

CHAPTER 1

The History of Treatment Toward People With Disabilities

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OVERVIEW

For those born in the last half of the 20th century, it might appear as though people with disabilities have always been treated with kindness and a helping hand. Historically, this indeed was sometimes the case in certain parts of various countries by certain entities such as the church and other nonprofit organizations. Some cultures even revered people with disabilities and held them in high esteem. Gallagher (1995), for example, stated that among the Dahomeans of West Africa, infants born with disabilities were believed to be the result of supernatural forces and said to be good luck in some instances. Indeed, adults with deformities were often selected as state constables. In addition, among the Chagga of East Africa, children with disabilities were believed to satisfy evil spirits, which in turn safeguarded others from misfortune (Obermann, 1965).

Unfortunately, these views were but isolated incidences. The history of treatment and attitude toward people with disabilities has often been marked by societal fears, intolerance, ambivalence, prejudice, and ignorance regarding disability. Taken in total, throughout the ages, people with disabilities have been subjected to infanticide, starved, burned, shunned and isolated, strangled, submerged in hot water, beaten, chained and caged, tortured, gassed, shot, sterilized, warehoused and sedated, hanged, and used as amusement (Chubon, 1994; Gallagher, 1995; Sand, 1952). Surprisingly, many of these practices continued up until the end of World War II, and although this inhumane treatment was drastically curtailed in the last half of the 20th century, atrocities toward people with disabilities continue in various parts of the world today. Gostin (2008) indicates that despite the 1991 United Nations adoption of Principles for the Protection of Persons with Mental Illness (World Health Organization, 2005), as well as the 2006 United Nations Convention on the Rights of Persons with Disabilities, people with mental illness throughout the world are still treated inhumanely and are living under deplorable conditions, including in prisons, on the streets, and in asylum-type settings.

Exactly why people with disabilities have been historically treated so inhumanely is a complex question with many answers; however, most notably, they are devalued and perceived as less than human (Gostin, 2008). Depending on the era, infants with

disabilities were put to death for economic or spiritual reasons (Chubon, 1994). Among the Jukun of the Sudanese Kingdom, children with deformities were abandoned in caves or bushes because they were believed to be possessed by evil spirits. Plato and Aristotle sanctioned infanticide for eugenic and economic reasons, believing that infants with disabilities would burden the system's resources (Gallagher, 1995).

EARLY CIVILIZATION (BCE–CE 500)

Some evidence exists that people with severe disabilities sometimes survived adulthood but still not a normal life expectancy during early civilizations (Lowenfeld, 1975). Archeological and anthropological skeletal finds suggest that people with spina bifida lived during the Neolithic period (Sigerist, 1951). Venzmer (1968) reported evidence of disability during the Old Stone Age, again with the remains of people with spina bifida being found as well as osteomyelitis, congenital hip dislocation, and spinal tuberculosis. With physically disabling conditions such as these, it is obvious that even back then, it would seem likely that loved ones must have taken care of their disabled members. As no evidence of adaptive aids such as wheelchairs or walkers exists, it is believed that non-disabled family members may have carried their disabled loved ones from place to place.

Although it appears that some people with disabilities survived during these earlier times, because of the lack of medical understanding and technology, people with congenital disabilities either died of complications such as infections shortly after birth or were killed for economic, eugenic, or religious reasons (Deutsch, 1949). The Greeks believed the body and soul were one entity and that a blemish to the body (disability) also signified a blemish to the soul (Dickinson, 1961). Infanticide of infants with physical disabilities was practiced for eugenic reasons as advocated by Plato, and economic reasons as sanctioned by Aristotle (Deutsch, 1949). The body and soul connection by the Greeks also led to religion-based fears, as many believed that a disability signified punishment from God for having sinned (Turner, 1987). This belief was especially true for people with mental illness who were believed to be suffering from demonic possession. The Greek physician Hippocrates, however, rejected this premise and instead believed that the cause of mental illness was because of environmental reasons and brain impairment (Coleman, 1964). As a result, Hippocrates established the first sanitarium for what turned out to be well-off families who had a member with mental illness. Other people with mental illness did not fare as well and were often starved, chained, whipped, caged, or put to death (Sand, 1952). For both the Greeks and Romans, infants with disabilities were routinely killed or abandoned. Greeks who became disabled later in life, however, were permitted to live and often became beggars, whereas some people with mental retardation were owned by wealthy Romans for amusement as court jesters (Kanner, 1964).

Sigerist (1951) identified four differing attitudes toward disability during this early period. The ancient Hebrews viewed disability as punishment from God for having sinned. The Greeks considered disability a matter of economics and social status, and thus people with disabilities (who often were beggars) were viewed as socially inferior; however, the Christians viewed disability as a curse or as being possessed, thereby needing prayer and charity. Today, despite the fact that many view disability primarily in a clinical sense as an organic chronic illness or disease, there are still others who believe disability to be caused from having sinned.

MIDDLE AGES (600–1500)

The Middle Ages were dominated primarily by the principles of Christianity. The Scripture in the Old Testament linked sin against God with chronic illness and disability (Gallagher, 1995). A reference to people with disabilities found in Leviticus 21:18 that states, “he is unclean, and thus may not be a priest, or even approach the altar” conveys an unfavorable attitude about disability. In Samuel 5:8 it is written that “The blind and the lame shall not come into the home.” Byrd (1990) enlisted the assistance of pastors in Alabama to cite the number and type of listings relating to disability in the Bible. The top five terms and their frequency of use were “blind” mentioned 93 times, “sick” cited 88 times, “afflicted” cited 88 times, “leprosy” noted 67 times, and “drunken” cited 50 times. Ultimately linked from the Bible to the present day is the notion that a person’s disability can be healed if he or she has faith in God and repents of his or her sins. Gallagher (1995) cites the biblical passage where Jesus states to a blind man, “I have healed you, go and sin no more,” implying, or at least interpreted as, sinning had caused the blindness.

Medicine and the medical profession were poorly regarded because physicians were not well trained and often ineffective in treating people with various diseases. The public opposed human dissection, and thus medical knowledge and understanding slowed considerably during this period (Rubin & Roessler, 1995). Chubon (1994) noted that medicine became a moral issue because disability continued to be largely viewed as a punishment from God. Physicians were replaced by monks and priests, whose initial practices were humane. People with disabilities were treated in monasteries and hospitals where methods such as exorcism, prayer, incantations, magical herbs, and laying on of the hands were used (Obermann, 1965). Despite best efforts, the monasteries and the hospitals were too few to meet the needs of the poor, the homeless, and those with disabilities.

With these noble efforts to treat people with disabilities, Christianity’s reach only went so far. Lowenfeld (1975) reported that the German and Slavic people of Central Europe continued to abandon and kill people with disabilities who could not care for themselves. As the plight of people with disabilities was viewed as God’s punishment, no attempt was made to find out the underlying cause of the disability. Coleman (1964) noted that humane treatment of people with disabilities gave way to more inhumane treatments once again as the Middle Ages progressed. People with disabilities were feared and tortured, whipped, immersed in hot water, and starved to rid the person’s body of the devil (Safilios-Rothschild, 1970). It was indeed contradictory for the Catholic Church to be compassionate and benevolent to people with disabilities on the one hand, and yet at times be inhumane and cruel on the other. These human behaviors likely reflect individual interpretations and personal attitude differences among people rather than the will of the Catholic Church itself.

THE RENAISSANCE PERIOD (1500–1700)

During the period between 1500 and 1700, attitudes began to change regarding disability and treatment modalities. Coleman (1964) noted how the view of people with mental illness as possessed slowly changed to them being viewed as sick or ill. Chubon (1994) stated

that knowledge regarding the cause and symptoms of disability and illness began to be studied again, and physicians were allowed to dissect and study human cadavers. People with mental illness and mental retardation began being sent to the ever-growing number of asylums rather than monasteries. The asylums, unfortunately, offered no treatment or therapy, and instead functioned as prisons, some of which chained and caged noncompliant or acting-out patients (Coleman, 1964). During the great witch hunts between 1480 and 1680 reported in the *Malleus Maleficarum* book known as *The Hammer of Witches* (Kramer & Sprenger, 1971), it is estimated that between eight and 20 million people, mostly women, were tortured and put to death as witches in Europe. A good portion of this population often had a mental illness, or a visible disability, or a disfigurement. The book identified how to spot witches by their impairment or by giving birth to children with impairments.

Despite some of the inhumane treatment that continued for people with mental illness and mental retardation, there were some positive steps toward rehabilitating people with disabilities during this period as well. Obermann (1965) cites how people who were deaf were taught how to write during the 15th century and later were taught how to speak and read as well. Sand (1952) additionally notes how people who were deaf and blind were taught how to communicate by forming letters on their arms.

EARLY AMERICA (1620–1800)

For the settlers in the 13 colonies, disability was perceived as God's punishment. People with mental illness or related acting-out behavior were often persecuted and burned or hanged like witches. For the most part, however, disability was viewed as a moral problem, often bringing disgrace to families who had a disabled loved one (Chubon, 1994). Physicians continued to be trained poorly or were self-trained and often treated illnesses such as influenza, yellow fever, and typhoid fever by having patients drink different concoctions (Miller, 1966). This was also a period where "bleedings" (boring a hole in the head to release poisons from fever) occurred (Weisberger, 1975). People with mental illness from wealthy families were typically kept at home if they were nonviolent; however, if they were violent, they were locked up and essentially treated as criminals (Deutsch, 1949).

In 1752, Benjamin Franklin aided the Quakers in establishing the first colonial hospital in Philadelphia (Miller, 1966). Although this hospital was designed to treat all disorders, including mental illness, the quality of care was lacking (Grob, 1973). A second hospital was built in 1791 in New York. A few years later in 1798, the first Marine Hospital service was opened to treat merchant seamen with disabilities, and this eventually evolved into the U.S. Public Health Service (Singer, 1928). In addition, during the 1760s and 1780s, the first three medical schools in the United States were opened. Dr. Benjamin Rush trained some 3,000 doctors during this period and believed that disease could be driven from the body. Rush also believed in and practiced bleeding as a form of treatment for fever.

THE INDUSTRIAL REVOLUTION (1790–1870)

The Industrial Revolution between 1790 and 1870 brought some interesting developments concerning people with disabilities. First was the changing infrastructure of the United States as urbanization began to flourish, leading to the building of more hospitals.

This also led to greater advancements in treating people with various illnesses. Second, there was mechanization and the development of factories, primarily in these urban areas. Factory working conditions were often likened to those of present-day sweat shops, whereby workers were given few breaks, had to meet stringent quotas, and were supervised in a coercive, authoritarian manner (Cheit, 1961; Chubon, 1994). Indeed, industrial capitalism was geared to having healthy able-bodied people able to work long hours in mass production lines, thereby excluding people with mental and physical limitations of these types of work environments (Turner, 2006).

With industrialization came a new type of prevalent disability: injured workers. Workers who were injured on the job were often customarily fired if they could no longer produce, leaving them without any recourse but to sue their employers as workers' compensation legislation did not yet exist. Historically, the first workers' compensation legislation was passed in Germany in 1884, Hungary in 1887, Great Britain in 1897, and in the state of Maryland in the United States in 1902 (Worrall & Appel, 1985). Workers' compensation is best defined as an agreement between employer and employee, in that an employer automatically covers medical and wage replacement benefits for employees injured on the job, regardless of who is at fault. In turn, injured workers agree not to sue their employer. Before this legislation, however, employers virtually won all lawsuits brought against them by injured employees mainly because of three existing tort laws: the doctrines of "contributory negligence" (a worker contributed to his or her injury), "assumption of risk" (a worker knew the risks of the job and voluntarily did it anyway), and "fellow servant" (an injury occurred as the result of a coworker's negligence). These laws most often heavily favored the employer, and the burden of proof was with the employee (Berkowitz, 1960; Cheit, 1961).

In other arenas, services for people with disabilities continued to improve. Thomas Gallaudet, a theologian by education, became interested in working with the deaf population and studied educational methods in teaching people who were deaf in Europe (Holbrook, 1957). Later, with the help of Congress, Gallaudet raised money to open the first U.S. school for educating people who were deaf in Hartford, Connecticut, in 1817. Similarly, for people who were blind, the first attempts to educate and vocationally prepare this population occurred in Paris in 1784 by Valentin Haüy. Between 1791 and 1827, six other institutions for people who were blind were opened in the United Kingdom (Nelson, 1971). The first institution for the blind was eventually opened in the United States in 1832 by Dr. Samuel Howe. By 1887, Howe's success and his public relations efforts led to the opening of similar schools in over 30 states (Holbrook, 1957). In France, there were about 60 schools for deaf children by 1870, primarily run by Catholic congregations, starting with the two oldest and state-protected schools in Paris and Bordeaux founded in 1760. This proliferation of deaf schools stemmed from the fact that there were believed to be twice as many deaf children as there were blind (Buton, 2006). Interestingly, the majority of Parisian teachers were deaf themselves. Although the majority of the deaf population favored teaching French Sign Language (FSL), French education administrators pushed for teaching deaf students oral methods, which was ultimately passed by the Milan Congress in 1880 and immediately introduced that year. As a result, the majority of deaf-mute teaching candidates were banned until FSL was finally reimplemented in France in the 1990s.

People with mental illness during this time did not fare as well. Mental illness was not only misunderstood and feared by many people, but it was also seen as incurable (Rubin & Roessler, 1995). In the United States, Dr. Benjamin Rush advocated for the humane treatment of people with mental illness by surrounding them with pleasant conditions and conversation with others. Rush's plea, however, went largely unacknowledged as people with mental illness continued until recently (the 1960s) to be institutionalized with little or no psychological treatment and often under brutal living conditions. It was only after researcher Dorothea Dix investigated over 100 of these psychiatric hospitals and made her findings public that more humane treatment and living conditions came into effect (Holbrook, 1957). By 1860, Dix's impact led many state legislatures to provide funds to build more hospitals that provided humane treatment to people with mental illness. Unfortunately, deinstitutionalization has resulted in thousands of people with severe mental illness being confined in prisons or homeless in the streets without any assistance of any kind and no access to medication or counseling (Gostin, 2008).

Before the latter half of the 19th century, most people with physical disabilities such as muscular dystrophy and spinal cord dysfunction died because of various complications such as pneumonia and infections. This was the case until the development of antiseptic surgery by Joseph Lister in 1865, which greatly increased the survival rates (LaRue, 1972). Obermann (1965) noted that the first three hospitals for people with physical disabilities were opened between 1863 and 1884 in Philadelphia and New York. In 1893, the Industrial School for Crippled and Deformed Children was established in Boston, representing a first in the United States to vocationally train this population for jobs. Similar schools flourished after the polio epidemic of the 1940s (Chubon, 1994).

As developments for people with disabilities continued to slowly improve in most industrialized countries, there was concomitantly a growing philosophical and far-reaching issue that began to emerge. People with various disabilities had experienced differential types of treatment depending on what their disabilities were up until this point. How people viewed other people who were perceived as weak or different became clear in the years shortly following Darwin's infamous 1859 book, *Origin of Species*. Darwin's work set the stage for a barbaric movement that unfortunately continues in some parts of the world today.

THE HISTORY OF EUGENICS (1840–1950)

Smart (2009) noted that Sir Francis Galton, Karl Pearson, and Sir Ronald Fisher were all eugenicists and statisticians in academe. Galton originally coined the term *eugenics*, which is defined as “the study of hereditary improvements of the human race by controlled selective breeding” (Smart, 2009, p. 4). Galton essentially believed that society could be ruined if less intelligent people outreproduced those of greater intelligence, and espoused that government should encourage the rich to reproduce and prevent the less intelligent poor from doing so. Galton and his colleagues were statisticians who developed statistics still used today concerning the normal distribution curve and what is considered to be the “norm.” Their books, Galton's *Hereditary Genius* (1869) and *Inquiries Into Human Faculty and Its Development* (1883), as well as Fisher's *Genetical Theory of Natural Selection*, all delved into the concept of natural selection and selective breeding.

Darwin's 1859 *Origin of Species* specifically dealt with natural selection but addressed the concept only as it pertained to plants and animals. Gallagher states, "Darwin held that the members of a species will have various and sundry variations and that these variations will, in one way or another, influence the ability of the individual member to survive" (Gallagher, 1995, p. 44).

Twelve years later in 1871, Darwin's focus expanded from plants and animals to humans, with his second book, titled *The Descent of Man*, in which he stated:

We civilized men, on the other hand, do our utmost to check the process of elimination; we build asylums for the imbecile, the maimed, and the sick; we institute poor-laws; and our medical men exert their utmost skill to save the life of everyone to the last moment. ... Thus the weak members of civilized societies propagate their kind. No one who has attended to the breeding of domestic animals will doubt that this must be highly injurious to the race of man. (p. 90)

One of Darwin's followers, Herbert Spencer, actually coined the term *survival of the fittest* and applied Darwin's principles specifically to humans. In Spencer's 1884 book titled *Social Statics: Or the Conditions Essential to Human Happiness*, he stated that "under the natural order of things society is constantly excreting its unhealthy, imbecile, slow, vacillating, faithless members" (Spencer, 1884, p. 355). Both Spencer and Darwin's principles, along with Mendelian laws of heredity and genetics, became extremely popular with the public, politicians, academics, and physicians regarding the ideal order of the biological world (Gallagher, 1995). Fine (1956, as cited in Rubin & Roessler, 1995) noted that Spencer believed, "it was better for society to allow the poor and weak to perish than to sustain their existence and encourage their multiplication through government-supported public relief and health programs" (Rubin & Roessler, 1995, p. 17).

Spencer's Social Darwinism philosophy increased in popularity. It was an ethnocentric view advocated almost exclusively by White Anglo-Saxons of North European descent (Alemdaroglu, 2006). They believed that the wealthy and powerful were genetically superior to the poor and that poor people did not have the genetics or ability to ever be successful; hence, failure breeds failure. They believed welfare programs propagated failure and were dangerous to the health of the human race (Gallagher, 1995). As this movement grew, social scientists and others aiming to validate Social Darwinism held conferences and published numerous books and periodicals on the topic.

The Social Darwinism philosophy was perhaps no better exemplified than that found in Richard Dugdale's 1874 study where he pieced together the family tree of the Jukeses and Kallikaks. Dugdale traced six generations of the Jukes family (but failed to take into account those members who succeeded or did well) and found that of the 709 Jukes or those married to them, 76 were convicted of crimes, more than 200 collected charity or relief benefits, 128 were prostitutes, and 18 owned houses of prostitution (Gallagher, 1995). The Kallikak family situation was somewhat different but also supposedly strengthened Spencer's philosophy. During the Revolutionary War, Martin Kallikak had an illegitimate son by an apparently "feebleminded" girl. Although today considered a derogatory term, feeblemindedness during that era referred to individuals who were developmentally disabled. The son, who came to be known as "Old Horror,"

spawned 480 descendants over several generations, 143 of whom were classified as feeble-minded, 82 died in infancy, 33 were prostitutes, 24 were alcoholics, three had epilepsy, and three were criminals (Gallagher, 1995, p. 49). Kallikak later married a Quaker girl from a reportedly good family, and many of their descendants became doctors and lawyers. Although many of the Social Darwinism advocates were somewhat in agreement as to who the weaker of the species were (i.e., criminals, prostitutes, and people who were blind, paralyzed, developmentally disabled, mentally ill, or had epilepsy), there remained some controversy as to who else was considered hereditarily unfit.

In 1900, Duncan McKim came forward with a book titled *Heredity in Human Progress*, and essentially claimed that heredity was responsible for “insanity, idiocy, imbecility, eccentricity, hysteria, epilepsy, the alcohol habit, the morphine habit, neuralgias, nervousness, Saint Vitus dance, infantile convulsions, stammering, squinting, gout, articular rheumatism, diabetes, tuberculosis, cancer, deafness, blindness, deaf-mutism and color blindness” (cited in Gallagher, 1995, p. 50). McKim’s views began to show the confusion in thinking as to who the weaker section of the species was.

Several years before this, two new medical procedures, salpingectomy (tying a woman’s fallopian tubes) and vasectomy (tying the vas deferens of the male), were found to be an “effective and humane” way of sterilizing individuals at the time. Around the same time in 1896, Connecticut became the first state to forbid people considered to be “feeble-minded, imbeciles or having epilepsy” to marry or have sexual relations. Anyone breaking this law could find themselves facing a 3-year prison sentence. Other states followed suit with similar legislation and indeed expanded the list of disabilities to include people believed to be “insane, syphilitic, alcoholic, and certain types of criminals” (Haller, 1963, p. 47). Kansas passed similar laws in 1903, New Jersey and Ohio in 1904, and Michigan and Indiana in 1905. Public support continued to grow for the program, which soon expanded into sterilization.

On another front, during the last 30 years of the 19th century, a different kind of social discourse was occurring in the United States involving ethnicity, gender, and disability. Coco (2010) described San Francisco as having passed what came to be known as the “ugly act” in 1867 to remove unsightly beggars, most of whom had disabilities, off the streets. The law passed in some western and midwestern states over the subsequent 40 years, with Chicago’s Municipal Code Ordinance of 1911 stating:

No person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object or improper person be allowed in or on the public ways or other public places in this city, or shall therein or thereon expose himself to public view, under a penalty of not less than one dollar nor more than fifty dollars for each offense. (Chicago Municipal Code sec. 36034, cited in Coco, 2010)

Coco (2010) further noted that when people with disabilities were picked up off the street, they were sent to the Cook County poorhouse in Chicago, which had deplorable living conditions. Records from 1884 showed that 30,130 disabled people resided in these poorhouses compared with 22,896 able-bodied people. Among those with disabilities, 4,885 were described as lame or crippled, 7,780 as simply “sick,” 2,600 with epilepsy, and 1,648 as paralytic. Astonishingly, the last “ugly law” arrest occurred in 1974, before it was finally repealed in Chicago later that year (Kraut, 2010).

The first federal Immigration Act of 1882 prohibited U.S. entry to any “lunatic, idiot or any person unable to take care of himself or herself without becoming a public charge” (Baynton, 2001, p. 45). The “public charge” terminology allowed immigration officials wide latitude for discriminating against undesirable immigrants, even when a visible disability could not be determined. The Act to limit people with disabilities was further strengthened in 1891 when the words *likely unable* replaced the term *unable*. The 1907 law was even more exclusive in denying entry into the United States for anyone judged “mentally or physically defective, such mental or physical defect being of nature which *may affect* the ability of such alien to earn a living” (Baynton, 2001, p. 45). The whole intent of the immigration legislation was to exclude not only the disabled but also other perceived undesirable groups as well. The 1924 Immigration Act saw the institution of ethnic quotas wildly and subjectively tied to disability. Almost half of southern and eastern Europeans were described by “experts” as feebleminded. Jewish immigrants were viewed as neurotic, Slavik immigrants described as slow-witted, and the Portuguese, Greeks, and Syrians viewed as undersized, of poor physique, and physical degenerates.

African American slaves had already experienced Anglo-Saxon prejudice some 70 years earlier as some writers alleged that African Americans were intellectually inferior and therefore should not be set free because they could not care for themselves. Some physicians such as John Van Evrie, Samuel Cartwright, Samuel Forrey, and John Nott during the 1840s and 1850s wrote in prominent medical journals linking disability to African Americans. Van Evrie warned about race-mixing leading to abnormal and deformed offspring, supposedly resulting in the deterioration of moral and intellectual endowments. Cartwright differentiated and attributed two types of mental illness toward African Americans: one that was accompanied by body lesions that decreased one’s desire to work and engage in mischief, and another that caused slaves to run away from their masters (Baynton, 2001, p. 177). Forrey, writing in the *New York Journal of Medicine* in 1844, noted higher rates of insanity, deafness, blindness, and idiocy among free slaves that was not captured in the census. Nott, a year earlier, had compared Caucasian women with Black women in the *American Journal of Medical Sciences*, indicating that White women possessed lily skin, silky hair, and a Venus form, whereas “Black women were wenches with odorous skin, a woolly head, and animal features” (Baynton, 2001, p. 178). Forrey also saw many peculiar similarities among the American Indians.

Unfortunately, American women were not spared from being deemed disabled and inferior as well. Cynthia Russett wrote that “women and savages, together with idiots, criminals, and pathological monstrosities were a constant source of anxiety to male intellectuals in the late 19th century” (as cited in Baynton, 2001, p. 41). A common belief (among White males) at the time was that women possessed physical, intellectual, and psychological flaws and were often irrational with a high rate of hysteria. Neurophysiologist Dr. Charles Dana noted that if women were enfranchised to vote, this would lead to an approximate 25% increase in insanity because of their delicate nervous stability.

Back in the early 20th century, countries such as Denmark, Canada, and Switzerland passed sterilization laws for people with disabilities and undesirables such as criminals. Similar to the United States and Germany, these movements were largely the agenda of well-educated, elitist middle- and upper-class Anglo-Saxons who held positions of power (e.g., attorneys, physicians, politicians, academics). Although the eugenics movement was very popular with some elitists in Europe, France, and Turkey in the ensuing

years, the moves for sterilization and blocking marriages of certain groups were largely defeated by opposition from the church, the working class, and public health institutions in those countries (Alemdaroglu, 2006). In Turkey, forced sterilization and abortion are against Muslim values and beliefs, whereas most French eugenicists believed individuals' environments played a key role in their upbringing, and therefore future offspring could have a better life if living conditions were improved.

Regardless of other international laws and religious beliefs, it was the state of Indiana that finally passed the first U.S. sterilization laws of criminals, imbeciles, and rapists in 1907. By 1926, sterilization laws had passed in 23 other states and were affirmed by the U.S. Supreme Court in 1927 (Kanner, 1964, as cited in Rubin & Roessler, 1995). Gallagher (1995) noted some confusion and variation regarding who qualified for sterilization from state to state, but that most state laws had expanded to sterilize people with mental retardation, mental illness, and epilepsy. Several states also sterilized people considered alcoholic, homosexual, drug abusers, and repeat criminals. The state of Missouri, for example, even sterilized chicken thieves. Although the sterilization laws in the United States peaked in the 1920s, the practice continued into the 1950s and remained on the law books of 17 states until the 1980s. It is estimated that over 60,000 disabled and so-called unworthy able-bodied Americans had been forcibly sterilized by 1958 (Gallagher, 1995). The infamous 1927 Supreme Court decision *Buck v. Bell* permitted the sterilization of Carrie Buck who was believed to be incompetent and genetically inferior. Justice Oliver Wendell Holmes in his decision wrote, "Three generations of imbeciles are enough" in reference to Buck's mother having been institutionalized, and Buck described as promiscuous (Buchanan, 2007; Carlson, 2009; Smith, 1999).

Despite popular public and legislative support of the sterilization program, a group of ministers representing the Social Gospel Movement opposed Social Darwinism, arguing that the survival of the fittest mentality was against biblical teachings and that the Social Darwinism sentiment would promote selfish behavior and disregard for fellow human beings. However, not all Social Gospelers were in agreement, as many held firm to the notion that disability and illness were related to sin and defects within the individual (Hofstadter, Miller, & Aaron, 1959, as cited in Rubin & Roessler, 1995). In the end, despite the fact that the laws forbidding certain people to marry were never actually enforced and thus had little effect, psychologically the damage had been done regarding how society perceived and dehumanized people with various disabilities. As a result, Gallagher (1995) notes that many people with disabilities and their families during this period became ashamed or embarrassed of their conditions, and many became shut-ins and feared public ridicule.

EUGENICS TO AN EXTREME: EXTERMINATION (1899–1940s)

As the U.S. sterilization laws peaked during the 1920s, Germany passed its first sterilization law in 1933 (Gallagher, 1995). Leading to Germany's sterilization laws were the popular opinions of several people who influenced the debate on Social Darwinism. The Germans, much like the Americans, were anxious to preserve their racial heritage. However, Germany's anti-Semitic views misconstrued the primary philosophy of Social Darwinism; whereas Darwin and Spencer focused on heredity and the weaker section

of the species, some German thinkers extended these principles to justify the genocide of the Jews.

One of the earlier influential thinkers in Germany was the famous biologist and social scientist Ernst Haeckel, who in 1899 wrote *The Riddle of the Universe*. This text went through 10 editions and sold extremely well. In it, Haeckel wrote:

Such ravaging evils as consumption, scrofula, syphilis, and also many forms of mental disorders are transmitted by inheritance to a great extent and transferred by sickly parents to some of their children, or even to all of their descendants. . . hundreds and thousands of incurables-lunatics, lepers, people with cancer, etc., are artificially kept alive . . . without the slightest profit to themselves or the general body. . . Now, the longer the diseased parents, with medical assistance, can drag on their sickly existence, the more numerous the descendants who will inherit incurable evils, and the greater will be the number of individuals again, and over the succeeding generations, thanks to that artificial medical selection, who will be infected by their parent's lingering, hereditary disease. (as cited in Gallagher, 1995, p. 56)

Haeckel believed that certain disabilities were incurable and passed on through hereditary means. He believed this population to be a drain on the economy, and a commission was established to determine which people with deformities, mental illness, and other diseases should be allowed to live or die for what he referred to as “redemption from evil.” Haeckel also advocated for humanitarian reasons that certain people with disabilities should be killed at birth (Gallagher, 1995). This sentiment was essentially mirrored by another German scholar who followed Haeckel, Professor Heinrich Ziegler. Ziegler focused more on people with mental retardation, epilepsy, and alcoholism, stating that these people were primarily responsible for moral decay, murders, and other crimes. Ziegler believed that as crime was hereditary, it was pointless to try to rehabilitate or restrain criminals as they were incurable. He believed that all wrongdoers (e.g., drunks, vagrants, the poor, people with mental retardation or paralysis, and criminals) should be locked away for life and out of sight from the public (Gallagher, 1995).

In 1920, German psychiatrist Alfred Hocke and lawyer Karl Binding wrote what is believed to be a very influential book of its time for Germany: *The Permission to Destroy Life Unworthy of Life*. Both were professors who also believed in Social Darwinism; however, their views regarding natural selection and preservation of the race elevated to a new level. They argued that the medical profession should be allowed to administer a painless death to certain people for racially “hygienic” reasons (Gallagher, 1995). Hocke and Binding's book became influential primarily because a young Adolf Hitler was intrigued by their ideas and in fact endorsed the book.

Through films dealing with topics on euthanasia of people with disabilities, documentaries depicting people with severe mental retardation living in dismal conditions, and other types of propaganda, German society was ready in the late 1920s to embrace a sterilization law. Gallagher (1995) notes that even Nazi schoolroom textbooks illustrated the perceived low value of disabled lives. A mathematics text titled *Mathematics in the Service of National Political Education* (as cited in Gallagher, 1995) cites the following problem: “If the building of a lunatic asylum costs 6 million marks, and it costs

15,000 marks to build each dwelling on a housing estate, how many of the latter could be built for the price of one asylum?" Another problem read, "How many marriage-allowance loans could be given to young couples for the amount of money it cost the state to care for the crippled, criminal, and insane?" (cited in Gallagher, 1995, p. 61).

It was only after the Nazis had assumed full authority in the legislative block that the sterilization program in Germany became law in 1933. During the fall of the same year, the Ministry of Justice under the Nazi-controlled German penal code proposed a law to authorize euthanasia. The news spread and in the United States, the *New York Times* cited details of the proposal, "It shall be made possible for physicians to end the tortures of incurable patients, upon request, in the interests of true humanity." The proposed law, however, was never passed because of outcries from the Catholic and Lutheran authorities (Gallagher, 1995). Despite the failure of the euthanasia proposal, the concept continued to be supported and discussed among politicians, physicians, and scholars. All the while, between July 14, 1933, and September 1, 1939, the Nazis reportedly sterilized 375,000 people classified as congenitally feebleminded (203,000), schizophrenic (73,000), epileptic (57,000), and acute alcoholic (28,000), and those diagnosed with manic-depression, hereditary deafness, hereditary physical deformity, and hereditary blindness. During the same period, Hitler was secretly meeting with Nazi doctors, politicians, attorneys, and scholars to discuss and establish the systematic extermination of German citizens with disabilities.

Finally, on September 1, 1939, Adolf Hitler signed a secret order (unbeknownst to the public) to deliver what was termed "final medical assistance" to German citizens with disabilities. Specially selected physicians were made aware of the T4 killing program and how it was to be carried out. People with disabilities were described as "useless eaters" and "unprocessed inferiors" who drained the economy and burdened society without contributing anything in return. Gallagher (1995), in having reviewed Washington archives as well as the 1946 Nuremberg trial proceedings, notes how efficiently the killing program was run. Essentially, unknowing physicians across Germany were asked to provide lists of their patients with various disabilities. These patients were subsequently rounded up and exterminated, first by gas or injection, and eventually toward the latter part of the program, also by starvation, experimentation, and shooting. Those people with disabilities already in institutions were exterminated in much the same way. In the majority of cases, families were sent an urn of ashes with a letter regretfully indicating that their loved one had died of a contagious disease, and therefore had to be cremated for health and safety reasons.

Despite the remarkable organization of and initial efficiency in carrying out Hitler's secret order, it soon became fraught with problems. First, there was confusion as to who should be placed on "the list." Although Hitler initially excluded German war veterans with disabilities from being exterminated, toward the end of the program in 1941 this was no longer the case. Second, although the program initially began as one in which German citizens with disabilities were exterminated in a nonpainful manner, toward the end of the program they were being starved and shot to death. Third, some citizens who were placed on "the list" were arguably not disabled, especially when considering, for example, those with a single episode of reactive depression over the loss of a loved one but who were otherwise productive individuals. As Gallagher states, "When the German doctors decided to kill their insane patients, they destroyed the lives of many productive,

valuable citizens” (Gallagher, 1995, p. 41). Hence, the age-old debate regarding who was considered to be the weaker section of the species resurfaced and was just as riddled with contradictions as it was in earlier times. By the time the German public became aware of, as well as outraged by, the final medical assistance program, 2 years had gone by, and an estimated 300,000 German citizens and war veterans had been exterminated. Under extreme pressure from both the public and the church, Hitler put an end to the killing of German citizens with disabilities in August 1941.

KEY LEGISLATION AND ATTITUDES IN THE UNITED STATES (20th CENTURY)

Despite the fate of German citizens with disabilities abroad and the popularity of Social Darwinism, more humane treatment and services for people with disabilities were slowly occurring in the United States. As World War I was ending, the implementation of the 1917 Smith–Hughes Act designed to provide funds for vocational training for dislocated industrial workers became law. There was also some recognition that people with certain disabilities had the potential for vocational training (MacDonald, 1944). This was followed up with the 1918 Soldier’s Rehabilitation Act, which was established to rehabilitate veterans with disabilities (Obermann, 1965) vocationally. Arguments regarding the need for a similar civilian program failed to be mandated until 2 years later when the 1920 Smith–Fess Act was passed. The Federal Board of Vocational Education administered the program at the federal level and offered a 50–50 matching state fund split to entice states to participate (Rubin & Roessler, 1995). Watson (1930, as cited in Chubon, 1994) noted how the war positively influenced the attitudes toward people with disabilities as well as increased advances in orthopedic surgery.

Obermann (1965) cited the attitudes of the vocational rehabilitation field during the 1920s as paternalistic toward people with disabilities, and social service employees held stereotypical views of people with disabilities. It was believed that such people were incapable of making vocational decisions; therefore, vocational rehabilitation workers were viewed as all-knowing, not-to-be-questioned specialists who would make decisions for clients with disabilities. These attitudes have become more popularly known as stemming from the medical model paradigm and unfortunately are still held by some helping professionals even today (Trieschmann, 1988).

Politically, little else happened in securing greater funding for people with disabilities until President Franklin Delano Roosevelt (FDR) took office in 1932. Roosevelt had taken office in the midst of the Great Depression and was intent on providing economic relief for the disadvantaged, poor, and homeless. He did this by signing into law the historic Social Security Act of 1935, which also made the federal vocational rehabilitation program permanent. Roosevelt himself had contracted polio at age 39 in 1921 and was keenly aware of not only the lack of services but also the attitudes toward people with disabilities (Rubin & Roessler, 1995). In his book *FDR’s Splendid Deception* (1994), Gallagher describes how FDR had an understanding with the news media that he was never to be photographed or filmed sitting in his wheelchair. Although Roosevelt ambulated by wheelchair and leg braces, he was always photographed or filmed standing at the podium or in his car meeting the public without any assistive device. He believed

that the public would perceive him as a weak leader should it ever be known that he was disabled. With his condition, FDR also experienced a great deal of pain and spent much of his time in the therapeutic warm spring pools in Warm Springs, Georgia, which he later purchased and ran in 1927. Roosevelt spent so much time here, it became known by insiders as the “Little White House.” Despite his disability experience, Roosevelt did not specifically have a disability agenda. His interest was more with the poor and disadvantaged, and he even proposed a 25% reduction in funding the vocational rehabilitation program: an effort that did not pass Congress. It is ironic to note that FDR’s disability secret and fears of being discovered and perceived as weak is not how the public remembers him today. Having brought America through the Depression, passed the historic Social Security Act, and brought the United States through World War II, FDR is believed by many to be one of the greatest presidents this country has ever had.

World War II had a significant impact on the services, treatment of, and attitudes toward people with disabilities. A major development was the fact that over 12 million Americans went into the military, which freed up jobs in the civilian economy (Levitan, Mangum, & Marshall, 1976). Yelin (1991) cited that in all of the 20th century, people with disabilities had the highest employment rate during World War II. Yelin noted how the simple principles of supply and demand dictated what employers needed to do during the period. People with disabilities were hired in many of the factories that made products for the war. Unfortunately, once the war was over, many of the able-bodied males and females who returned home ultimately displaced employees with disabilities, once again increasing the high unemployment rate of this population, which continues to hover around 70% to the current day.

Following World War II, there continued to be medical advances that improved the life expectancy of certain disabilities, especially those with physical impairments such as spinal cord injury. Legislatively, the 1943 Barden–LaFollette Act extended rehabilitation services to people with mental retardation and mental illness. In addition, the first federal-state rehabilitation program for the blind was approved and continues today as a separate program. Services for people with mental retardation and mental illness were further expanded in the 1954 Vocational Rehabilitation Act Amendments (Parker & Szymanski, 1998). This Act also saw first-time funding for three universities to prepare training rehabilitation professionals to provide primarily vocational counseling for people with disabilities.

Although other disability-related legislation ensued over the subsequent two decades, the later key disability legislation came about with the 1973 Rehabilitation Act. Before this, the United States experienced the long overdue growing pains of the civil rights movement, culminating in the Civil Rights Act of 1964. This Act mandated equal treatment and opportunities for African Americans and other minorities. The women’s rights movement also occurred during this period, again demonstrating the effectiveness of peaceful, social activism as a powerful way to facilitate social change through federal government intervention (Rubin & Roessler, 1995). In addition, during the 1960s, consumerism and the consumer rights movement led by Ralph Nader demonstrated that consumers needed to be actively involved in the type and quality of services they received. These movements had a significant impact for people with disabilities who also continued to be disenfranchised from participating in employment, housing alternatives, and voting, as well as socially.

The Rehabilitation Act of 1973 was historic for several reasons. The first was the fact that President Richard Nixon was not a fan of vocational rehabilitation and wanted to cut funding. He had also previously twice vetoed bills to establish independent living centers, but finally agreed to fund a comprehensive needs assessment and six independent living center demonstration projects in 1973 (Rubin & Roessler, 1995).

Second was the establishment of Client Assistance Programs (CAPs), designed to advise clients of various services, and for counselors to act as ombudsman or mediator in situations where clients experienced problems in obtaining services for which they might be entitled. The Rehabilitation Act of 1978 gave further strength to CAPs by including assistance for legal remedies to ensure the rights of clients with disabilities. The third key aspect of this 1973 legislation was the implementation of the Title V Sections 501 to 504. Section 501 of the Act limited discrimination in any federal hiring, placement, and advancement of “qualified” people with disabilities in employment. In addition, affirmative action plans had to be developed for each government agency. Relatedly, Section 503 of the Act limited discrimination by private employers who received federal funds of \$2,500 or more. Although these actions were initially good first steps, private businesses that did not use federal funds were still allowed to discriminate against hiring qualified people with disabilities. The fourth key aspect of the 1973 legislation involved Section 502, where the Architectural and Transportation Barriers Compliance Board was established to ensure compliance with the Architectural Barriers Act of 1968. This Section also involved investigating transportation and housing barriers/needs, as well as promoting the use of the international accessibility symbol in all public buildings (Jenkins, Patterson, & Szymanski, 1998). Section 504 addressed equal opportunity and discrimination against people with disabilities in education programs, health care, housing, and employment. Regarding the employment provision, an individual could not be found unqualified if a reasonable accommodation could otherwise make the individual qualified to perform a particular job unless it caused the employer undue hardship (Rubin & Roessler, 1995). Again, although these were encouraging changes toward ensuring the civil rights of people with disabilities, they were limited to only those entities receiving federal funds.

The Independent Living Movement

The independent living movement essentially evolved as people with disabilities learned from the social activist movements concerning minority civil rights, consumerism, and women’s rights. Leading to the independent living movement, many people with disabilities were becoming frustrated with how society both viewed and treated them. People with all types of disabilities found themselves trying to negotiate an able-bodied world in which public phones were inaccessible to those who were deaf, buildings and transportation were inaccessible to those with physical disabilities and blindness, and segregation in schooling existed for those with mental and physical disabilities, especially those of ethnic minority status (Sue & Sue, 1999). Many people with disabilities were also angered by societal attitudes of them being incapable, sick, and helpless (DeJong, 1979a). Those with disabilities began to realize that in many instances, they knew what was best for themselves and that rehabilitation and medical professionals were not empowering them to live independently. Echoing this notion, DeJong (1979b)

cited three propositions that essentially described the philosophy of independent living: (a) consumer sovereignty—people with disabilities know best what their needs are; (b) self-reliance—people with disabilities must rely on themselves for their self-interests; and (c) political and economic rights—people with disabilities have the right to participate in economic and political life (Nosek, 1998).

DeJong (1979b) conceptualized the independent living movement as a paradigm in direct opposition to the medical model or traditional rehabilitation paradigm. In comparing the two, the independent living paradigm views environmental barriers and societal attitudes as the definition of what the problem is, whereas the medical model paradigm views the individual's disability and functional limitations as being the problem. The person with a disability is viewed as the "patient," with its implications of passively and unquestionably accepting what the professional advises in the medical model paradigm; however, in the independent living paradigm, the individual is viewed as a "consumer" of services, thereby needing to be informed of alternatives in order to select what he or she believes is the best alternative. In addition, within the medical model paradigm, the physician or rehabilitation counselor is supposedly all-knowing, and in control of making decisions he or she believes are in the best interest of the patient; however, in the independent living paradigm, the consumer is in control of ultimate decisions concerning his or her welfare. In solving the problem, the medical model paradigm views the rehabilitation team (physicians, therapists, rehabilitation counselor, and so forth) as having the ability to minimize the physical or mental impairments. Under the independent living paradigm, the solution revolves around self-help, advocacy, peer counseling (from others with disabilities who have negotiated the system in the community), and the removal of environmental obstacles and societal attitudes. Today, these extreme viewpoints have moved closer to the center in that consumers are more often being included and consulted in decisions about their welfare by the rehabilitation team.

The earliest origins of independent living came in 1962 when four students with physical disabilities at the University of Illinois at Champaign-Urbana advocated being moved into a home with attendant care rather than remain in a nursing home. After President Nixon funded the first six Centers for Independent Living (CIL) demonstration projects in 1973, the one located in Berkeley, California, assisted several students with physical disabilities to also relocate from the University health center wing to apartment housing with attendant care services (Nosek, 1998). Today, there are approximately 400 CILs in the United States offering by the mandate for federal funding at least four core services: peer counseling, information and referral, independent living skills training (essential activities of daily living), and community advocacy. Many CILs across the country offer other services, such as housing assistance, transportation services, equipment maintenance, attendant care or referral, financial and legal advice, community awareness in education, interpreter services, and other types of assistance (Nosek, 1998). In addition, many of the staff at the centers should ideally be people with disabilities, including its executive director; however, this is not always the case. Furthermore, the board of directors for the centers must consist of at least 51% of people with disabilities to continue to receive federal funding (Marini, 1994).

Psychosocially, the independent living movement and employees of CILs have done much to empower people with disabilities to live independently and accept control over decisions in their lives. Groups such as the Americans with Disabilities for Attendant

Programs Today (ADAPT) have forged ahead with effective demonstrations to create accessible transportation in various cities, and more recently have campaigned against forcing people with disabilities of all ages who need assistance with activities of daily living to go into nursing homes. ADAPT and others have advocated for the reallocation of some of the money earmarked for nursing homes to go toward a federally funded community-based attendant care program in which people with disabilities can choose where they want to live. Several demonstration projects have shown this to be a cost-effective and preferable option for people with disabilities.

Other Key Disability-Related Legislation

Other key legislation occurring in the 1970s was the 1975 Education for All Handicapped Children Act (subsequently called the Individuals with Disabilities Education Act of 1991). This Act provides equal rights and equal opportunities in education for students with disabilities in the “least restrictive environment” (e.g., mainstreamed or integrated into a regular classroom as much as possible). The Act also calls for an Individualized Education Plan (IEP) designed to follow, assess, and treat students with disabilities throughout their public schooling, whether the service is therapy, career counseling, or specialized teaching/tutoring. In addition, a student is monitored and prepared for the transition from school to work with a vocational rehabilitation counselor as part of the transition team. Research had previously shown that more than 80% of all special education graduates were neither employed nor in school 1-year postgraduation, with long waiting lists for entry into sheltered workshops.

The 1978 Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments Act expanded reader services for people who are blind and interpreter services for those who are deaf and established independent living services as part of the state-federal rehabilitation program. The National Institute of Handicapped Research (now retitled as the National Institute on Disability and Rehabilitation Research) was established, as was the National Council on the Handicapped (renamed the National Council on Disability). The Rehabilitation Act Amendments of 1986 established supported employment services, primarily for those with psychiatric disabilities, mental retardation, and head injuries. Also in 1986, the Air Carrier Access Act made Section 504 clear to all federally funded airlines that they could not discriminate against people with disabilities. Similarly, the 1988 Fair Housing Act Amendments was the first federal law that extended nondiscrimination mandates to the private sector, regardless of whether they received federal funding (West, 1991). This mandate was intended to ensure accessibility standards for all new multifamily dwellings.

The 1990 Americans with Disabilities Act (ADA) is considered to be the most significant all-encompassing civil rights legislation for people with disabilities to date (West, 1991). Leading to its passage, there was overwhelming evidence collected by Congress confirming that people with disabilities had historically been segregated and discriminated against regarding employment and social participation. Rubin and Roessler (1995) noted that there were 11 public hearings where testimony was gathered as well as 63 public forums covering all 50 states. Some of Congress’s concluding results at the time indicated the following: (a) There were more than 43 million Americans with disabilities, and this number was growing because of an aging population; (b) people with disabilities

had historically been segregated and discriminated against in areas of employment, education, housing, transportation, communication, recreation, public accommodations, institutionalization, voting, health services, and access to public services; (c) census data and national polls indicated that people with disabilities were disenfranchised socially, vocationally, economically, and educationally; and (d) people with disabilities were treated as a minority group without equal rights or opportunities, ultimately costing the United States billions of dollars to keep this population dependent and nonproductive.

Despite business and other lobbying groups advocating against the ADA because of fears of its costs and that small businesses would suffer financial hardship making accessibility accommodations, President George Bush signed the bill into law on July 1, 1990. The ADA contains five titles. Title I concerns employment and both strengthened and expanded the 1973 Rehabilitation Act against discrimination of “qualified” (must be able to perform the essential functions of the job) people with disabilities in hiring, training, discharge, and promotion policies (Adams, 1991). The Act was expanded to businesses with 25 or more employees in 1992, and again in 1994 for businesses with 15 or more employees (West, 1991). Employers had to make reasonable accommodations for employees with disabilities unless such changes would cause the employer undue hardship (financial hardship or accommodation that would negatively affect the business). They were also prohibited from asking questions about one’s disability in a job interview or having them submit to a medical exam without making all job applicants do the same.

Title II of the ADA contains two subtitles. Subtitle A extends Section 504 of the 1973 Rehabilitation Act prohibiting discrimination against people with disabilities in state and local government public entities receiving federal funds that provide programs, activities, or services (West, 1991). Subtitle B requires public transportation systems and facilities receiving federal funds to become accessible. This includes new railway cars as well as local and national route buses. Despite Subtitle B’s intended mandate, many smaller cities and rural areas continue to have inaccessible public transportation because of the presumed undue hardship it would cause the municipalities.

Title III deals with prohibiting discrimination against people with disabilities concerning public accommodations, covering all entities where the general public has full access to services and enjoyment. This is inclusive of all theaters, sports facilities, hotels, restaurants, museums, auditoriums, parks, day-care centers, gymnasiums, and so forth (West, 1991). Architectural barriers must be removed unless business owners can show undue hardship in making the required changes. Excluded from the Title III mandate are religious entities such as churches and private clubs. Unfortunately, as late as 2008, many people with physical disabilities still report that the top causes of frustration and anger for them are environmental barriers and negative business attitudes toward making the necessary accommodations mandated now some 20 years later (Marini, Bhakta, & Graf, 2009).

Title IV of the Act pertains to increased access to telecommunications for people who are deaf. This involves the availability of dual-party relay service systems where those people using a telecommunication device for the deaf (TDD) could communicate through the phone via an operator trained with the system (Hearne, 1990). Accompanying this legislation was the Television Decoder Circuitry Act of 1990 requiring all new televisions larger than 13 inches to come equipped with closed captioning.

Title V covers miscellaneous provisions that include personal behaviors not covered by the ADA. These include individuals who are currently engaging in illegal drug use, homosexuality, bisexuality, transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders, compulsive gambling, kleptomania or pyromania, and other substance abuse disorders resulting from illegal drug use (Jones, 1991). Title V also requires the Architectural and Transportation Barriers Compliance Board to set out guidelines on how historic buildings are made accessible. Section 507 requires a study to be conducted by the National Council on Disability regarding access by wheelchair users in wilderness areas. A confusing point about provisions in Title V is that no effective-date section was included; however, others argue that the enactment date was effective after the ADA was signed into law.

During the past quarter-century, Americans with disabilities have forged ahead in testing the ADA and “tweaking” it to fight for their civil rights. They have fared better in some arenas than in others. Blackwell, Marini, and Chacon (2001) researched the number and types of ADA lawsuits since the Act’s inception and found that people with disabilities were experiencing poor success with Title I filed complaints. Herman (2000) cited a 2000 issue of *Mental and Physical Disability Law Reporter*, which indicated that employees won their discrimination lawsuits only 5% of the time during the past decade. Individuals who instead had the Equal Employment Opportunity Commission (EEOC) handle their case fared a little better as 15% of these cases were in favor of the employee. The primary reason cited for the poor success rate was employees’ ignorance regarding court procedures and technical legal requirements of the ADA for those claiming workplace discrimination. Another interesting finding was that the majority of Title I complaints were from existing employees with less severe disabilities attempting to keep their jobs as opposed to new applicants suing for discrimination.

Other areas of the ADA that have been consistently challenged pertain to Title III on public accommodations. Marini (2000a, 2000b, 2002a; Marini et al., 2009) cites numerous cases and consumer frustration regarding businesses electing to fight the finer details of the ADA by challenging it in court. Airlines have been sued for not allowing wheelchair users to store their chairs in the closet. In addition, flight crews have forgotten disabled passengers onboard for extended periods after the plane has landed. In other areas, the first movie theater chains that began building stadium-style seating initially only designated the very front row of the theater (arguably the worst seats in the house) for wheelchair users. The courts have upheld wheelchair user complaints, concluding that people with disabilities must be afforded “similar lines of sight” (equal access to the best seats, which have been determined to be 1/3 to 1/2 the way from the front row) as non-disabled patrons (Gilmer, 2000). Other Title III legal battles include international cruise ships not having to abide by the ADA regulations despite the fact that they dock and pick up U.S. passengers constantly, or major retail stores crowding their aisles with merchandise racks, thereby restricting wheelchair access. Hotels have also been sued for not securing prior reservations of accessible rooms. Wheelchair users complained of being stranded upon arriving at hotels where they had previously reserved an accessible room, only to find the room had been rented out. Similarly, various hotel chains have been sued for inaccessibility, or for too few rooms designated as accessible (Marini, 2000a). Finally, in sports, the U.S. Supreme Court ruling on *PGA (Professional Golf Association) Tour, Inc. v. Martin* (Marini, 2000a) permitted professional golfer Casey Martin to ride in a golf cart

between shots at PGA Tour events. Association officials had argued that allowing Martin to ride a cart while other golfers could not gave Martin an unfair advantage (Blackwell et al., 2001). The Court ruled, however, that under the ADA, this was a reasonable accommodation for Martin to be able to play the game. Martin's disability makes it painful for him to walk long distances and places him at risk of injury.

The last piece of legislation related to the ADA was the Americans with Disabilities Amendments Act of 2008 (PL 110-325, S3406) enacted by Congress largely because of some lower courts having slowly, but gradually, marginalized the full intent of the ADA. Perhaps one of the most egregious and deadly aspects of disability in America in 2017 is the ongoing fight for emergency preparedness and disaster relief. Despite President Bush's Executive Order on July 22, 2004, and the Post-Katrina Emergency Management Reform Act of 2006 designed to plan and implement emergency evacuation and shelters for people with disabilities, these orders have been slow to be implemented or implemented at all in many cities across the United States (Weibgen, 2015). In Weibgen's *Yale Law Review* article, he discusses the cases of New York's tropical storm Irene in August 2011 and tropical storm Sandy in October 2012.

Weibgen (2015) noted the uncoordinated and catastrophic failings of New York City's emergency response and shelter accommodations following Irene, and by the time tropical storm Sandy hit 14 months later, there remained significant gaps in policy and procedural coordination. In the *Brooklyn Center for Independent Living of the Disabled v. Bloomberg* class-action trial, Judge Furman found the city of New York guilty of not providing adequate emergency response and shelter to its residents with disabilities. Specifically, the judge found Mayor Bloomberg/the city negligent for (a) waiting almost 2 weeks to send responders to check high-rise buildings without power; (b) cutting all transportation; (c) giving 911 and 311 operators no information on how to evacuate people in wheelchairs; and (d) not having a coordinated plan to evacuate those with disabilities. In his ruling, Judge Furman cited discrimination that resulted from "benign neglect" of those with disabilities. He indicated that the shelters and evacuation centers were inadequate and/or inaccessible to the needs of those with disabilities; evacuation should occur before and not after a disaster; canvassing efforts with trained personnel had to be improved; and that people or entities representing those with disabilities had to become part of first response training and planning efforts. Weibgen stated this ruling was the first and most encompassing of only two such successful plaintiff cases regarding emergency response and shelters. He claims that when it comes to disasters, people with disabilities are often viewed by many as the least worthy of saving. This sentiment echoes across industries where airline policies are that in the event of an emergency, those with disabilities will be assisted only after all able-bodied people are evacuated.

Today, most cases are mediated without going to court as businesses forcefully must make required changes that they have ignored for the past 27 years. However, some continue to not only flagrantly violate the law but also fight making the required changes until mandated by the courts. Blackwell et al. stated, "Although the government can legislate laws, it cannot legislate peoples' stereotypical or sometimes prejudicial attitudes. These attitudes result from misunderstanding and discrimination and result in low expectations about things people with disabilities can achieve" (Blackwell et al., 2001, p. 405). Much like the 1964 Civil Rights Act, the 1990 ADA in all likelihood will be the

first and last major civil rights legislation for those with disabilities despite the ongoing areas and issues that remain barriers to full participation for those with disabilities (Graf, Marini, & Blankenship, 2009).

The final piece of legislation that indirectly impacts people with disabilities is the recent Workforce Innovation and Opportunity Act (PL 113-128) signed into law by President Obama in 2014 and taking effect Fall 2016. Among many changes in providing services for people with disabilities, the public sector Vocational Rehabilitation Program that provides rehabilitation guidance and counseling, among other services, to assist those with disabilities to find jobs and live independently has been subsumed into a one-stop center; whereas vocational rehabilitation counseling has for over a decade been a standalone service provided by master's-level trained, and mostly nationally certified, rehabilitation counselors, the new WIOA waters-down who is now qualified to provide these specialized services. Specifically, the new law allows for the hiring of individuals with a baccalaureate degree in a field such as economics, business, and marketing. Numerous dissenters commented on this regulation, noting the specialized training to become a rehabilitation counselor involves knowledge of the medical aspects of how various disabilities functionally impair an individual's ability to perform certain jobs. The field of rehabilitation counseling also includes training regarding the psychosocial adjustment to disability, job placement training, learning how to perform and interpret vocational assessments, and knowing how to match a client's residual abilities to jobs that his or her clients would be physically and mentally capable of performing. By opening the door to hire lesser educated individuals with little to no knowledge about the capabilities of those with disabilities is not only degrading to the profession but also ultimately harms those with disabilities in their pursuit of adequate employment (McClanahan & Sliger, 2015).

IMPLICATIONS AND THE FUTURE OF DISABILITY: REVISITING DARWIN AND EUGENICS

Have we learned from our past? As we begin to enter a new era of being able to determine that a mother's unborn fetus carries the gene for a congenital disability such as mental retardation or muscular dystrophy, parents and their physician can decide early on whether to abort and start over. The gene(s) responsible for later-in-life neuromuscular diseases, such as Alzheimer's or Huntington's disease, will soon be able to be eradicated as well. Similarly, extracting stem cells from aborted fetuses or growing them in a Petri dish may help millions of people with neuromuscular diseases such as Parkinson's as well as spinal cord injury and other disabilities. Couples today can also choose to have a designer baby by being impregnated with eggs for sale by a supermodel if they desire (Wilson, 1999). Smart (2009) cited an October 1999 Associated Press story about a *Playboy* photographer who started a website selling supermodel eggs. In just the first morning of bidding, 5 million people visited the site with the highest bid for an ovarian egg from the supermodel listed at \$42,000. In another process called pre-implantation genetic diagnosis, parents can choose their child's gender, and have their unborn fetus genetically altered for eye or hair color. Cloning also appears to be inevitable. Some scientists indicate that various diseases and disabilities may be eradicated

by harvesting and extracting healthy cloned body parts and implanting them in their disabled host. Finally, some surveyed physicians have anonymously indicated that they have assisted terminally ill patients to end their lives as well as having not provided life-sustaining assistance for newborns with severe congenital disabilities (Singer, 1995). Are these changes viewed as a step forward or backward in human development? This is not easily answered. Olkin (1999) states that by preventing babies with disabilities from being born, and because of advertising or charity drives portraying the “suffering” of people with disabilities, society negates the very existence of those with congenital disabilities and conveys the message of the disabled being better off not existing at all than to exist with a disability. As Olkin, who was born with polio, indicates, however, most people with disabilities would not have chosen to be aborted and do not consider themselves to be suffering.

Nevertheless, with genetic testing becoming more common, would-be parents are rarely counseled to carry an unborn fetus suspected of a genetic defect. Roberts, Stough, and Parrish (2002), for example, found that of high-risk women referred by their physicians for genetic testing, 65% indicated they would abort if there was a defective gene found. Those women who were provided additional information about the potential disability her child might have were more likely to continue with the pregnancy. The women also reported that no real effort was made to educate or discuss the pros and cons of raising a child with a disability. Such findings beg the question: “Do any of us have the right to impose our values to assume what does and does not make life worth living or know what is best for parents?” These are questions bioethicists and society morally grapple with as we continue to advance the medical sciences.

In the first few pages of her book *Disability, Society, and the Individual* (2009), Julie Smart contemplates, “What is normal?” She indicates that normal is often defined as the absence of deviance or disability. *Webster’s Dictionary* defines the word *normal* as “conforming with or constituting an accepted standard, model or pattern; esp., corresponding to the median or average of a large group in type, appearance, achievement, function, development, etc.” (*Webster’s Dictionary*, 1980, p. 970). Smart (2009) argues that typically the majority culture or those in power are the ones who define what is normal. This was also the mindset a century ago among primarily White Anglo-Saxon male academics, politicians, and physicians in power who contemplated who the weaker section of the species was who should be prevented from procreating. Similar logic also epitomized Nazi Germany’s extermination program in pursuit of the superior race in the 1930s and 1940s.

We continue to revisit this issue today as eugenicists proclaim the decline of civilization. Van Court (1998) notes that civilization depends on innate intelligence and that ancient civilizations fell when intelligence declined. Of course, there is no empirical way to prove this assertion. Herrnstein and Murray, in their controversial 1996 book *The Bell Curve*, conclude that with the sample they studied, a majority of social problems occurred when the average IQ in their sample dropped three points from 100 to 97. Princeton University professor Peter Singer continues to draw criticism from disability advocates for his views that fetuses with genetically detected disabilities should be aborted and that parents should have the right to terminate the life of their severely disabled infant within 30 days of its birth (Marini, 2002b).

Recently, the science of eugenics has focused more on IQ arguments and the science of “dysgenics.” Dysgenics refers to the study of intellectually superior scoring people having fewer children, while uneducated or lower IQ parents are having more children (Lynn & Van Court, 2004; Lynn & Vanhanen, 2002; Van Court, 1998). Specifically, in Lynn and Vanhanen’s (2002) book *IQ and the Wealth of Nations*, the authors argue that the decline of IQ is correlated with an increase in crime, high unemployment, greater poverty, and dependence on welfare by many single mothers. Conversely, of the 81 countries assessed, those with higher IQs had higher levels of education, had greater economic success, and made more contributions to their social infrastructure.

CONCLUSION

Ironically, because of medical advances, the life expectancy and quality of life for people living with disabilities in industrialized nations continue to improve from a medical perspective for those who can afford health care. To this end, the United States continues to arguably have a “survival of the economically fittest” mentality if universal health care is not soon realized. For the estimated 76 million baby boomers presently transitioning to retirement, the golden years may not be something to look forward to given the increasing health care costs. In 2010, President Obama became the first president since FDR to pass a major health reform bill, but with health insurance companies arguably still largely in control and Congressional Republicans always looking to repeal health care, the resulting impact remains to be seen.

Finally, as far as our current medical capabilities to genetically screen out and abort fetuses with a potential disability gene, it is difficult to think of a world without the likes of Franklin D. Roosevelt, Stephen Hawking, Beethoven, Albert Einstein, Stevie Wonder, Wilma Rudolph, and the thousands of other gifted people born with congenital and adventitious disabilities who have undoubtedly positively influenced the human condition. Nevertheless, the Darwin debate continues today in the eugenics guise of genetic screening and humankind’s ongoing quest for the perfect being as well as the survival of the financially fittest.

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INSIDER PERSPECTIVE

The Story of Patricia E. Moniot

I am writing to let people know that life can be lived despite a mental disability, and they are not alone. There are others who have survived rock-bottom conditions of life and built a productive lifestyle with the help of professionals, other mental health consumers, and supportive family and friends.

My particular brand of disability is a bipolar affective disorder, manic-depressive illness. The disease first manifested itself in 1968, after my graduation from college. I had earned my BA in mathematics and was preparing to attend the University of Detroit, where I had a fellowship for my PhD. However, I had a serious bout of manic-depressive illness, and my parents drove me back to Jamestown and soon put me at Gowanda Psychiatric Center for 2 months in 1968 because they had no health insurance.

I knew something was wrong when my parents and I stepped off the elevator. A young man lounging against the wall was grinning ghoulishly at me. His eyes flashed a greeting: Welcome to Gowanda's Little Shop of Horrors. I felt like a new, uninitiated inmate of an insane asylum for the first time. My impulse was to turn and run, but the elevator had gone down, and the doors were locked. I clung to my belief that I was only physically ill, in danger of dying, and in a true hospital where I would receive the best and quickest care.

In the doctor's office, I told Dr. Battersby that I felt like I was going to die. By reading upside down, I was able to see the doctor write "hypochondria" on my admission form. I would later wonder why a hypochondriac would be given 900 mg of Thorazine and 900 mg of Stelazine on the first day before any tests had been given.

My parents, full of misgivings, left for home. Two nurses took me into a large, white room to be admitted. I was feeling faint and nervous. They could not get a blood pressure reading on me with either of the two blood pressure machines. Subsequently, they told me to take off all my clothes, including my glasses and watch. I had never been naked in front of anyone, and I could not see without my glasses. In terror, I refused to strip unless they got me a robe. The nurses were angry, but they did give me a robe. When they unfolded a sheet on the floor and tied up all my belongings in it, I did not know that they needed to mark everything; I thought they were trying to cause me grief and pain.

After I was weighed and my temperature was taken rectally, they deposited me in a single room. I felt for a moment that I was going to be okay: I had a room and nurses to take care of me. That's what I thought! In fewer than 5 minutes, a barefoot old hag of a patient shuffled into my room and made off with my shoes and glasses. I was forced to run after her and grab them back. Then the nurses told me to go into the day room and get acquainted with the other patients. I was shocked by what I saw.

The kleptomaniac who had taken my glasses and shoes was shuffling around, gathering up all the ashtrays and dumping them into the window sills. There were bars on the windows, which let in very little air. The room was blue with smoke from patients' and nurses' cigarettes. There was a stench of urine. Several women in nightgowns were sitting around with their heads hanging down. I felt like I had died and gone to hell, rather than being treated in a hospital, as I had expected.

I was unable to walk down the halls because I was light-headed, dizzy, and restless. To cross the day room floor, I had to run. To go to the dining room, I had to crawl on my hands and knees, unless I could hold onto the arm of a patient. I was so utterly humiliated by this crawling that I would always end up crying and losing my appetite.

The bathroom was a long white room with a row of 20 toilets along one side. There were no lids, seats, doors, or partitions in the toilets. Therefore, there was no privacy. Toilet paper was locked up in the nurses' station.

We, patients, were herded around for medication, meals, and allocation to our cots in the wards. During a blizzard, we found that the wind was blowing drifts of snow into our bedrooms, and there were only a few blankets available.

One of the patients was very obese and had to be helped off the toilet and off her chair. The nurses were always yelling at her. One day the lady had a heart attack and collapsed on the day room floor. For 3 hours the nurses walking by would kick her in the side and say, "Get up, Michaeline! Get up, you lazy pig!" Finally, a nurse checked her vital signs and started to yell, because the lady was not alive, and the nurses were in trouble. After that, we did not feel secure that we would get well and leave the hospital

alive. I did not think that the nurses liked us; all they wanted to do was smoke cigarettes in the nurses' station.

After being in Gowanda for 2 months, I worked hard on my own to learn to walk. I started to say things to please the doctor, who appeared twice weekly to ask me how I was doing. I do not remember any therapy that helped me. Aggressive patients dominated the group meetings. To help my coordination and concentration, I learned to crochet and did other crafts each day; and I made myself slippers and doll clothes. I think that the knowledge that my family, who visited me every weekend, would be waiting for me, and that the other patients were kind to me, kept me going and were the most important factors in my recovery.

From 1968 to 1973, I tried to establish my residence in Buffalo and get a job. However, I returned again and again to Buffalo's institutions and lived briefly in various group homes.

After 5 years in institutions and group homes, my parents brought me home and put me to bed. I remained in depression for 3 solid years, never leaving my room, except for meals and personal needs.

In 1976, I was invited to play the organ at our church. At last, there was a light at the end of the tunnel. I was inspired to try moving into the sunlight, and my depression lifted through the healing influence of music.

Soon I moved into a tiny attic apartment in Jamestown. I started out with three old saucepans and a floor lamp donated by my mother. At the time, I was thrilled with these awesome gifts. Looking back, I think a "coming out shower" would have been better. I lacked many living skills that I was not taught in hospitals, such as lighting pilot lights, assembling appliances, and setting digital clocks. The Friendship Peer Support Line and the Southwestern Independent Living Center were helpful in managing questions like these.

In my tiny attic apartment, I felt isolated. I coped by calling the Crisis Line, taking walks, and visiting the library. I became restless. I asked about a volunteer clerical job at Jamestown General Hospital. A wonderful lady named Helen took me under her wing and taught me outpatient billing. One year later, I went from volunteer to paid employee by passing a Civil Service test and by demanding to be hired when an opening occurred. I worked there for 12 years, learning to use a computer and how to deal with the public, especially the elderly or disabled.

My counselor advised me to seek job training through the PIC (Private Industry Council) programs. The first step was to take an aptitude test; I found high scores in clerical and music interests. The counselor, John Theismann, was polite and elevated my self-esteem by his attitude of respect. He placed me in a keyboarding class, where I was uplifted by a quick increase in typing and computer skills and had a good time.

In a few weeks, PIC placed me in a supported position at the United Way Project DIAL office. My supervisor there, Judith Brentley, trained me gently to perform referrals to agencies using a computer. Eventually, I was able to produce a volunteer training manual for office use.

The entire PIC program was positive and made me feel competent. The job was a stepping stone. Years later, when I had won other positions, PIC declared me a success and put my name in their Hall of Fame.

Another program in which I was rehabilitated was vocational and educational services for individuals with disabilities (VESID), the State Education Department of Vocational

and Educational Services for Individuals with Disabilities. The VESID program trained me in clerical skills at the Niagara Frontier Vocational Rehabilitation Center in Buffalo, New York. My clerical supervisor regarded me as intelligent and worthy of obtaining a secretarial position. The VESID personnel were kind and patient, even though my behavior was altered by medication problems. My self-esteem rose when I could type 65 words per minute, and I produced a regular newsletter, *The Rehab-Ability News*, written by disabled clients. I felt comforted by the feeling that the personnel cared and believed in me. I used my clerical skills in all the jobs I have had since then. In my present position, I send invoices to both PIC and VESID to cover the transportation costs of other clients participating in these programs.

In 1985, I was correctly diagnosed with bipolar affective disorder, and I have been well ever since on lithium, learning to drive a car, and living independently. My goal is to remain employed and to continue my volunteer work.

My favorite ways of thanking God for bringing me through these obstacles are playing the piano in nursing homes, working in agencies that provide services for the elderly and disabled, advocating for handicapped people through writing on their behalf, surprising the lonely and poverty stricken with special cards and gifts, and being supportive by phone to housebound friends. These activities are my way of adding joy and meaning to my life.

Writing has become one major outlet for my energy, a way to capture on paper memories of long ago, and a way to share an account of my ongoing recovery from mental illness. Like the large, light snowflakes on the first day of winter, my ideas drift down and land on my notebook with almost no effort at all.

I have a message to mental health professionals about the needs of their clients and patients. It may well be misunderstood by anyone who has not experienced mental illness himself, although the disabled have shown that they understand. Here is a list of our needs in counseling sessions:

1. Give the patient a large appointment card that is not likely to be lost, or use a calendar page with appointments and family events marked on it.
2. Praise the patient when he/she makes it on time to your office.
3. Offer the patient a free cup of coffee or other drink, for it may be difficult for him or her to talk at length. Having coffee is a symbol of friendliness.
4. Be on time yourself; this will set a good example for promptness. The patient has a schedule, too, and his or her time is valuable.
5. Do not label the patient "discourteous" or "lazy" if his or her illness contributes to his or her inability to show up. Believe that he or she is sick and cannot always get to a phone. Do not expect the patient to think correctly at all times.
6. Be careful not to complain about how much money is lost when a patient fails to show up. This promotes resentment and guilt.
7. Explain about the waiting list; the patient will realize that his peers may be denied treatment because he or she did not call to cancel his or her appointment.
8. Contact friends or relatives who can be relied on to remind the patient of his or her appointment.

I close with a list of 10 most urgent needs of consumers who were deinstitutionalized and are now living independently in the community:

1. Preventing a problem from becoming a full-blown crisis
2. Coping with small-scale manic or depression moods
3. Discussing living skills
4. Regaining a sense of safety or security
5. Obtaining comfort in the middle of the night
6. Choosing services through referral information
7. Confiding feelings about relationships
8. Confessing fears and deciding if there is a real crisis
9. Relaxing with “shrink” jokes and using humor to minimize anxiety about treatment
10. Unburdening memories of the old institutions

We just want a vehicle where we can express our thoughts and feelings in a friendly, non-judgmental atmosphere. We want others to deal with us on the strength of our character, not by our labels as mental health consumers.

DISCUSSION QUESTIONS

1. Do you believe we should put a limit on the number of children disabled people or others who do not contribute to society traditionally (e.g., collect welfare, etc.) can have?
2. What is your opinion regarding physician-assisted suicide? Under what conditions would it be okay, and are we on a slippery slope?
3. Should we allow embryonic stem cell surgery to help treat neuromuscular diseases and other disabilities?
4. Is genetic testing a good idea, and what would you do if you were told your child was going to have Down syndrome?
5. If you could select your unborn baby’s characteristics, what would you choose (e.g., eye color, gender, height, IQ, hair color, skin color, or any particular abilities)?

EXERCISE

- A. The class represents politicians, academics, physicians, and attorneys from 1895 debating which people comprise the weaker section of the species who should start being sterilized. Four examples are brought up: (a) a welfare single mother of four children; (b) a physician who has epilepsy; (c) a professor who is paralyzed from an accident and requires an attendant; and (d) a physically healthy homeless male.