMPLOYMENT DATA

Employment figures as well as prospects for future employment of blind and visually impaired people are dismal in every country across the globe. Public policy toward blindness is measured in terms of economics—cost-benefit ratios. Statistics are gathered about how much blindness prevention, treatment, and rehabilitation costs, and then are analyzed in comparison with productivity levels to determine if governments are making a good capital investment. Blindness and blind people are characterized as "financial burdens."

No other socioeconomic group in the Unites States has more unemployment than do blind people (AFB 2001). Less than 50 percent of all blind/visually impaired Americans are employed. More than one-third of those who are employed report being underemployed (U.S. Bureau of the Census 1996).

ATTITUDES TOWARD BLINDNESS AND BLIND PEOPLE

The World Health Organization (WHO) began its fact sheet on blindness, "The loss of eyesight is one of the most serious misfortunes that can befall a person" (WHO 1997a). The World Bank uses "suffering" and "overcoming" in its reports about projects "fighting blindness." Many medical, humanitarian, and philanthropic organizations describe blindness as a "tragedy." The idea that blindness is a horrific fate is long-standing and well documented. Blind people are often portrayed within such negative stereotypes as "deserving of pity and sympathy; miserable; in a world of darkness; helpless; fools; useless; beggars; unable to function; compensated for their lack of sight; being punished for some past sin; to be feared, avoided and rejected; maladjusted; immoral and evil; better than sighted people (idealized); mysterious" (Monbeck 1973:25). Writers of ancient biblical texts used metaphors of illness and impairment to dramatize moral, ethical, and religious lessons as well as to inscribe exclusionary laws.

BLINDNESS AND EDUCATION

In many countries, blind (and other disabled) children have systematically been subjected to school segregation. Even though the curriculum was purposefully similar to general public education, blind children were segregated into their own schools, and many of these schools are still in existence. The first school for the blind in America was founded in Baltimore, Maryland, in 1812. In 1832, a school named the Massachusetts Asylum for the Blind opened. It later changed its name to Perkins Institute (and is currently named Perkins School for the Blind) (Shapiro 1994).

BLINDNESS AND RELIGION

While it is so that the writers of the Bible used earthly language to describe and explain the inexplicable (God), one need only scratch the surface of metaphors of impairment to unearth negative attitudes toward and societal stereotypes of the blind and the damaging consequences of being blind. "You shall not curse the deaf or put a stumbling block before the blind" (Leviticus 19:14) has been interpreted throughout the centuries to symbolize various negative actions. "The Bavli (Babylonian Talmud) used the stumbling block metaphor in cases of serving wine to those who ascribe to prohibitions against drinking wine (Avodah Zarah 6a-6b); lending money without witnesses (B. Baba Metsia 75b); or deliberately irking someone to test their temper (B. Kiddushim 32a). In these examples, blindness is used to illustrate enticement and temptation, inability to control one's desires, or deliberately acting cruelly toward another human being. All the examples equate blindness with helplessness. Blinding someone seems to be the weapon of choice in the following examples: In Genesis 19:11, young and old alike were struck with blindness so that they would wear themselves out groping for the exit; Samson was blinded by the Philistines (Judges 21).

The stigma ascribed to visual impairment is found, for example, in the story of Leah, who was devalued as a potential wife because she had "weak eyes." Under the cover of darkness, Leben, Leah's father, deceived Jacob into marrying Leah (Genesis 29:16–25). The inference is that blind people are easily tricked and that sight is the most valuable sense despite evidence that touch is the most reliable of all the senses. Exodus 23:8 warns, "And you shall take no bribe for a bribe blinds the officials, and subverts the cause of those who are in the right." Again, blindness represents corruption and deceit. By sheer number of mentions, blindness appears to be the favorite disability metaphor in Scripture.

The use of blindness metaphor in religious contexts is not confined to Judeo-Christian texts. The Qur'an uses allegorical descriptions of eyes to connote faith in Allah, e.g., "Thus Allah strengtheneth with His succour whom He will. Lo! herein verily is a lesson for those who have eyes" (The Family of Imran, The Third Surah of the Qur'aan [verse 13], Pickthall Translation). Thus, impairment, illness, and disability have become bound up in institutionalized religious doctrine of sin, evil, God-decreed punishment, uncleanness, sorrow, and pity. However it is talked about, blindness is almost always perceived to be a "tragedy."

Blindness has been used as a metaphor to describe ignorance, denial, stupidity, naïveté, prejudice, drunkenness, carelessness, unconcern, thoughtlessness, and unawareness. "Blind" has represented something tricky that is intended to conceal the true nature of a thing, as in "blind taste test" and "double blind" research study. And, in botany, a plant is "blind" when it fails to flower.

MODELS OF BLINDNESS

Until the advent of disability studies, blindness was conceptualized only as catastrophic. Artists and writers used blind figures to represent either pitiful, lost creatures groping their way through an unseen world or vessels of supernatural powers. Blind people were to be avoided because they could see inside your thoughts (Barasch 2001).

Research on blind people has been dominated by literature written from the perspectives of medicine, rehabilitation, and psychology. The focus of these studies has tended to be disease and its effects, psychological aspects of blindness (loss, grief, and eventual "acceptance"), adaptation, and coping strategies.

Blindness is positioned absolutely on the individual with little societal context taken into consideration, as if blindness occurs in a social vacuum. This approach

tends to assume that blindness is solely a physiological event, and not a social process. One exception to this pattern was Scott's (1969) pioneering social constructionist approach to blindness and society. Scott's phrase "blind men [*sic*] are born, not made" emphasized the role of blindness workers in the socialization of blind people. Scott's work has been built upon in the past decade by interdisciplinary blindness literature, strongly influenced by blind disability studies scholars (e.g., Michalko 1998, 1999; Kleege 1999; Kudlick 2001; French 1993, 1999, 2001).

CURRENT TRENDS IN BLINDNESS LITERATURE

Type in "blindness" on any Internet search engine and the typical search results mainly concern disease, rehabilitation and counseling services, product catalogues, blindness "etiquette," blindness prevention, and medical research. There is a sparse sprinkling of information about organizations *of* the blind, which are initiated and controlled by blind people themselves and are consumer and rights oriented. More common, however (and more well funded), are associations *for* the blind, which have deep historical roots in the medical model and are usually administered by sighted people. These organizations are often charities that promote blindness prevention media campaigns, information about specific eye diseases and related services and product information, and reports of medical research aimed at prevention and cure. Generally, neither type of blindness organization conducts independent social or medical research.

Some charity-based organizations may raise money to help fund prevention and/or cure research (and to fund their own jobs). However, the actual protocol decision-making and research work in these cases is usually left to medical and educational establishments. Medical institutions typically devote their energies to prevention, diagnosis, treatment, and cure. On the other hand, educational institutions tend to address matters of adaptation, accommodation, and rehabilitative training.

Many medical, rehabilitation, and educational establishments have laudable achievements in helping to improve the lives of blind people. However, the gaze of medical model research is on the function of the eyes, so it largely fails to inquire about social processes or even about the personal experience of blindness. The new interdisciplinary discipline of disability studies is changing all that by re-theorizing blindness within sociocultural contexts.

Disability studies tends to promote work *by* organizations of disabled people, as opposed to organizations *for* disabled people. There is a significant distinction between the two types of organizations in that disabled people themselves organize, lead, and set their own purpose and policy agenda in organizations *of* disabled people. On the other hand, organizations *for* disabled people are most often administered by nondisabled people who speak for and assert authority over disabled people.

At present, disability studies literature tends to be dominated by projects based in the humanities, so actual participant research projects are rare. Until now, the most common genres for addressing issues of blindness have been historical literary analysis, memoir, autobiography and autoethnography.

The writings of a young blind girl in post-Revolutionary France were recently translated by Kudlick and Weygand (2001). The first half of the book contains Adele Husson's writings about her experiences, while the translators devote the second half to commentary. What is most remarkable and valuable about this brief story of one person's blindness experience is how little things have changed with regard to dominant societal attitudes toward blindness and blind people. Husson (2001) wrote:

> When they [blind people] appear in public the stares of the multitude are fixed upon them, and agonizing words strike their ears: "what a shame!" "How unfortunate!" "Death would be preferable to such a cruel privation!" There are even some people who seek out the blind to tell them these things so that they don't miss any of the sad exclamation. (p. 25)

Kudlick (2001) framed blindness within the cultural context of Victorianism by analyzing historical documents. She explores the origins of an important ideological split within the blindness community, which continues to this day. Some blind people believe that to be perceived as equal in a sighted society, blind people should not seek environmental

accommodations such as audible signage or tactile warning strips. They also believe that only blind people can help other blind people and have instituted their own vision training centers run entirely by and for blind people. Conversely, other blindness organizations actively advocate for environmental access, accept training from sighted guides, and perceive blindness as more of a medical and consumer issue than one of social acceptance. Kudlick's commitment to recording the cultural aspects of blindness history is important, because it is a marker of the growing respect for disability studies as a legitimate, serious discipline, as well as a reflection of the strength of the disability civil rights movement. Social movements are often measured by new interest in their histories.

In *Sight Unseen,* Georgina Kleege (1999) described her experience of growing up with progressive vision loss. Throughout this memoir, Kleege used examples from her own life to place blindness within a cultural context. Her book is divided into three main sections: Blindness and Culture, Blind Phenomenology, and Blind Reading: Voice, Texture, Identity. These topic headings might convey the idea that the book is oriented within the social model of disability. However, Kleege's exaggerated emphasis on impairment rather than disability often contradicts such an approach. For instance, she stated, "Writing this book made me blind" (p. 1), "This book made me understand for the first time how little I actually see" (p. 2), and she characterizes the book as "my attempt to specify my own visual experience" (p. 103) and "a coming out narrative." Clearly, the main theme of her memoir is identity formation.

Rather than embracing blindness as an alternate way of being in and knowing the world, Kleege writes that blindness "really isn't as terrible as you were always led to believe" (p. 34) and that it is "not so bad" (p. 32). Throughout *Sight Unseen,* Kleege often uncritically reproduced the concept of normativity—a problematic concept for the discipline of disability studies. She often used the word "normal" in a phrase without italics or quotation marks to contest the concept. For instance, she refers to "normal daily activities" (p. 167). This uncritical citation of the term "normal" seems to indicate that she accepts the notion of normality, which is highly problematic from a social model perspective. By using such controversial terms in her descriptions of the blindness experience, Kleege may be unconsciously endorsing a nondisabled, medicalized discourse that positions blindness as a loss and an exclusively negative experience. Other personal narratives from blind people suggest that the experience is far more complex and nuanced than such simplistic descriptions would suggest.

The humanities play an important part in the interdisciplinary nature of disability studies, and *Sight Unseen* is a significant contribution in that regard. In her review of this memoir, Sally French (2002) said she found *Sight Unseen* "unsurprising," but she states that it "provides good material for anyone interested in the meaning of visual impairment and the growing field of disability studies" (p. 859).

Given that she uses the genre of memoir, it should not be surprising that Kleege's work focuses largely on the individual's adaptation to blindness rather than turning the gaze back onto society's treatment of blind people. Nevertheless, from the perspective of disability studies, memoirs can be problematic because readers may understand them to be "inspirational" stories about personal triumph over tragedy, or as reinforcing other medical model stereotypes about disability as an individual problem.

A memoir such as *Sight Unseen* can also be criticized for relying solely on one individual's perspective, which could be seen as enabling the author to develop theoretical generalizations without being required to apply the rigors of social scientific citation, which builds on prior academic knowledge and requires the author to substantiate such positions. Consequently, even when an author committed to the social model of disability writes a memoir, the danger is that the theoretical reframing of disability and impairment from the perspective of the social model of disability may fail to be noticed or understood.

In contrast to literary analyses and memoir writing, White (2003) relied on an interdisciplinary approach that combines queer theory, disability studies, and blindness literature. White examined the social construction of blindness as a heterosexual experience by critiquing the social construction of heterosexuality in blindness sex education for young blind people. White delved into dominant beliefs about sexuality being a visual process, and how this construct frames young

blind people as sexually underdeveloped. He wrote, "Blind people are in a sense queer, in that heterosexuality, at least in its institutionalized forms, presumes a sighted subject" (p. 134).

Sally French (1993, 1996, 1999, 2001) used prior social model of disability literature to buttress her analysis of how society disables blind people. She stated that "conflicting discourses arise when sighted people define what is 'acceptable' and 'normal' behavior for a visually disabled person and use these definitions to contest that person's identity" (1999:21). French (2001) used a grounded theory approach in her study of visually impaired physiotherapists so that she could address issues of both impairment and disablement. French relied on the use of questionnaires and semistructured interviews to examine such issues as how society has perceived physiotherapy as a legitimate profession for visually impaired persons, and she uses participant interview transcripts to elucidate how visually impaired physiotherapists perceive their engagement in the profession as points of advocacy. Her informants describe how they meet and manage barriers that arise in their everyday work lives. French's growing body of work combines both her personal experience of blindness and a social model analysis; thus, her work helps shape the future of disability studies literature, in general, and blindness research in particular.

Rod Michalko, a postmodern sociologist, deconstructs medical, psychological, and societal ideas and practices around blindness. In particular, chapter 4 of *Mystery of the Eye and the Shadow of Blindness* (1998) is devoted to a critical examination of blindness rehabilitation. Noting that once ophthalmologists have diagnosed their patient as destined for permanent blindness, they refer the patient out for rehabilitation. Michalko wrote, "Ophthalmology is recommending *agency* as an *actor* presented as qualified to speak about, and act upon, permanent blindness. This suggests that blindness requires agency and needs to be acted upon in order for it to be lived with. . . . Rehabilitation, too, conceives of the seeing life as the only good life" (pp. 66–67).

In another book, *The Two in One: Walking with Smokie, Walking with Blindness* Michalko (1999) used autoethnography as a methodology so that he could describe and analyze his experience of vision loss and his acquisition of a guide dog. He relied on postcolonial concepts of "home" and "exile" to describe his personal experience of living in a world built by and for sighted people and explained how his dog, Smokie, lives in exile in a world built by and for humans, but how their relationship brings "home" into both of their lives. Michalko also examined how the dog guide school creates expectations of blind students' behavior and the school's physical environment based on sighted notions about the blindness experience. Sherry (2003) argued that Michalko's most important contribution to blindness and disability studies literature is his postmodernist deconstruction of the blindness/sightedness binary, which extracts blindness from its perceived "lack" and places it, instead, on its own merit as an alternate way of knowing the world. Michalko (1998) wrote: "Blindness, when compared with sight, becomes a thing of shadows . . . anything seen as a mere shadow of its former self is understood as less than or not as good as the original. . . . Sight *is* status and is a status *former* to blindness. Sight is not a mere shadow of its former self since it has no former self. Thus sight is not regarded as needful of restoration" (pp. 67–68).

Michalko's work is important and will have far-reaching impact on both blindness research and on how societal institutions perceive, teach about, and treat blind people. However, one largely ignored theoretical approach to blindness is materialism, which is important in several other areas of disability studies. Although a materialist approach has been adopted by disability scholars such as Oliver (1990), Gleeson (1999) and Thomas (1999), it is a relatively underexplored perspective within studies of blindness. Oliver (1990) argued that material factors are fundamental to understanding the social model of disability. In this regard, it is important to note that blind people experience economic oppression and social isolation in even larger percentages than other disabled people, through higher unemployment and underemployment rates and lack of access to basic print information and accessible transportation. Potential employers, community development and urban planners, mainstream technocrats, rehabilitation agencies, and retailers alike often balk at the financial cost of environmental barrier removal and universal design, leaving blind people stranded in or altogether shut out of the workplace, and therefore,

exiled from a consumer economy. In addition, government agencies, nonprofit charities, and for-profit businesses employ tens of thousands of sighted workers engaged in maintaining institutionalized oppression of blind people. Failure to examine these factors as influences in blind people's lives is failure to mine a deep and rich source of research data.

Another flaw with some of the blindness literature is that it generally focuses *either* on impairment or disability, but not both. In addition, distinctions between impairment and disability are muddied because authors often use these terms interchangeably. Such conceptual blurring can cause confusion and linguistic chaos because it becomes difficult for readers to grasp theoretical concepts when key terms such as *disability* or *impairment* are being used in inconsistent or ambiguous ways.

FUTURE DIRECTIONS

Advances in technology and medicine, demographic trends, a global economy, and political developments can be expected to shape the futures of blind and visually impaired people around the world. Technological advances will assist in agricultural practices reform and improvements in sanitation, which will further the current trend toward reduction in cases of bacterial-related blindness. On the other hand, medical advances continue to prolong life; therefore, a steady rise in cases of age-related blindness such as glaucoma, macular degeneration, and cataracts is expected. Coupled with general population gains, the overall number of blind people will most likely increase, especially in the developing world. The WHO (1997) estimated that by the year 2020, 50 million blind people will be living in developing countries, which will put a tremendous strain on eye health care and social service monetary and human resources. More cost-effective technologies such as outpatient cataract surgery may help alleviate the strain on service provision.

Gene therapies and genetic counseling may play a role in the future size of the blind population, especially in the majority world. Genetic manipulation of the human race is a controversial topic. Societal attitudes about disability and disabled people strongly influence decisions about which children are worthy of existence. Disability studies as a discipline is addressing the ethical issues and implications for disabled people and the science of genetic manipulation. Because many eye diseases are genetic, it is likely that those interested in the social model of blindness will participate in the discourse.

CONCLUSION

There are approximately 148 million blind people in the world, with most of them living in underdeveloped countries, and many international health promotion organizations are implementing blindness prevention and treatment programs. Blindness is a continuum, which can be measured according to different scales. For instance, most government departments distinguish between people who are totally blind, legally blind, and partially sighted, and they use these categories to determine eligibility for services. However, these definitions of blindness rely on a medical model of disability, which places most emphasis on measuring impairment levels, but which does not focus on the experience of disabling barriers.

It should not be assumed that there is a direct relationship between a person's degree of blindness and the difficulties he or she faces in everyday life. Some of the factors affecting the social inclusion and exclusion of blind people include the accessibility of their environment, the degree of support they have, and their financial resources. For many blind people, the experience of disabling barriers greatly limits their rights and freedoms. Some of those barriers include discrimination in employment, exclusion from regular education, and stigma. Prejudice and stereotypes affect many perceptions of blindness and are present in religion, education, charities, the media, and many other areas of life. In response to these barriers, organizations of blind people have been struggling for increased rights, and blind authors within disability studies have made an important contribution to the cultural reevaluation of blindness.

—Beth Omansky

See also Autobiography; Blind, History of the; Disability Studies; Religion.

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BOBATH, BERTA AND KAREL
(BERTA, 1907–1991; KAREL, 1906–1991)

English (German-born) physiotherapist (Berta) and neurologist (Karel)

Mrs. Berta Bobath, physiotherapist, and her husband, Dr. Karel Bobath, originated a therapeutic approach to the treatment of persons with neuropathology and resultant sensorimotor impairments currently called the neuro-developmental treatment approach (NDT). Berta and Karel Bobath were born in Berlin, Germany, but developed these therapeutic concepts after they immigrated to London, England, prior to World War II. The treatment approach grew out of Mrs. Bobath's astute observations of normal posture and movement and Dr. Bobath's belief that scientific evidence must support clinical practice. They published many books and journal articles, teaching doctors and therapists their methods of examination and treatment from 1948 through 1990.

Although the Bobaths did not conduct any original research or collect clinical data in ways that offered the medical and scientific community evidence for the effectiveness of their treatment approach, NDT continues to be a commonly used method for the management of motor dysfunction following adults who

have had a stroke or children who have cerebral palsy. The Bobaths committed their time and energy to developing their treatment approach, which, while it has evolved over the years, includes the following characteristics. Examination and treatment strategies target the neuromuscular and musculoskeletal impairments that interfere with functional skills in clients with neuropathology. Treatment includes hands-on facilitation of selective posture and movement and inhibition of unnecessary, inefficient motor responses so that ultimately the client can develop effective movement synergies that are in tune with task demands and contextual requirements. Treatment outcomes are defined as measurable, observable functional changes made in meaningful contexts.

—Janet M. Howle

See also Cerebral Palsy; Neurological Impairments and Nervous Disorders; Neuropathy; Stroke.

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BODY, THEORIES OF

"Body theory" is shorthand for a nexus of contemporary scholarship concerned with the definition, tracking, and management of kinds of bodies and the social ideas about bodies that configure self-perception. Work in body theory resists the Enlightenment idea that human definition should be based on a quality of consciousness. Instead of the often cited conceptualization of humans in the terms espoused by the Enlightenment-era philosopher René Descartes, "I think therefore I am," body theorists take human commonality to reside in the inhabitation of bodies. Rather than participating in a lengthy philosophical tradition (largely Western) that eschews bodies as secondary to the intellectual life of the mind, body studies reintroduces the materiality of lived experience as a significant site of analysis.

Premises in body theory have provided for scholars to study the effects of management practices. Most important, in studying discourses and ideas about bodies a scholar does not need to simply oppose or endorse institutional practices as necessary for the conduct of institutional life. Michel Foucault, a post-Holocaust historian of confinement practices, evaluation methods, and professional discourse, often receives mention as formative to body theory. Partially as a result of Foucault's methods, many contemporary policy studies, for example, now also investigate social ideas about the means for regulating the conduct of bodies without having to endorse them. Foucault himself studied the origins of disciplinary and regulative techniques for the operation of institutional life in schools, hospitals, prisons, asylums, and clinics. When social workers and prison guards complained that his book *Discipline and Punish* did not have much use for them, Foucault replied that he had not written it for them.

In work that theorizes the dynamics of power, Foucault contended that public executions, inasmuch as they directly display brutality and torture, deliberately expose the violent operations of a state in seeking compliance from its citizens. Rather than implicate the state in practices presumably enacted to deter transgressions, the Victorian era sought to conceal the workings of state power upon bodies: Executions became sequestered, judicial affairs as the product of massive deliberations that conceal directly punitive acts. Within this approach, oppression occurs as a matter of excessive evaluation, regulated body life, and administrative protocols so that the operations of power become diffuse. Increasingly, punitive bureaucracies came to implement such operations. During this period, definitions of a variety of "mental defects," in a casebook that is put to use by medical and judiciary organizations alike, subjugate citizens by casting an ever-expanding number of human characteristics as abnormal. Discussion of human abnormalities is entered into wholesale by the judiciary and a field of psychiatry that grows up as an adjunct to the courts, in France, and as the operators of institutions in the United States. Psychiatry was a field that had

taken discourses about human pathology as a primary domain of expertise and qualification. In part, because of the collusion of German psychiatrists in eugenics and murder practices of disabled persons during the period of National Socialist Governance, psychiatry was also in general disrepute after World War II.

Contending that professional discourse about anomalous bodies such as the kind undertaken by rehabilitation and medical professions had become a "monologue," and one that had literally silenced subjects to death in state-mandated evaluation procedures in Germany, many of Foucault's writings contemplate the silencing of the voices of objects of study by discourses ostensibly "about" them. Body theory thus resists the idea that one can ascertain the views of the confined, the subjugated, the studied, and the disciplined, from the case notes and judiciary records of those who write about them. Nonetheless, scholarship can effectively study the confinement of bodies and the techniques to control and illicit kinds of "abnormality" that make manifest the operations of power in a social order.

A principal innovation of institutional life was to develop a written case study, and maintain observational notes, on each client. This is likewise the case for the advent of contemporary practices in judiciaries that are also concerned with identifying and punishing abnormality. With these notes from psychiatric institutions now making up a substantive archive of collected materials, other scholars have also sought to find ways to listen to the voices of confined objects of medical observation and scientific study. Some study the discursive patterns of expression that have been recorded by professional observers in order to contemplate the messages avowed by, for instance, someone termed "schizophrenic." Others study locations in clinics and hospitals as spaces for the performance of anomaly and abnormality, noting, for example, that the performance of hysteria in the famous medical school of Jean Martin Charcot often entailed inciting an epileptic seizure in one of the subjects.

Hence body theory has provided for a means to study the classification of bodies and their performance of symptoms without having to validate (nor necessarily refute) medical findings. Many subjects viewed as abnormal also expressed symptoms bound up with violation of feminine norms and standards. Understandably, then, body theory is also largely associated with feminist and gender studies. This line of thinking contends that under patriarchal societies, women experience disqualification from tasks on the basis of perceptions concerning attributes associated with an inferior biology. Feminist scholars thus research historical and professional locations that gauge equal participation in terms of body qualification. Cast as the "weaker sex," women have historically struggled with being limited and defined on the basis of bodies that were rigidly classified in terms of reproduction, as well as feminine norms and expectations. Body theory might say that humans with feminine reproductive organs, under a gender classification system that divides the world into those with wombs and those without them, will view women's bodies as making them innately unsuited for leadership, moral vision, certitude, or professional life. Intimately bound up with body theory, gender studies researches the ways in which different reproductive anatomies in bodies have been opposed in a dualistic fashion. Herein, masculinity comes to define a specific set of qualifications associated with body features whereas femininity offers a contrasting, and frequently less stable, range of possibilities.

Existentialism, a significant branch of philosophy during the first half of the twentieth century, grounds a substantial part of theorization about gender and the body. The primogenitor of existentialism, Jean-Paul Sartre, formulates feelings of emancipation in terms of the success of exceeding limits so that one experiences momentary escape from one's body demands. In contrast, Simone de Beauvoir, Sartre's partner, and the author of *The Second Sex* (1949), demonstrates how a masculine subject's sense of liberation from material constraint casts women in perpetual association with the fleshy, immured life of bodies. Within this patriarchal schema, women are made secondary by their continual association with the fluids and constraints of bodies while male agency occurs through its dominion and escape from the body into the life of the mind.

As a rejoinder to this detrimental tradition, a school of thought termed *l'ecriture feminine,* or "writing the body," is associated with feminist philosophy in France from the late 1960s to the present. Preeminently, Helene Cixous, in pieces such as "The Laugh of

the Medusa" (1975), sought to expand imaginary associations between feminine body elements such as breast milk and the act of written expression. Whereas the classical story of the Medusa involved a male hero who turned the tables on a gorgon who had an appearance that, when gazed upon, turned men to stone, Cixous rewrites mythology from the perspective of a femininity that was only perceived, by masculine storytellers, as monstrous. Her philosophical tracts are thus also explicitly efforts to refigure denigrated and mythological female bodies by pressing the limits of poetics.

The feminist philosopher and gender ethicist Luce Irigaray, in many of her philosophical works, but most explicitly in *The Sex Which Is Not One* (1985), casts femininity as a purely negative, nonexistent state supplied only as a contrasting "other" to masculine subjectivity. She points out, for example, that a masculine philosophical tradition sees women's sexual organs in terms of mere absence of a phallus. Since femininity exists only as negation, one can attempt to realize a feminine subjectivity through interrogative questions and bodily experiences that escape masculine definition. The semiotics theorist and philosopher Julia Kristeva famously recorded her experience of embodiment during parturition in "Stabat Mater" (1983). In doing so, Kristeva reclaims feminine fluidity as a value rather than an abject vehicle. While influential in vastly divergent fields, all these writings nonetheless seek to expand imaginative thinking about the bounded nature and singularity of bodies. They also seek to resist equations of femininity with less and masculinity as the ideal of normative embodiment.

In a significant divergence from *l'ecriture feminine,* transgender theorist Judith Butler challenges the political utility of inverting values associated with a masculine/feminine dualism. Instead she argues against the existence of any embodied experience not already filtered by language. For Butler, gender is not the cultural layering of meaning upon the raw material of sex, but rather sex itself proves fully conditioned by cultural investments in naturalized bodily capacities. Studies of transgender experience interpret the effects of dualistic gender thinking upon bodies that do not suit an either/or classification of masculine/feminine. Instead a transgender studies approach analyzes the production of ambiguously gendered bodies that exceed inflexible sex/gender divisions. Transgender theorists analyze the resistant potential of gender ambiguity as undermining of normative heterosexual conventions.

Since body theory undertakes a historical tracing out of the ways in which bodies are viewed in different societies, analyses of racial discourse are also key to the field. Such an undertaking immediately necessitates parsing out the operations of racial and ethnic thinking in body image production. As late-eighteenth and nineteenth-century ideologies produced gender-related pathologies, race itself moved from a marker of cultural difference fueling ethnic tensions to a physical sign of biological inferiority itself. Increasingly, one finds justifications for enslavement, for instance, based on paternalistic models of racialized populations' presumed inability to care for themselves. African and South Asian societies in particular came to be referenced by European anthropologists as evolutionary throwbacks. Freud, for instance in *Totem and Taboo* (1913), identified Maori communities in New Zealand and Zulu peoples in Africa as evidence of premodern totemic societies that had not effectively repressed their baser, primeval impulses. In addition, some ethnic populations such as Jews were cast under suspicion because they were thought to be hyperequipped to handle the demands of rapid industrialization and modern economic orders. Consequently, scholars examine the ways in which Nordic Western races have historically bolstered their biological superiority through the denigration of other bodies as inherently deviant based on subjective racial characteristics.

Outside of more psychoanalytic models, other traditions in body theory interpret the role of body classification in terms of economic and class-based effects. Second-wave feminism, for example, explored how Karl Marx, in *Das Kapital* (1867), conceived of the worker's body under industrial capitalism as inherently male. As a result, feminist socialist theory has worked to expand definitions of labor by querying formerly unrecognized modes of labor such as the role of reproduction as erased under capitalist economies. Theorists in this tradition have pointed out that work in the domestic space, though not usually and directly remunerated under professional business practices, qualifies nonetheless as expended labor and thus should be recognized as work that results in use value.

Likewise, disability body theory examines how Marx's conception of workers' bodies necessarily excludes from labor participation those bodies deemed less evidently productive by ableist labor orders. Indeed, the enemy element under industrial capitalism is the capitalist himself who parasitically invests capital but does not expend his own labor in the production of commodities. The capitalist's body is thus traditionally depicted as corpulent and excessive while the debilitated laborer's body provides evidence of capitalist indifference. While unbridled industrialism would therefore be culpable for disabling otherwise healthy worker bodies, there is also little room to discover alternative routes of employment for disabled bodies if they do not pass muster as "able" laborers from the start.

In a parallel effort to body studies, disability studies takes up the necessity of evaluating the often restrictive location of bodies identified as nonstandard. In doing so, disability scholarship often investigates sites of transportation, sequestration, confinement, seclusion, disenfranchisement, regulation, display, promotion, and clustering of disabled bodies. Like studies of obesity or age, disability studies analyzes the social world, from airplanes to classrooms, to discuss the ways in which an environment is built to anticipate some bodies while excluding others. Just as the politics and oppression of prostitution became a central concern for feminism, so does the history of employment in freak shows galvanize scholarship for disability scholars. Some kinds of disabled bodies, like racialized and exotic "others," seem particularly qualified for employment as an exhibition or freak act. These include bearded women, atrophied men, obese persons, those possessed of extraordinary height, persons of short stature, conjoined twins, and persons who appear to lack arms, legs, or body sections. Toward the end of the nineteenth century, medical researchers sought to examine persons employed in freak show exhibits. Discussion abounds concerning the efforts of sideshow barkers and managers, such as Phineas Taylor (P. T.) Barnum, to protect his band of freaks from them.

Cultural theorists such as Leslie Fiedler propose that the attainment of freak spectacle was reserved for only a special class of human anomalies and that the rest were simply consigned to the experience of regular disability and social suffering. Objecting, most of all, to being called a "freak," transgender and disabled commentator Eli Clare examined the economic realities that would bring about employment as an exhibited "extraordinary" human. She likens work in freak show industries to labor as a prostitute—drudge labor that nonetheless pulls one out of life as a beggar or a charity case. Then, in a key turn for disability studies, she returns to the insights of body theory and queries the medical team approach to examination that continues as a common practice in hospitals. Disability studies braves the radical insights of body theory by asking about the value of gait training examination and medical theaters from the perspective of those who have experienced being exhibited in these forums. For example, the gaze of medical and therapy practitioners upon different bodies may result in more harm than good and be utterly ancillary to the supply of a useful brace or mobility aid. Thus, disability studies also begs a question of political economy at its foundation in it querying of the necessity of medical evaluation regimes and the experimentation entailed by treatment plans, such as limb casting. How much does medical discourse have to produce "proof" of unacceptable traits and features in bodies? How much of the habit of gazing on body features involves merely assuring the professional gazer about their own normalcy? How much do professional practices rely on demonstrating the unacceptability of different body traits and features in terms, not only of standards of health, but merely for aesthetic purposes? And what are the implications of the rampant medical photographing of so many abnormal bodies during the twentieth century?

In addition to these methodological alliances, disability studies also reviews the significant absence of disability awareness in contemporary body theory. After all, body theorists may reference "cyborgs" as exemplary of a highly technological postmodern subject and toss in examples of someone "with detachable parts," without contemplating the sudden appearance in public of post-deinstitutional-era disabled persons. In other words, body theory often dematerializes into elegant discussions of the ascription of homophobic, racist, and sexist associations onto bodies in order to show that queer, racialized, and gendered bodies are socially produced. In many ways, this means that such bodies are not really

"defective" or insufficient but only perceived as such by unjust social views of them.

Embodiment analyses in disability studies propose that physical disabilities are perceived as a private room in a public space—and that ideologies of disability assume a transparency to the motives and psychic life of physically disabled subjects. Thus, while disabled bodies have been rendered largely invisible historically, popular literary and media texts often present such bodies as readily interpretable. A prime example occurs when malevolency and vengeance are easily assigned to persons with physical anomalies or illiteracy to someone who may be hard of hearing. A simple discounting of disabled persons occurs as the result of onlookers making assumptions about someone's "inner" disposition and thus rendering them transparent. Because such simplistic ascriptions between psychological deviance and physically disabled bodies are common, these representational tactics constitute a significant layer of oppression for physically, cognitively, and sensory disabled persons alike. This historical intertwining of forms of deviance that seem to mutually reference each other has resulted in the deepening debasement of all bodies, particularly given that oppressive and discriminatory treatment often proceeds by making one form of devalued difference underwrite another.

Disability body theory has recently begun to analyze the degree to which eugenicist writings depend on the diagnosis of cognitive defects through scrutiny of physical anomalies and vice versa. Practices under eugenics where syphilis in one generation was argued to result in cerebral palsy and a propensity for promiscuity in the next provide a potent instance of cross-referencing practices that devalue bodies. Another area of interest is the degree to which racialized populations have been socially disqualified due to presumed inferior intelligence. Thus, one of the key insights of disability body theorists is that social disqualification occurs in a stigmatizing process whereby multiple identities are cross-referenced, and insomuch as these traits are configured in the same body, family, or communal unit.

—Sharon L. Snyder

See also Feminism; Michel Foucault; Freak Show; Gender; Gender, International; Identity; Racism.

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BORDERLINE PERSONALITY DISORDER

The term *borderline* was first brought into psychiatric terminology by A. Stern in 1938 to describe patients "on the border" of psychosis, and it has since been used to define alternately a clinical entity, a syndrome, or a personality organization. For roughly 70 years, the diagnosis of borderline personality disorder has been and still is a subject of intense debate.

Personality disorder is characterized by chronic instability in the individual's sense of identity, mood, and relationships. Afflicted individuals exhibit a deep lack of confidence and instability in relation to their sexual, professional, and social identities. They frequently experience disappointments and are prone to express anxiety and depression symptoms. Antisocial acts, affinity for psychoactive substance abuse, erratic lifestyles, a tendency for self-mutilation, and suicide attempts are common, and a sense of emptiness and meaninglessness prevail all along. The clinical presentation may show wide variability depending on the cultural background.

In individuals younger than age 18, these symptoms warrant a diagnosis of identity confusion. The prevalence of borderline personality disorder is in the order of 0.2–4 percent in the general public overall and 15–25 percent among hospitalized psychiatric patients. It is two to three times as common in women as in men. Alcohol and substance abuse and eating disorders are commonly co-diagnosed.

Etiologic explanations vary. Some hypotheses focus on constitutional defects in the brain's various neurotransmitter systems such as the adrenergic, cholinergic, dopaminergic, and serotonergic systems. Other hypotheses examine the association of this disorder with past or present history of head trauma, epilepsy, encephalitis, severe hyperactivity, distractibility, and learning disabilities. From a developmental perspective, arrest in normal development, excessive frustrations in early childhood and constitutional predisposition (weak ego structure prone to regression), disturbed separation-individuation process, early parental loss, traumatic separation from parental figures, and childhood physical-sexual abuse leading to ongoing posttraumatic stress disorder are all considered to be possible contributing factors.

Long-term analytic or reality-oriented supportive psychotherapy is a therapeutic mainstay along with the use of a wide range of pharmacologic agents including antidepressants, antipsychotics, and mood stabilizers for specific symptoms, often used in low dosages.

—Selahattin Şenol

See also Psychiatric Disorders.

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BOURNE, RANDOLPH (1886–1918)

American literary critic and essayist

Randolph Bourne was born in New Jersey in 1886. Facially disfigured as a result of a "messy birth," he was further impaired by spinal tuberculosis, which developed when he was four years old.

In 1911, while still a student at Columbia, his essay "The Handicapped—By One of Them" was published anonymously in *The Atlantic Monthly.* After graduating from Columbia University in 1913, he began to write for *The New Republic.* His first book, *Youth and Life*—which included a revised version of his essay "The Handicapped"—saw young people as a force for social change and prefigured many ideas about youth culture that would gain currency in the 1960s. His strong opposition to growing militarism and to World War I resulted in the end of his association with *The New Republic.* The crucial essay that marked this break was "The War and the Intellectuals," which appeared in *Seven Arts.* Bourne saw war not as an aberration but as an inherent feature of the modern state.

Following Bourne's death from influenza during the 1918 pandemic, two more volumes of his writing appeared: *Untimely Papers* (1919) and *The History of a Literary Radical and Other Essays* (1920).

—Anne Finger

See also Journalism.

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BOURNEVILLE, DESIRE MAGLIORE (1840–1909)

French scientist and activist

Desire Magliore Bourneville was an influential neurologist and pediatrician who made numerous contributions to the disability field in medical science, intellectual disability, clinical care, rehabilitation, and social policy. He was born in the village of Garaecieres in Normandy, studied in Paris with Charcot, and became an *interne des hopitaux* at the Bicetre, the Salpetriere, the Hopital St. Louis, and the Pitie. He served as a surgeon in the Garde Nationale during the Franco-Prussian War. After receiving his doctorate in 1870, he was physician at the pediatric

service of the Bicetre from 1879 to 1905 where he advanced the current understanding of pediatric neurological conditions. In 1873, Bourneville founded the journal *Progres Medical* and in 1880 the *Archives de neurology*. Besides his own work, he facilitated publication of the works of the famous French neurologist Jean Martin Charcot (1825–1893). He also met with and was influenced by the work of Maria Montessori.

Bourneville founded the first French school for mentally retarded children and directed Fondation Vallee where he focused his energies on the treatment of mentally retarded children. On Saturdays, he held open house at the Bicetre where his disabled charges performed exercises and dances for the staff and public. In 1873, he became a member of parliament and in 1876 a member of the Paris City Council. In these capacities, he advocated for disabled people, created a school for the education of nurses, and championed special wards for sick children.

—Henri-Jacques Stiker

See also Jean Martin Charcot; Maria Montessori.

BOWEL CONTROL

Controlling the elimination of rectal contents at socially acceptable times and places is called fecal continence. The loss of this control is a major personal and social disability. In some cultures, loss of fecal continence is cause for being ostracized from the community; in U.S. culture, many consider fecal incontinence indicative of a quality of life not worth living. Factors affecting continence include normal function of the entire muscle mechanism, adequate rectal capacity, normal stool consistency, and normal anal sensation.

Synchronized function of all components results in normal control of defecation and includes several elements: The rectum must fill, then sense the contents of the rectum; there must be relaxation or actually un-contraction of the entire sphincter mechanism, and at the same time there is a voluntary increase of intra-abdominal pressure.

Several problems can occur with the synchronized musculature: It may be cut, stretched, dented, diseased, or tired as a result of the aging process.

Cut muscle results from childbirth, surgery for abscess or fistula disease, or controlled muscle incision used to treat anal ulcer or fissure. The muscle may also be stretched or dented from obstetrical injury, extreme sex, surgery, or obstructed defecation (a malfunction of the entire pelvic floor). The mechanism is especially fragile in women, where there is only one small anterior muscular loop, which if injured, results in incontinence. The use of a midline episiotomy during childbirth, a common procedure in the United States, is a major source of injury.

The muscle may be diseased by such processes as inflammatory bowel disease, especially Crohn's disease; collagen or vascular disease; radiation injury; cancer; AIDS; or congenital abnormality. Muscle malfunction is also related to the aging process and is becoming more important with an aging population. Aging can cause overflow incontinence, which is frequently seen in combination with the pelvic floor malfunction of obstructed defecation. Special considerations exist for the surgeon who is treating a patient with Crohn's disease. Usual surgical procedures may not be safe because the future risk of incontinence necessitates preservation of all muscle function. Radiation injury to the muscle also disturbs normal function, now more common as adjuvant radiation therapy is used for various forms of pelvic cancer.

Other sources of incontinence result from disease processes in the neighboring organs, for example, in the large intestine; the small intestine, which may be shortened or diseased; Crohn's disease or ulcerative colitis; radiation injury; or irritable bowel syndrome. Another major source of lost control stems from injured nerves supplying the muscles of continence. Neural injury occurs with trauma as above, or with diabetes, spinal cord injury, multiple sclerosis, or congenital defects.

A process to differentiate causes of incontinence leads to proper treatment. Mechanical defects are sought first, but if absent, a diffuse impairment is sought. Specific diagnostic studies help in the process. The necessary studies include systemic evaluation, digital rectal exam, sigmoidoscopy or colonoscopy, and sometimes a small retention enema, which tests the function of the entire mechanism. Specialized diagnostic procedures include transrectal ultrasound, manometry, nerve function studies, defecography, and psychological studies.

Incontinence has various therapies. The simplest is an attempt to control bowel function, dealing with such problems as constipation and fecal impaction. Next is treating such diseases as Crohn's disease, colitis, radiation injury, or irritable bowel syndrome. If simple measures fail, biofeedback can be used to retrain the muscle and allow relearning of the process of defecation.

Should these simple measures fail, surgical correction becomes a consideration. If it is a straightforward problem, reconstruction of the sphincter mechanism is possible, as in the case of obstetrical injury in healthy women or acute trauma to the muscle itself. The issue becomes more complicated with sphincter reconstruction complicated by previously unsuccessful repairs, an elderly patient, or systemic diseases, as above. In these cases, specific diagnostic procedures are selected, especially to evaluate nerve function, quantity of muscle, and function of the organs of the pelvic floor.

In some cases, surgical repair is not a possibility, as when the nerve is severely damaged, when there is severe scar tissue, or when there is inadequate muscle to allow repair. In these cases, special complex surgery is a final recourse. These include encircling the incontinent muscle, a special repair of the muscle itself, bringing in muscle from elsewhere in the pelvic region, insertion of an artificial mechanical anal sphincter, or construction of a good colostomy. It is important to realize that in desperate cases with complete fecal incontinence, the patients have a de facto colostomy because they have no anal muscle control; these patients are better served with a well-constructed colostomy on the abdominal wall where they can affix an appliance, and live an otherwise normal life.

In summary, to understand bowel control, disability, and their relationship, it is important to know the cause of the disability, to diagnose and treat any systemic disease, to verify the presence of muscle and adequacy of nerve function before contemplating any surgical correction, and to remember that the quality of life of the individual is paramount.

—Ira Kodner

See also Aging; Bladder Control.

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BOWEN, ROBERT WALTER "MIKE" (1887–1948)

South African lawyer and politician

Robert Walter Bowen, "whom everyone called Mike" (Blaxall 1965:34), began work as a railway clerk in Natal, South Africa, and served in the militia. He was blinded during war service at Ypres, Belgium, in 1917, after which his life changed gear. He passed through St. Dunstan's in London, studied at Cambridge University, became a barrister in 1920, and practiced in Cape Town. There he did some important legal work for black South Africans. By 1925, he was in the Cape Provincial Assembly, and from 1929 until his death he was a member of the South African Parliament. A skilled Braille user, Bowen worked tirelessly for educational and vocational training for blind people of whatever race. Together with Reverend Arthur Blaxall, Bowen set up the National Council for the Blind, which he chaired from 1929 to 1948. Blaxall (1965) noted Bowen's typical response on hearing of obstacles in starting a first school for blind African children: "Mike Bowen said forthrightly, 'It is a damn shame,' picked up the telephone receiver and dialled a number. That same day we were sitting with the Minister for Education" (p. 34).

—Kumur B. Selim

See also Blind, History of the; Experience of Disability: Sub-Saharan Africa.

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BRAILLE

See Blind, History of the; Blindness and Visual Impairment; Braille, Louis

BRAILLE, LOUIS (1809–1852)

French educator

Louis Braille was born in Coupvray (Seine et Marne) in 1809. Blinded in childhood, he created a writing system for the blind consisting of raised (embossed) dots. His system was an immediate success and today bears the name of the Braille alphabet.

At the age of three, Louis Braille was injured, and he progressively lost his sight. He was totally blind by the age of five. In 1819, he enrolled as a pupil at the Royal Institute for Blind Youth in Paris. When he became a teacher there in 1828, he modified a raised-dot system of code invented by Charles Barbier, and it became a new means of writing that permitted his pupils to take notes during his lessons. His system makes silent reading possible for people without sight and facilitates written communication with the sighted. It is based on an alphabet consisting simply of two vertical rows of three raised dots. Reading is effected by passing the fingertips over the raised dots. To write manually, heavy paper and a punch are used.

In 1854, two years after Braille's death, his system was officially recognized in France. In 1878, the Universal Congress for the Improvement of the Lot of the Blind came out in favor of using the Braille system in all countries. There were problems with the lack of uniformization and, in part to resolve this, the World Braille Council was officially created by UNESCO in 1952. The remains of Louis Braille, a historical figure in the world of the blind, was moved to the Panthéon in Paris at that time.

—Jean-François Rivaud

See also Blind, History of the; History of Disability: Early Modern West.

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BRAZIL

See Experience of Disability: Brazil

BREAST CANCER

One in eight American women will be diagnosed with breast cancer during her lifetime, and in 2001, more than 40,000 women died of the disease (men are also occasionally diagnosed with breast cancer, and make up about 1 percent of all cases). Most physicians and cancer advice books urge breast cancer patients to think of the disease as a chronic, rather than a terminal, condition. For this reason, one can understand breast cancer in many of the same ways one understands disability—as a state of physical difference that may require some accommodations in order to function in particular physical environments. The connections between breast cancer and disability go deeper, however, especially when one considers some important moments in the history of cancer activism and disability rights in the United States: the public acknowledgment of breast cancer as something that is not shameful, the emergence of organizations of patients dedicated to activism on behalf of other patients, the appearance of art and literature specifically dealing with the disease, and the specific link made between breast cancer and the Americans with Disability Act in *Alabama v. Garrett* in 2001.

Breast cancer diagnoses have been rising since 1900. There is much debate over whether the

increased incidence of the disease is due to better detection methods (mammography), longer lifespans, or increased toxicity in the environment and food supply. Breast cancer is the most common cancer among American women (excluding skin cancers). It is second only to lung cancer as the leading cause of cancer deaths among women, but even though diagnosis rates have been steadily rising, mortality has declined throughout the twentieth century and into the twenty-first century underscoring the status of the disease as a chronic condition.

Even though many famous women writers in the twentieth century were diagnosed with (and often died of) breast cancer—most notably reform writer Charlotte Perkins Gilman and environmentalist Rachel Carson—it was not until 1974 that breast cancer became a public topic of conversation. During that year, the year after Section 504 of the Rehabilitation Act was passed (though not signed), both First Lady Betty Ford and Rose Kushner, an investigative reporter, were diagnosed. Ford broke the public silence about breast cancer by acknowledging her disease on national television. Thereafter, she worked to increase public awareness of the disease. Kushner began a campaign to work on behalf of patients' rights that did not end until her own death from breast cancer. Starting with her book in 1975, *Breast Cancer: A Personal History and Investigative Report,* and ending with her advocacy of a congressional bill to provide Medicare coverage for screening mammograms, Kushner argued for the rights of patients to have a say in their treatment, to be allowed options and choices when it came to surgery, and to fund breast cancer research.

Another important figure in the history of breast cancer advocacy is Audre Lorde, whose *Cancer Journals* serves as a touchstone for disability studies. In addition to recording some of the journals she wrote during her treatment and recovery, the book includes essays about the silence that surrounded breast cancer and mastectomy in the 1970s, and about the falseness of prosthesis and reconstructive surgery. Though Lorde does not mention disability explicitly, much of the book resonates with the disability theory and activism of that era. She argues that prosthesis is a means of silencing bodily experience, a way of hiding women with breast cancer from each other, and of keeping them from being able to share their sense of rage and the knowledge they have gained from the experience. She argues further that prosthesis hides breast cancer from public awareness, allowing people to ignore its politics. Lorde claims that prosthesis works as a lie, a way to avoid the reality of amputation, and that the emphasis on "looking normal" after mastectomy works to keep women within a stereotypical femininity, treating their bodies as aesthetic objects. It is perhaps this last argument, against the falsity of "the normal," that connects Lorde most clearly to contemporary disability studies. Lorde lays the groundwork for a theory of bodies that emphasizes diversity and difference in both appearance and experience. Furthermore, she argues for a politicized understanding of illness that likewise connects to disability studies, urging an awareness of environmental factors that cause cancer, and political coalitions to work against pollution and carcinogenic working conditions.

Following Ford's, Kushner's, and Lorde's leads, many women who had lived through breast cancer or who had lost close friends and relatives to the disease undertook conscious campaigns of activism in the late 1970s and early 1980s. In 1978, Mimi Kaplan and Ann Marcou founded the Y-Me organization to provide support to breast cancer patients; in 1982, Nancy Goodman Brinker founded the Susan G. Komen Breast Cancer Foundation to raise funds to study and eradicate the disease. Since then, more than 60 other nonprofit organizations have been formed around the disease, to promote research, environmental health, patient support and information, and financial assistance for poor patients. By the early twenty-first century, breast cancer may well be the most publicized disease in the United States, with innumerable products marked with pink ribbons, and with fund-raising events modeled after the Komen Foundation's "Race for the Cure"—"Shop for the Cure," "Plant for the Cure," "Art for the Cure"—becoming ubiquitous.

Breast cancer has also become a frequent subject in the arts and literature. Since the appearance of Deena Metzger's 1988 poster, "I Am No Longer Afraid" (also called "The Tree" after her book of that name), and Matuschka's self-portrait of her postmastectomy body on the cover of 1993 issue of the *New York Times*

Magazine, artists have not shied away from representing bodies affected by breast cancer. Often this art joins with activism, as in the collection *Art.Rage.Us.* Writers have also followed Audre Lorde's lead in resisting silence about breast cancer, often writing about it directly, as in autobiographies such as Christina Middlebrook's 1996 *Seeing the Crab: A Memoir of Dying before I Do,* collections of stories, poetry, and essays, and Hilda Raz's *Living on the Margins* from 1999, or documentaries such as Gerry Rogers's *My Left Breast,* released in 2000. Breast cancer may also play an indirect part in fiction, as it does in Margaret Atwood's *Bodily Harm* or Jane Smiley's *Thousand Acres.*

During the 2000 term of the U.S. Supreme Court, breast cancer and disability activism became firmly linked, when the Court ruled that the Americans with Disabilities Act (ADA) does not give anyone the right to sue a state. Patricia Garrett was a nurse at the University of Alabama hospital and was asked to take a lesser position because she was in treatment for breast cancer, despite having been acknowledged to be able to perform her job adequately. On the face of it, *Alabama v. Garrett* was decided as a states' rights case, the Court arguing that Congress did not have the right to pass a law that would award money damages to a citizen from a state unless it had clear evidence that the states had historically violated their citizens' constitutional rights. The language of the decision and concurrence, however, suggest to some that the decision has broader ramifications for people who would bring suit under the ADA, since Justice William H. Rehnquist argues that the ADA does not provide for "special accommodation" and since Justices Anthony Kennedy and Sandra Day O'Connor argue against using the law to redress discrimination by the states and suggest that it may be instinct to recoil from people who are different from ourselves. Despite the work of breast cancer and disability activists, there is still much to be done to challenge public attitudes about chronic disease and difference.

—Diane Price Herndl

See also Autobiography; Cancer.

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Y-Me National Breast Cancer Organization, http://www.y-me.org

BRIDGMAN, LAURA DEWEY (1829–1889)

American deaf-blind pioneer

Laura Dewey Bridgman was the first deaf-blind person to receive a formal education. Bridgman achieved worldwide notice for her accomplishments. Charles Dickens visited her one time and then wrote a chapter about her in *American Notes* (1842).

Bridgman was born in Hanover, New Hampshire. She contracted scarlet fever at two years of age, which left her without vision, hearing, and sense of smell or taste. Her only mode of communication with the world around her was through her sense of touch. By touching her mother as she went about the daily household chores, Bridgman learned how to clean, sew, and knit. When she was seven years old, Dr. Samuel Gridley Howe took Bridgman to live at the Massachusetts Asylum for the Blind (later renamed Perkins Institute, and currently known as the Perkins School for the Blind) in Boston. Like other blind children, Bridgman was made to wear a green scarf around her head to cover her eyes. Through a progressive series of exercises and grooved paper, she learned the manual alphabet used by deaf-blind people. When she learned something new or repeated a lesson correctly, her teacher patted her on top of her head. If she answered incorrectly, the teacher struck her on her left hand.

Bridgman lived out the rest of her life at the institution, and died on May 24, 1889. Six of her letters, photos of Bridgman, and a piece of lace she made are

preserved at the Leonard H. Axe Library, located at Pittsburgh State University, in Pennsylvania.

Many educational publications have been written about Bridgman's life. Current deaf-blind education methods can be traced back to those used to teach Bridgman communication and daily living skills.

—Beth Omansky

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

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BRIGHAM, AMARIAH (1798–1849)

American institution administrator

Amariah Brigham was one of the leaders of the asylum movement in mid-nineteenth-century America that sponsored the creation and public support of specialized, congregate insane asylums led by experts in the emerging profession of psychiatry. His approach characterized the powerful optimism of these early asylum superintendents. As superintendent of the Utica State Asylum in New York from 1842 until his death in 1849, Brigham was also one of the 13 founders (along with Thomas Kirkbride, Isaac Ray, Pliny Earle, and others) of what is now known as the American Psychiatric Association. Brigham himself began publication of the *American Journal of Insanity* (printed with the help of inmates at Brigham's asylum in Utica), one of the first English-language journals devoted exclusively to mental illness. The scientific optimism of the era is illustrated in this passage from Brigham's introductory essay to the initial issue of the journal: "Insanity is but a disease of that organism [i.e., the human brain], and when so regarded, it will often be prevented, and generally cured by the early adoption of proper methods of treatment."

—Philip M. Ferguson

See also Mental Health.

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BROCA, PAUL (1824–1880)

French surgeon and anthropologist

Paul Broca was a French surgeon, pathologist, anatomist, and anthropologist. Today, he is best remembered for localizing speech in the frontal lobes, recognizing cerebral dominance, performing the first surgery based on localization, studying race and intelligence, and investigating ancient trepanned (opened) skulls.

In 1859, Broca founded the world's first anthropological society, the Société d'Anthropologie. It was here that scientists discussed human origins, intelligence, and the functional organization of the brain. In 1861, he used the case of Leborgne to argue for localization of fluent speech in the anterior lobes of the brain (Broca's area). A few years later, he recognized that the left hemisphere is more important than the right for speech (cerebral dominance).

Broca hypothesized that the right hemisphere may be able to take over for a damaged left hemisphere, particularly if brain damage occurs early in life. He also recommended speech therapy for aphasic patients. In 1868, Broca conducted the first successful brain surgery based solely on functional localization.

In the late 1860s and 1870s, Broca concerned himself with ancient trepanned skulls. One of his theories was that cranial openings were made during the New Stone Age to treat childhood seizure disorders. At the time of his death in 1880, he had more than 500 publications.

—Stanley Finger

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

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BROWNING, CHARLES ALBERT "TOD" (1880–1962)

American filmmaker

The 1930s Hollywood horror film director Charles Albert "Tod" Browning was born in Louisville, Kentucky. Best known for *Dracula* (1931) and *Freaks* (1932), Browning's career was clearly influenced by a childhood interest in carnival life. His experience acting in nickelodeon pieces and D. W. Griffith films is often overshadowed by his later directorial success. His early work in silent cinema, especially directing the esteemed character actor Lon Chaney, prepared him for his most famous portrayal of people with disabilities in the most controversial Hollywood feature film to depict people with disabilities playing themselves. In addition to his time spent traveling with circus performers, the year Browning spent hospitalized after a serious car accident (1915) may have affected his characterization of people with disabilities in *Freaks*. During his recovery, he penned film scripts leading to his feature film debut, *Jim Bludso* (1917).

Throughout his career, Browning challenged acting norms by having actors play Harlequin puppets (1916), by using double-exposure techniques so that Mabel Taliaferro could play opposite herself (1917), by casting Lon Chaney as more than one principal character in the same film (1925), and by casting circus sideshow artists in a cinematic treatment of their world (1932). Browning was nicknamed "Hollywood's Master of the Macabre" and "The Wizard of Odd."

—Sally Chivers

See also Film; Freak Show.

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BUCK (EAGLE DETAMORE), CARRIE (1906–1983)

American sterilization plaintiff

Born to Emma Buck, an unmarried and institutionalized woman, Carrie Buck was raised by J. T. and Alice Dobbs in Charlottesville, Virginia. At age 17, she was assaulted by a nephew of the Dobbses, and became pregnant. Mr. Dobbs then had her committed to the Virginia Colony for Epileptics and Feebleminded in Lynchburg. There, in 1927, she was sterilized against her will, in compliance with the Virginia Statute for Eugenical Sterilization, upheld by the U.S. Supreme Court earlier that year in the *Buck v. Bell* decision. Carrie Buck married her first husband William Eagle in 1930 (he died in 1966), and during her middle years worked as a housekeeper and agricultural laborer. Buck's only daughter, Vivian, was raised by the Dobbs family until she died of an acute illness in 1932. Buck's younger sister, Doris Buck Figgins, was also sterilized as a teenager. Carrie Buck Detamore died as a result

of poverty-related exposure and malnutrition. Her second husband, Charles Detamore, survived her. In 2002, a roadside historical marker was erected in Charlottesville, marking the 75th anniversary of the *Buck v. Bell* decision and telling Carrie Buck's story.

—Penny L. Richards

See also Sterilization.

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BUCK, PEARL S. (1892–1973)

American author

Pearl S. Buck was an American writer and Nobel Prize winner for literature in 1938. Buck described her own experience as the mother of a child with mental retardation in the widely read "The Child Who Never Grew," an essay for *Ladies' Home Journal* in 1950, which was later expanded to book length and translated into many languages. Along with other mid- twentieth-century parent narratives, it increased visibility for middle-class families of children with developmental disabilities while assuring parents that institutionalization was the best possible solution. (It is still in print today.)

Buck also wrote themes of family and disability into her fiction. Her best-known novel, *The Good Earth,* published in 1931, concerns a Chinese family in which the eldest daughter has developmental disabilities and cannot speak. Other works share this concern for the care of children, especially girls, with disabilities, among them, *The Mother* (1934). Buck's literary success allowed her to fund research that eventually discovered the metabolic cause of her daughter's developmental disability—phenylketonuria—which, in turn, led to universal newborn PKU testing and food labeling in the United States. Buck's daughter, Carol (1921–1992), lived at Vineland Training School in New Jersey for most of her life.

—Penny L. Richards

See also Developmental Disabilities.

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BULWER, JOHN (1606–1656)

English physician and author

Influenced by Francis Bacon, who criticized Aristotle for his inattention to gestures and the role of the body in rhetorical delivery, and also apparently influenced by contact with his deaf daughter (named Chirolea) and his work as an early deaf educator, John Bulwer wrote three late-Renaissance texts that called on his knowledge of deafness and sign languages: *Chirologia, or, The naturall language of the hand* (1644); *Philocopus, or the Deaf and Dumbe Mans Friend* (1648); and the unfinished *Pathomyotamia, or, A dissection of the significative muscles of the affections of the minde* (1649).

Chirologia is an important text in the history of elocution, a movement in rhetorical theory and practice that focuses on the effects of gestures, expressions, and body language on persuasion. *Philocopus* explores the "philosophical verity" of lipreading, which, according to the book's frontispiece, is "that subtle art, which may enable one with an observant eye, to hear what any man speaks by the moving of his lips." *Phathomyotamia* was intended to further the work of *Chirologia* and to do for the head—and its affective powers of movement—what Bulwer had already outlined for "the naturall language of the hand."

—Brenda Jo Brueggemann

See also Deaf, History of the; Sign Language.

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BUNKER, CHANG AND ENG (1811–1874)

American (Thai-born) performers

Conjoined twins Chang and Eng Bunker were nineteenth-century freak show performers who were known as the "Original Siamese Twins." They were born in Thailand, which was then known as Siam. For much of their childhood, they worked as duck egg merchants until they met Robert Hunter, a British merchant based in Bangkok. In 1829, Hunter and his associate, Abel Coffin, secured permission from their mother and Siamese King Rama III to take Chang and Eng to the United States to undertake a touring career. They became naturalized U.S. citizens, adopting the surname Bunker.

The twins took a break from performing in 1843. Chang married Adelaide Yates, and Eng married Sarah Yates in a double wedding. They settled in Wilkes County, North Carolina, bought a plantation with slaves, and had 22 children between the two of them. The end of the Civil War brought Chang and Eng out of their temporary retirement, and they reentered the touring circuit. Over the course of their career, they traveled throughout much of the United States and Europe, along with engagements in Canada and Cuba. They died in 1874 with Chang expiring first and Eng following a few hours later.

—Cynthia Wu

See also Freak Show.

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BURNOUT

See Stress, Burnout, and Neurogenesis

BURNS

Burns injuries are traumatic, functionally impairing, excruciatingly painful, and cosmetically disfiguring. The key to minimizing disability after injury is rapid wound closure and early aggressive rehabilitation. Burn severity and outcome are directly related to the depth and percent total body surface area burned.

Burn depth is measured by degree. First degree is a superficial burn involving the epidermis. Second degree is partial thickness involving part of the dermis. Third degree is a full-thickness burn involving the epidermis and all of the dermis. A fourth-degree burn extends to muscle, tendon, or bone. Full-thickness burns need to be grafted with skin taken from another part of the body. With this depth of burn, hair follicles, sweat and sebaceous glands, and nerve endings are destroyed and do not regenerate. Therefore, areas of full-thickness burn do not have hair or normal sensation and do not perspire or self-lubricate.

A major disability after burns is scarring. Areas of burn can be lighter or darker than normal skin. Scars can also become thick and dense (hypertrophic). Although pigmentation may improve and thick scars may soften, it is important to recognize that most burn scars are permanent. Pain in the scars and itching may persists for years. Custom pressure garments or silicone patches may help flatten scars and decrease pain and itching.

The key to maximizing outcome and minimizing disability after burn injury starts with aggressive prevention measures. Contractures, which limit joint range of motion, are a common complication following major burn injury, affecting 30–50 percent of patients. Treatment focuses on stretching and proper positioning. If full range of motion cannot be obtained, the patient can be treated with splinting or serial casting. If a scar band is unresponsive to conservative treatment, surgical release will be necessary.

Neuropathy, a nerve injury, with associated weakness occurs in 10–15 percent of patients after major burn injury and is more common with an electrical etiology. Amputations are necessary following burns that involve muscle and bone. Careful prosthetic fitting

is essential to avoid skin breakdown over the stump. A silicone sleeve can be used to maintain moisture and decrease shear forces across the residual limb.

Psychological distress following burn injury is common. Severe pain can escalate anxiety. Sleep disturbance, itching, and nightmares may add to distress. Posttraumatic stress disorder is rare but can be seen particularly in those patients injured by electricity.

Most burn patients perceive themselves as having a good quality of life. Return to work usually occurs in 14 to 17 weeks. Ninety percent are back to work at 24 months, but only 37 percent return to the same job with the same employer.

Burn care has changed dramatically in the past century with a significant improvement in overall survival. Patients with much larger burns now are surviving the acute care treatment but are often left with significant long-term functional impairment including decreased hand function, amputations, heat intolerance, cosmetic changes, pain, itching, and psychological difficulties. These can be limited by aggressive early comprehensive care.

—Karen J. Kowalske and Phala Helm

See also Amputation; Neuropathy; Pain.

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BYRON, LORD (GEORGE GORDON) (1788–1824)

English poet

The celebrated English Romantic poet Lord Byron enjoyed substantial renown during this lifetime. He became a cult personality of sorts and often found himself condemned for questionable morality by his peers. Diagnosed with "clubfoot" at birth, the label seems to cloud rather than reveal much useful information about the nature of his impairment. For instance, whereas his mother referred to the affected foot as his right one, his prosthetics manufacturer of the time claimed to have constructed a raised shoe for his left foot. Furthermore, his close military colleague Edward Trelawny, who fought with Byron in the war for Greek independence, claimed that both feet exhibited the effects of spasticity. Most contemporary researchers now suggest that Byron had Little's disease (an early diagnostic category for cerebral palsy). Many friends and relatives have claimed that Byron proved particularly sensitive about his disability. He would act defiant and melancholy when others discussed his lameness.

These descriptions of his attitude toward his disability bear much in common with the extreme sensitivities of the "Byronic hero," a characterization method he created in his poetry and fiction. Yet one might argue that such parallels are merely the product of a conflation of author with character; or, it might be equally insightful to identify something of the Byronic sentiment as akin to a defiant disability demeanor toward the world. In either case, Byron only wrote about his disability explicitly in his final, unfinished work published posthumously as *The Deformed Transformed.* In this play, the hunchbacked protagonist, Arnold, despairs about his disability status as a socially maligned condition and considers suicide. A "stranger" appears just as he is about to commit this desperate act and offers him a deal of Faustian proportions: Trade his disabled body for a more able-bodied prototype from history. Arnold accepts the offer immediately. After rejecting a number of possibilities on the basis of superficial defects, he chooses the physically idealized body of Achilles from Greek mythology. Ironically, the stranger dons Arnold's former disabled body to demonstrate that one can navigate the world successfully despite a visible disability. In fact, Byron's ironic commentary in the drama turns on the idea that once Arnold adopts an "unblemished" masculine exterior, he runs off to fight a war and puts his new, able body immediately at risk. This text further contextualizes Byron as one who did not despair over the presence of impairment as much as he

condemned the false superiority that sometimes attends able-bodiedness itself.

—Sharon L. Snyder

See also Poetry.

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