

Part I

Context for Practice

One of the most important tools for effective human service practitioners is an understanding of our personal values. This particularly holds true for those who work with persons with disabilities. Our internalized values and beliefs come from a variety of sources, including the aggregate culture, various subcultures, family teaching, life journeys, and educational experiences. Values and beliefs concerning disability affect the work that you will be doing with one of the largest minority groups in the world—persons with disabilities.

To understand personal views regarding persons with disabilities, it is necessary to explore the various ways societies and cultures perceive persons with disabilities. This understanding is also extremely important in determining intervention approaches and activities that facilitate or support the development of enfranchised, empowered, and independent human beings.

How does the society in which you live view disability and where do these perceptions come from? What are your views of disability, and how are they connected to history, culture, and society? A current cultural perspective on disability involves the idea that persons with disabilities are objects of pity who exist to be taken care of. Some fear persons with disabilities either because they feel they may tear the very fabric of society or because they remind nondisabled folks of their own vulnerability and mortality. Others see disabled persons as sick. Some see them as perpetual children, sexless and in need of care. Still others see persons with disabilities as incompetent. Some see them as freaks. Others see them as either a gift or curse from God. And some see persons with disabilities merely as people who are, in superficial ways, different from people without disabilities. They recognize that persons with disabilities are, like everyone else, striving to get by, to live, to have good jobs, to have nice homes, to have fun, to lead fulfilling lives.

The etiology of these various beliefs and viewpoints can be traced to a myriad of sources. They stem from various religious beliefs and ideologies.

They stem from the idea that humans should be, and are capable of being, perfect. And they can stem from creative thinking, research, and political action.

The origins of beliefs about disability, their impact on society, and their impact on the human service professions influence each of us as professionals. How we choose to approach persons with disabilities depends on how we view disability and being disabled. If we see disability as a curse from God, our assessment will look for unchangeable deficiency or immorality. If we see persons with disabilities as incompetent or as perpetual children, we will expect them to be helpless. If we perceive persons with disabilities as competent and having potential for success, we will recognize the strengths they possess and that they can use to empower themselves.

Our values and beliefs about disability also guide our work with persons with disabilities. If we see persons with disabilities as sick or incapable, we will take care of them. If we see them as a menace, we will segregate them by locking them away in institutions or hiding them in their homes. If we see them as a minority group that has been stereotyped and subjected to discrimination, we will advocate social justice and seek the changes in society, economics, and politics that will empower them.

The first five chapters of this text provide a context for human service practice with persons with disabilities. We explore historical and current societal values and beliefs about disability. We examine the effects of these beliefs in the lives of disabled folks. We also explore how societal values influence human service practice.

Chapter 1 reviews the history of disability, including the origins and impacts of models used to define disability. Chapter 2 explores theories of human behavior and disability and these theories' implications for practice with persons with disabilities. It reviews multiple perspectives including psychosocial development, social, and economic theories and discusses their limitations as they apply to disability. Chapter 3 examines, in depth, the various stereotypes applied to persons with disabilities and how these stereotypes emerge from social constructions of disability. It addresses the influences of various professions on how practitioners approach practice with persons with disabilities. It also offers ways you can begin to examine your own values and beliefs about disability. Chapter 4 introduces the unique view that, out of their minority status, persons with disabilities have created a culture of Disability with a characteristic history, language, and values. Chapter 5 presents readers with an overview of the evolution of perspectives on disability around the world and provides readers with samples of important American and international social policies and legislative milestones.

1

The Meanings and History of Disability in Society

STUDENT LEARNING OBJECTIVES

1. To understand the complex history of persons with disabilities and how it affects current human service practice methodology toward disabled people
2. To understand the impact of disability history on the identity development of people with disabilities
3. To understand the ever-developing language used to describe disability

DISABILITY IN HISTORY

Throughout history, societies have attempted to explain the place of disability in the social order. Neolithic tribes believed disabilities were caused by spirits (Albrecht, 1992), and skull surgeries were performed to release evil spirits. The Spartans, with their rugged individualism, left persons with disabilities, both young and old, to die in the countryside. Ancient Greeks believed disabled persons were not human and that they should be abandoned to die (DePoy & Gilson, 2004; Plato, 1991). Plato, to whom we owe much of our ethical framework, saw persons with disabilities as standing in the way of a perfect world. He wrote in Book 5 of *The Republic* that “the offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place, as they should be” (Plato, 1991, p. 183).

The Romans, who borrowed the concept of reciprocity from the Greeks, gave assistance to adult persons with disabilities with the expectation they would express their appreciation through complacency (Morris, 1986). But like the Greeks, they also at times abandoned disabled and deformed infants to die, justifying their actions by defining those children as not fully human. However, the Romans did not perceive all disabilities as problematic, particularly those disabilities that did not manifest in physical differences. For example, Julius Caesar had epilepsy, known as falling sickness, and claimed that he had visions during his seizures.

4 CONTEXT FOR PRACTICE

In ancient Asia, disability was viewed similarly to the way it was viewed in Western culture. Life with disability was viewed as substandard, and people with disabilities were often forced to beg for sustenance. However, because religious vows of poverty were common in some parts of Asia, the act of begging may not have been viewed as negatively as in Western culture. Both heroic and malevolent disabled characters are featured in ancient Asian history. Yet ancient Zoroastrian scripture dating back 2,500 years in Persia envisioned a perfect world without disabilities (Miles, 2002).

Judeo-Christian thought, upon which much of Western culture is based, teaches that humans are made in God's image and are different from and superior to the rest of the animal kingdom. Livneh (1980) contends that persons with disabilities remind those without disabilities of humankind's link with the rest of the animal kingdom and bring to consciousness their fallibility. Thus, disabilities remind people of humankind's imperfections and dissimilarities to God while illuminating humankind's relationship to the imperfect animal kingdom.

Judeo-Christian and Muslim scripture portray disability negatively. The Bible and Koran are full of references linking disability to sin and evil. The Koran depicted the deaf, blind, and "dumb" as being without understanding. Disability signified sinners to the ancient Hebrews, and people with disabilities were thought to be possessed by demons. The Old Testament prohibited people who were deformed, crippled, or of short stature from officiating in priesthood rites. The Old Testament forbade the blind or lame from entering the houses of believers (Wright, 1983). However, disability was not universally condemned. For example, according to the texts of both the Koran and the Torah, although Moses lived with a significant speech impairment, it did not disqualify him from leading the Israelites out of Egypt.

The New Testament portrayed disability as arising from sin and spiritual deficiency. Blindness and other disabilities were believed to be caused by the sins of disabled people or their parents. Those with disabilities that are characterized today as "mental illness" were thought to be possessed by demons. However, Jesus also displayed compassion for disabled persons, setting a model for subsequent charitable efforts in Western culture.

Judeo-Christian tradition was prevalent among Europeans during the Middle Ages and beyond; during this time, persons with disabilities were thought to be expressions of God's displeasure (Livneh, 1982). Although Judeo-Christian philosophy did not advocate their killing, people with disabilities were ostracized and stereotyped.

In the Middle Ages, disability continued to be explained in moral and spiritual terms. People with disabilities were perceived as being out of harmony with God or the natural order of the universe. When disabilities were believed to arise from demonic or other evil influences, people with disabilities were rejected by society. Some were even burned at the stake. On the other hand, churches sometimes articulated the belief that the presence of

disabled folks created the opportunity for the nondisabled to practice charity. People with leprosy were segregated to protect society physically and spiritually; however, some believed lepers' infirmities helped them achieve salvation faster than others. Thus, while moral explanations prevailed during the Middle Ages, explanations for the meaning of disability for individuals varied widely (Metzler, 2006).

The Enlightenment brought a new emphasis on rational inquiry that competed with traditional religious and spiritual explanations of disability. As early as 1600, Francis Bacon refuted the idea that "madness" was a form of moral punishment. Disability from birth was considered a monstrosity, while acquired disabilities were more acceptable (DePoy & Gilson, 2004). Individuals injured during wartime were given special consideration. In Europe, blind persons especially were afforded higher status; this resulted from the wartime practice in which prisoners of war were blinded by their captors and allowed to return to their homes. This practice was considered a humane alternative to executing prisoners that still neutralized the threat they posed. The vestiges of this unique position for the blind continue contemporarily. For example, in Spain, one of the national lotteries is staffed and managed by—and proceeds are dedicated to—blind citizens.

The Belgian social statistician Adolphe Quetelet (1796–1874) was influential in framing a new overall view of disability. Quetelet applied the mathematical concepts of the bell curve and normal distribution to human beings, presenting the average man as society's ideal. Thus, the typical became defined as desirable, and deviations from the norm were considered undesirable mistakes. This provided a framework from which to view people born with physical and mental differences from the norm collectively rather than as distinct entities or groups (DePoy & Gilson, 2004; Snyder & Mitchell, 2006). Normal became a standard to strive for, providing justification for systematic efforts to fix those considered abnormal.

By the mid-1800s there were two distinct but overlapping societal models of disability. The moral model, present from earliest recorded history, viewed disability as a moral defect resulting from factors such as sin or the disorder of nature. The emerging medical model viewed disability as an innate deviation from the normal and desirable that could be treated by medical and scientific interventions. Both models labeled disability an undesirable condition to be prevented. Since both the medical and moral models maintain prominence in contemporary life, we will discuss them in greater detail in chapter 3.

As scientific inquiry increasingly supplanted moral explanations for disability, moral and supernatural explanations for disability began to be replaced by physical and scientific explanations, increasing the emphasis on curing, or at least treating, biological inadequacies. The increased industrialization and urbanization that corresponded with the Enlightenment contributed to changing perceptions of disability. More and more, the worth of

6 CONTEXT FOR PRACTICE

individuals was measured by their ability to work and contribute to the economy. Whereas agrarian and rural communities cared for people with disabilities through family, church, and community, industrial society led to the proliferation of institutions to house the unproductive, including those with disabilities. Although the stated intent of many of these institutions was to cure or serve people with disabilities, segregation and the dearth of resources often turned them into warehouses with subhuman conditions.

The height of the Industrial Revolution, concomitant with the Victorian era in the 1800s, brought increasing modernity and scientific advances in architecture, photography, health, and science, as well as changing social and political sensibilities. Charles Darwin's observations challenged perceptions about the nature and development of humanity. Inventions and advances produced optimism, and professionals held great hope that "deviants" could be molded and changed to be more acceptable to society (Rothman, 1971). However, as the century progressed, a new philosophy of social Darwinism gained prominence. Social Darwinists argued that just as competition promotes biological evolution, social evolution occurs in human populations and government policies can be instrumental in fostering desired social and societal development. These beliefs gave rise to the eugenics movement, which became prominent from the late nineteenth century through much of the twentieth century. Thus, by the turn of the twentieth century, intellectual elites were campaigning for the elimination of the poor, non-productive, and undesirable while advocating the procreation of those with desirable traits (Wiggam, 1924). Whereas Darwin advocated natural selection, eugenicists implemented draconian social engineering measures to promote the survival of the fittest and discourage the reproduction of undesirables in an attempt to purify society. Eugenics was used to justify laws forbidding interracial marriage and mandating the sterilization of disabled people and led to the proliferation of large institutions with degrading living conditions (Longmore, 1987). In a portend of things to come, Alexis Carrel, a French 1912 Nobel Prize winner in medicine and active eugenicist, advocated the "humane" disposal of mentally defective, insane persons and other undesirables through the use of lethal gas in small euthanasia institutions (Carrel, 1935; Szasz, 1977).

In the first half of the twentieth century, both the moral and medical models were firmly entrenched in Western culture, and people with disabilities were segregated from society. Parents of children born with disabilities were expected to institutionalize their children. Institutions for the "retarded" and the insane proliferated. Public access was denied people with mobility disabilities. The 1924 *Buck v. Bell* decision of the Supreme Court of the United States legitimized the forced sterilization of disabled persons. Longmore (2003) recounts the history of Randolph Bourne (1886–1918), a brilliant and articulate antiwar intellectual and feminist who had a "highly visible disability, a twisted mouth, face, and ear from a difficult birth, a

severely curved spine and stunted growth from childhood tuberculosis” (p. 35). He was denied jobs and educational opportunities, was isolated socially, and was forced into economic dependence. His critics equated his “deformed” body with a “deformed” mind. A Chicago ordinance forbade people like Bourne from appearing in public, warning, “No person who is diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object or improper person to be allowed in or on the public ways or other public places in this city, shall therein or thereon expose himself to public view” (qtd. in Longmore, 2003, p. 36).

Eugenics distinguished people born with disabilities from those who acquired disabilities. Acquired disabilities, especially when acquired from injury or accident, were more tolerable. For example, World War I produced hundreds of thousands of persons with disabilities in Europe and the United States, and responses to their needs reinforced and strengthened the disability role of the worthy poor (British Broadcasting Corporation, 1999). Franklin D. Roosevelt was elected president of the United States in spite of his experience with polio; however, he went to great lengths to hide his physical disability from the public. Increased survival rates of persons who were born with or acquired disabilities, public responsibility to care for veterans disabled by wars, and technological advances led to increased awareness of and attention to the need to “treat” disabled persons.

Nazi Germany used the eugenics philosophies to justify the T4 program and the genocide of between 75,000 and 200,000 physically and mentally disabled people in Germany. Franz Stangl, commandant of the infamous extermination camps at Sobibor and later Treblinka, gained his expertise using gas to exterminate people while serving as an administrator at Hartheim, a hospital that was converted into an extermination center for disabled people (Garscha & Kuretsidis-Haider, 1997). Joseph Goebbels, Hitler’s propaganda minister, who was disabled from polio, nevertheless led the publicity effort portraying disabled persons as subhuman and incurable, justifying the T4 program that defined their murders as mercy killings and release by comfortable death. And while Hitler and his minions justified the genocide of Jews and Gypsies because they viewed them as inferior races, they also justified killing racially “pure” but otherwise “defective” Aryans such as disabled people, and later gay men and women, whom they also labeled defective. In fact, disabled people were used to perfect the extermination techniques later used in the camps.

Early in the twentieth century, the seeds of disability rights were being germinated. For example, in 1935 the League of the Physically Handicapped, a small group of mobility-disabled persons and their supporters, protested against job discrimination against those with disabilities (Longmore, 2003). In the 1940s, the research of people such as Roger Barker and Beatrice Wright began showing similarities between the experiences of disabled persons and other groups who experienced discrimination. The turbulent climate of the 1960s that gave rise to the civil right movements for racial

minorities and the women's movement also provided a genesis for a disability civil rights movement. Activists such as Ed Roberts and Judy Heumann, both polio survivors, argued that they were denied the right to education and employment because of discrimination, and they rejected arguments that they were unemployable because of their disabilities. The demand for civil rights promulgated the independent living movement, established with the assertion that society is comprised primarily of the nondisabled and that persons with disabilities are a minority who have been subjected to discrimination and lack of opportunity. Societal barriers, not individual characteristics, present the greatest challenge to full participation for people with disabilities.

DISABILITY IDENTITY AS MINORITY IDENTITY

Negative perceptions of disability have been predominant throughout history, resulting in deeply felt beliefs, often unconsciously held. As we have discussed, ancient texts and scripture, upon which modern societal values are based, treat disability as pathological and immoral. These values have been found in cultures throughout the world in all ages. Often feelings such as pity, fear, and revulsion are unconsciously and automatically experienced. Bryan (1996) observes that "Although rooted in superstition and ignorance, the bias against persons with disabilities is generally not meant to be malicious or segregate the population into a caste system. Regardless of the intentions, many 'nondisabled' persons exhibit feelings of frustration, uncertainty, and bigotry when encountering a person with a disability, especially if the disability is severe. . . . These attitudes served to separate the 'nondisabled' from the 'disabled,' which further disenfranchised persons with disabilities" (pp. 6–7).

Wolfensberger (1972) illuminates common attitudes held toward persons with disabilities. He contends that people with disabilities are frequently labeled deviant and assigned societal role expectations based on these stereotypes. He also observes that people internalize these societally imposed roles. Wolfensberger states: "When a person is perceived as deviant, he is cast into a role that carries with it powerful expectancies. Strangely enough, these expectancies not only take hold of the mind of the perceiver, but of the perceived person as well. It is a well-established fact that a person's behavior tends to be profoundly affected by the role expectations that are placed upon him. . . . Unfortunately, role-appropriate behavior will then often be interpreted to be a person's 'natural' mode of acting, rather than a mode elicited by environmental events and circumstances" (pp. 16–17). Wolfensberger's ideas aid us in addressing the complex issues of the identity of persons with disabilities, the place of disability in society, and the development of Disability culture. Historically, people with disabilities have been

perceived as deficient and have been expected to fill roles foisted on them by larger society. For example, persons with intellectual and mental health disabilities have routinely been institutionalized. When their behavior has displayed signs of institutionalization, it has reinforced stereotypes and justified the perception that they need to be institutionalized. Thus, society creates the environment that reinforces its expectations: in these instances, dysfunctional behaviors and limited social functioning. With limited opportunities, persons with disabilities have little choice for anything else.

Let's look at comparisons between people with disabilities and racial and ethnic minorities. For example, people of color in the United States, blacks who lived under apartheid in South Africa, Arabs in some areas of northern Europe, and biracial and non-Japanese individuals in Japan have been subjected to pervasive negative societal images. Lesbian, gay, bisexual, transgender, and questioning (LGBTQ) persons have been subjected to negative images of LGBTQ people. Women have been denied opportunities based on their perceived limitations. Similarly, persons with disabilities have formed their social and personal identities based on the negative stereotypes placed upon them by history and the societies in which they have found themselves (Riddell & Watson, 2003). Like other minorities, persons with disabilities find themselves devalued, objectified, and subject to oppression.

Societal attitudes have tended to separate people with disabilities, denying them full societal participation. Isolation and unfamiliarity have, in turn, in a pernicious cycle, led to stereotypical attitudes toward persons with disabilities and ableism. We use the term *ableism* to describe the belief that people with disabilities are inferior to nondisabled people because of their differences. (Others use the term *disableism* to mean the same thing.) Ableism is similar to other isms such as racism and sexism, wherein the dominant segment of society defines the minority or non-dominant segments of society in stereotypical and/or negative ways. Ableism devalues people with disabilities and results in segregation, social isolation, and social policies that limit their opportunities for full societal participation. Just as with the other isms, when ableism is operationalized into policy and practice, professionals such as government officials, educators, social workers, and health care providers underestimate capabilities, limit self-determination, and behave oppressively toward the people subjected to the ism.

Unfortunately, persons with disabilities are also susceptible to internalizing stereotypes and negative beliefs. This process, which we call *internalized ableism*, is similar to internalized racism and sexism. The concepts of ableism and internalized ableism were developed in the disabled community and have become recognized by scholars and researchers. These isms perpetuate, and are in turn reinforced by, stereotypes. In the next section, we discuss the stereotypes most commonly encountered in today's society.

COMMON STEREOTYPICAL ATTITUDES TOWARD PERSONS WITH DISABILITIES

Disability stereotypes embedded in the medical and moral models continue to be common today. In this section, we discuss commonly held stereotypes.

Perpetual Children

The stereotype of the person with a disability as a perpetual child is embedded in terms such as *handicapped* and *crippled* (Bogden & Biklen, 1993). Charles Dickens's 1843 story *A Christmas Carol* presents Tiny Tim as a cute but powerless and ineffectual child whose primary reason for existence is to remind nondisabled folks how well off and fortunate they are in not being crippled.

Contemporarily, the annual March of Dimes telethon perpetually describes people with disabilities as "Jerry's kids," whether their age is one day or one hundred years. Wolfensberger (1972) labels this the stereotype of the "eternal child." Rather than being expected to go through developmental processes, perpetual children have few expectations placed on them; thus few opportunities for growth and development are provided for them. Low expectations result in the expenditure of fewer resources that would help them reach their potential.

An Object to Be Pitied

A common societal image of persons with disabilities is that of pitied or pitiful individuals: people whom no one would envy, persons no one would want to be (Shapiro, 1993). Wolfensberger (1972) identifies the common view of persons with disabilities as objects of pity, which is displayed in a variety of ways. Contemporarily, public pity is consistently used to raise money for organizations that work with people with disabilities. Posters, billboards, and telethons depict people with disabilities as brave but pitiable. Shapiro (1993) reveals the feelings of Evan Kemp Jr. regarding telethons. An advisor to George Bush Sr., a prime mover of the Americans with Disabilities Act, and a person with a disability himself, Kemp believes that "by arousing the public's fear of the handicap itself, the telethon makes viewers afraid of handicapped people." Kemp goes on to say, "Playing to pity may raise money, but it raises walls of fear between the public and us" (qtd. in Shapiro, 1993, p. 22).

The pity stereotype is born out of ignorance. Even when intentions are altruistic, fund-raisers such as telethons create pity, exploit guilt, and pigeon-hole the supposed beneficiaries of charity. Bogdan and Biklen (1993) state: "Thus, the crippled child becomes a poor soul whose disability evokes pity and guilt and the spirit of giving, but also lessens the possibility that disabled

people can be regarded as people with personalities, with individual aspirations, and with an interest in being perceived as ordinary people” (p. 74).

This pity is manifest in other ways. The 2004 Clint Eastwood film *Million Dollar Baby*, which garnered Academy Awards for Best Picture, Best Director, Best Actress, and Best Supporting Actress, provides a graphic example. Hilary Swank plays an aspiring boxer who, after sustaining a spinal cord injury, seeks to end her life. Ultimately, her trainer, played by Clint Eastwood, mercifully euthanizes her, thus putting an end to her misery. In other words, life with a serious physical disability is considered worse than death. In the 1981 film *Whose Life Is It Anyway?* Richard Dreyfus’s character begs for the right to end his life after an automobile accident leaves him with quadriplegia and needing renal dialysis. The film intends for the audience to be relieved when this likable, charismatic character is granted his wish. Again, life with a disability is portrayed as worse than death, a message that is loud and clear to the audience. In another example, Morris (1986) recalls that opposing forces debating the abortion issue often find agreement that abortion is acceptable when a fetus has a severe disability. Prior to acquiring a disability herself, Morris, like many others, was unaware of the embedded societal assumption that disability is a horrible fate.

A Menace or Threat to Society

Yet another stereotype centers on persons with disabilities as menaces or threats to society—people to be feared (Wolfensberger, 1972). Literature, films, and television persistently present persons with disabilities in the roles of criminals, monsters, and villains. Thus, persons with disabilities are portrayed as deviant. They may be perceived as immoral, if not criminal. They are seen as unworthy and deserving to be shunned because of the way the media portrays them in the movies, television, and literature (Bogden & Biklen, 1993). Persons with mental health disabilities are often portrayed as violent criminals. Most monsters are in fact persons with disabilities, whether the disability is a deformed face, another physical atypicality, or a mental health condition.

One of the authors found these attitudes strongly displayed in his personal life when, on separate occasions, he was asked to become involved in community efforts to keep two group homes out of his neighborhood. One of the group homes was to serve persons with developmental/intellectual disabilities; the other was for people with mental health disabilities. The rationales expressed for keeping them out were similar. There was a strong plea to “protect our children.” People were terrified that their children would be sexually molested and physically attacked by “retarded” and “crazy” people. Neighborhood activists believed group home residents would prey on the community. The rhetoric expressed in door-to-door contact and community meetings included calls for violence, if necessary, to protect the community from these people. The group homes were eventually located in the

12 CONTEXT FOR PRACTICE

neighborhood. However, even though problems failed to materialize, some community residents continued to shun people living in the group homes.

The perception that people with disabilities are a menace to society has been documented by Rhodes (1993), who recounts how societal fears have led to institutional segregation, marriage restrictions, and sterilization. Draconian measures have been taken to prevent contamination of the gene pool and to protect persons without disabilities.

Sick

Another common stereotype portrays people with disabilities as being sick, thus creating an additional negative identity. This stereotype, which is commonly internalized, portrays those with disabilities as persons to be taken care of. They are believed to need special treatment just because they are disabled. They may be excused from commitments and responsibilities. They may be seen as incapable of contributing to society and as entitled to be served. The internalized stereotype of sickness may leave persons with disabilities dependent on others, prevent them from taking the risks necessary for development, and leave them with self-images as people who do not take risks. In return, they are expected to be grateful for services they receive, even though the system that provides their services punishes them if they try to be independent and exercise self-determination (Bryan, 1996; Devore & Schlesinger, 1999; Mackelprang & Salsgiver, 1996; Zola, 1993).

People with physical disabilities who need attendant care are often forced into the sick role. Rather than having the opportunity to manage their own care, they are forced to rely on physicians to write orders and on nurses who provide care. Instead of directing their own care, they are forced to rely on home health agencies that control purse strings and personnel.

A language of sickness is endemic in popular and professional language relative to people with disabilities. People with disabilities are “confined” to wheelchairs or “wheelchair-bound,” just as sick people are confined to bed. Language such as “*afflicted* with cerebral palsy” and “mental *illness*” conveys widely accepted attitudes that persons with disabilities are sick.

Making sickness synonymous with disability maintains a power imbalance that victimizes persons with disabilities. The health care industry has massive financial incentives for placing people with disabilities in the sick role. Health care providers maintain status, professional worth, and income by exercising control over those who are forced to rely on them for services. Professional control creates a conflict of interest in which increased client or patient autonomy would reduce jobs and incomes, thus threatening the status of health and human service professionals. For example, the physician’s status is maintained when people must rely on physicians to obtain medications, durable medical equipment, therapy, or attendant care. Individual autonomy in obtaining these needs would decrease the need for, reduce

the role of, and reduce the income of physicians, nurses, pharmacies and pharmacists, medical equipment providers, social workers, psychologists, and others.

A Burden to Society

The sick role perpetuates the myth that disabled persons are a burden to society, therefore justifying their isolation and segregation. Many persons with disabilities feel isolated. They never quite fit in. They are forced to see themselves as different from everyone else (Gill, 1993). Not only are they different, but their differences are abnormal and costly to society. The institutionalization of persons with disabilities adds to this identity, along with the segregation that is promoted by group homes and other “special” accommodations. In addition, segregating people with disabilities furthers the perception that societal resources directed to them are costly to society.

Ugly and Sexless

Another common stereotype portrays persons with disabilities as ugly and sexless, an ableist identity internalized by many. How can persons who internalize and adopt the belief that they are “damaged goods” consider themselves beautiful and sexy? In the history of human civilization, there is a dearth of examples of persons with disabilities portrayed as beautiful. In the current media, aside from a few television commercials featuring actors with a disability, beauty and disability or sexuality and disability are rarely combined (Hahn, 1993). The 1928 D. H. Lawrence novel *Lady Chatterley’s Lover* portrays a wealthy woman who takes a laborer as a lover because of her husband’s paralysis and subsequent impotence. The multi-award-winning 1996 film *Breaking the Waves* tells the story of a woman whose husband coerces her to engage in sex with multiple partners after he is paralyzed in an industrial accident. Rendered asexual himself, he derives vicarious satisfaction by compelling her to tell him the specifics of her sexual encounters. In both stories, the husbands’ disabilities are portrayed as having completely robbed them of their sexuality.

Incompetent

Another common stereotype is that of incompetence. Innumerable wheelchair users have felt the sting of this stereotype in restaurants and other establishments when they have been with companions who do not use wheelchairs. Rather than taking the wheelchair user’s order, servers ask their companions what the wheelchair user wants to eat, the assumption being that the user is incapable of ordering and needs the help of someone else.

14 CONTEXT FOR PRACTICE

One of the authors, who uses a wheelchair, attended a conference in Washington, D.C., with a colleague who did not. At the airport while they were together, the ticket person asked his colleague whether or not he needed to be pushed to the airplane. The ticket person assumed that because the author used a wheelchair, he could also not talk or respond intelligently to questions. After a quick and articulate response, the ticket person became very much aware of the intellectual ability and verbal skills of someone with a disability.

The perception of incompetence is manifest in various ways and to various degrees. In health settings, these assumptions may be covert, but the meaning can still be clear, as recounted one person who had experienced a spinal cord injury:

[In rehabilitation] they really blew it. They told me when to get up, when to go to bed, when and what to eat. They told me when I had to take my medications and didn't always bother to tell me why I was taking them. I had to go to therapy at 9:00 a.m. It didn't matter that I've always been a late sleeper. They even told me when I could and couldn't take a crap. Then after three months of this, I was told that I was ready to go home and live completely independently. Hell, what a joke. (qtd. in Mackelprang, 1986, p. 43)

McRuer (2006) discusses the impact of the stereotype of incompetence on rehabilitation services. Social Darwinism and its social ideology of the "survival of the fittest" are manifest in vocational rehabilitation programs wherein funding and programs are cut back, and in assessment and the medical model diagnosis, which are used as a means of solving the "problem of disability" by determining who can compete and who cannot. Proponents of this perspective argue that those who cannot function in competitive employment should not receive rehabilitation services.

Assumptions of incompetence are often displayed when professionals take control of the lives of persons with disabilities. When professionals wrest control over the lives of persons with disabilities, these assumptions can be proved correct because people do not develop the skills to manage their lives. In the situation described in the quote above, for example, the individual was ill prepared to manage his medications because he was uninformed as to their uses and side effects. His capabilities were limited because of a dearth of opportunity to develop and assert independence.

Cursed by God

Another stereotype is that disabilities are the result of a curse from God. This attitude was displayed in the New Testament when the disciples of Jesus assumed that a man was born blind because either he or his parents had sinned. By logical extension, people with disabilities are less worthy and are less favorable in God's eyes than people without disabilities. Contemporarily, AIDS was ignored by the U.S. government for years because it affected

gay men and was perceived as resulting from immoral lifestyles. Eventually, in 1996 Congress enacted the Ryan White Care Act, the first concerted federal effort to provide funding for care of low-income people living with HIV/AIDS, which was intentionally named after a hemophiliac teenager, an “innocent victim” who contracted HIV from the transfusion of contaminated blood products and died of AIDS.

Individuals with disabilities and their families experience much guilt and shame as a result of this perception. Parents blame themselves and each other. Internalized ableism can lead people with disabilities to believe that God views them with disfavor. An example of this occurred with an individual with whom one of the authors worked for several years. Upon learning that he had been diagnosed with a progressive neuromuscular disorder, he sought religious help. He received a blessing that he would be healed if he had “faith and live[d] a worthy life.” Initially, he refused to believe his condition was permanent, even refusing all treatment. However, his condition steadily progressed. Three years later, he was depressed and maintained little self-worth. He could not understand what he had done in his life to deserve this “curse from God.” He blamed himself for his unsuccessful faith healing. He knew God was punishing him and held him in disfavor. He stated that the only reason he did not commit suicide was that suicide led to “eternal damnation, not just the damnation on this earth” caused by his disability. Parenthetically, members of his religious community also questioned his worthiness and wondered what he had done to deserve God’s curse.

A Gift or Test from God

Conversely, disability can sometimes be perceived as a gift or test from God. Some individuals and families find divine purpose when events such as the onset of disability enter their lives. Religious and spiritual beliefs should be respected and can be great sources of strength. However, divine explanations can also lead people to ignore the larger picture. As Condeluci (1995) states, “If raising a child with cerebral palsy is seen as being more difficult than raising any other child then we need to look, not at God, but at people and society. Why is it harder for a family with a child with a disability? One reason is that people have not understood, nor accepted. Another is because our society has not adjusted to welcome someone who might move, talk, or think differently. These don’t seem to be God’s problems but ours” (p. 22). We acknowledge the value of people finding spiritual meaning to events in their lives. However, there is danger in establishing an identity primarily based on speculations about God’s interventions or intentions.

Freaks

People with disabilities have often been treated as freaks. Circuses exploit this through freak sideshows, in which people pay to gawk at people with

unusual appearances, many with disabilities. Similarly, grand-rounds presentations, in which naked or nearly naked people are paraded in front of large groups of medical professionals, may have some educational value, but the practice dehumanizes people with disabilities. Quasimodo, the mythical subject of Victor Hugo's *The Hunchback of Notre Dame*, written in 1831, illustrates the long-standing perception of people with disabilities as freaks. Pregnant women were cautioned not to look upon him out of fear for their unborn children. His "ugliness" was equated with evil, and he was mocked without mercy. As a freak, Quasimodo was dehumanized; his life and feelings were unimportant.

Stereotypical attitudes are pervasive in society. Close monitoring of personal reactions to people with disabilities can help people identify and deal with their personal attitudes based on stereotypical beliefs. It is important to acknowledge that stereotypes are not always born of negative presuppositions. Some are born of compassion and sympathy. However, even these stereotypes have negative results. Negative societal attitudes and stereotypes may adversely influence the self-image and future independence of newly disabled individuals. Human service professionals, who may have a vested interest in the dependence of their "clients" and "patients," have a direct effect on the general public's view of disability. Their attitudes are also perpetuated as they influence their students, the future human service professionals. They can reinforce the perception that problems rest exclusively with individuals and small systems, ignoring meso and macro impacts on people's lives.

The stereotypes discussed above arise directly from pejorative social constructions of disability harbored in pathology-based models and paradigms of disabilities. These stem from and are perpetuated in the aggregate society by the moral and medical social constructions of disability.

DISABILITY AS DIVERSITY

Clearly, throughout the ages, in Eastern and Western cultures, and in ancient and contemporary times, disability and persons with disabilities have primarily been perceived as negative, abnormal, and to be avoided. Disabilities have been explained as being out of order with nature and/or God (the moral model). In recent centuries, scientific inquiry and knowledge have produced new explanations of disability as deviation from what is considered normal and desirable (the medical model). Contemporarily, a new perspective on disability has arisen that explains disability as a variation of the human condition, another characteristic among the broad range of traits present in society. We call this approach the *social/minority model* and contrast it with the traditional pathology-based models of disability. We introduce the three models here, and in chapter 2, we will discuss them in detail.

Traditional moral and medical paradigms define the nature of disability in terms of individual deficiencies and the biology of the disability. For example, customary justifications for keeping disabled children out of regular public schools have centered on their impairments. In contrast, the social/minority model focuses on society, its beliefs, and resulting discrimination. The social/minority model rejects traditional justifications for denying disabled children access to education. It contends that children with disabilities have not been allowed to go to regular schools because they have not been allowed in. As a group, as a minority, they have been denied their rights to education (Meyerson, 1990). This approach calls for disability policies based on a civil rights rather than a social services perspective.

The social/minority model offers a constructive alternative to traditional ways of viewing persons with disabilities. The paradigm shift from individual incapacity to environmental discrimination is in itself empowering. Society can only understand the behavior, the self-concept, the educational achievement, and the economic success of persons with disabilities by looking at people with disabilities as a minority group, one that is subjected to discrimination found in the social environment (Fine & Asch, 1993). This perspective encourages persons with disabilities to begin to assert their capabilities, personally and politically, rather than remain objects of pity. It encourages persons with disabilities to see themselves as part of the great mosaic of diversity that makes up our society. Rather than remaining passive objects of service and service providers, people with disabilities become active and capable consumers. Rather than organizing their lives around their deficits and problems, they begin to acknowledge and build upon their strengths and take control of their lives. Personal decision making replaces passivity; empowerment replaces powerlessness. This awareness of strength and control has resulted in significant social and political change.

THE POWER OF LANGUAGE

Language is a system of representation that people use to communicate such concepts as ideas, emotions, and beliefs (Thomas, Wareing, Singh, Peccei, Thronborrow, & Jones, 2004) and that provides a foundation for social identity (McGroarty, 1996). Language reflects the larger society in which we live, while concomitantly social and political forces influence language use (sociology of language) (McKay & Hornberger, 1996). Words and phrases shape our realities, the ways in which we perceive the world.

We examine the meaning of a few words to illustrate the ways in which language is used to describe our thoughts and feelings. From antiquity, the term *patriarch* has been used to describe those who are revered and respected. Ancient patriarchs were considered prophets and benevolent leaders, icons to be exemplified in religious and family life. However, in recent decades, gender studies has reevaluated the meaning of patriarchy,

often concluding that it is a system of male dominance that perpetuates the subjugation of women and children. Thus, contemporarily there are highly contrasting perceptions of the concept of patriarchy and patriarchy.

The 1934 musical comedy *The Gay Divorcee* portrays Fred Astaire searching for love interest Ginger Rogers. Other movies such as *Gay Desperado* (1936), *Gay Caballero* (1940), and *Es war eine rauschende Ballnacht (It Was a Gay Ballnight)*, 1939) all portrayed heterosexual characters and themes. But in 1969 the film *The Gay Deceivers* portrayed heterosexual men who pretend to be gay in order to avoid military service. Of forty-seven films listed by the online *Movie Review Query Engine*, all twenty-five films released after 1969 that had *gay* in the title referred to homosexual orientation, whereas none of the films before 1965 did. Ninety-nine of the first one hundred sites netted by a Google search of the word *gay* referred to homosexual orientation. The meaning of *gay* changed dramatically in the second half of the twentieth century. Today, terms such as *gay rights* and *gaydar* affirm the lives of gays and lesbians. *Homophobia* and *heterosexism* describe negative opinions about and discrimination against gays, while terms such as *the gay agenda* and *the gay lifestyle* are used to conjure negative and dangerous images of homosexual persons.

Historically, the language used to describe disability has been negative and exclusionary. Terms such as *invalid*, *crippled*, *deformed*, *crazy*, *spastic*, *insane*, *mad*, *retarded*, *defective*, and *handicapped* are used pejoratively and raise negative images. Common words and phrases used to describe the conditions of people with disabilities include *confined* and *bound* (e.g., “confined to a wheelchair” and “wheelchair bound”), *retarded* (e.g., “You are soooo retarded”), *crazy* (e.g., “That’s just crazy”), and *tragic* and *tragedy* (e.g., “tragic accident” and “It’s a tragedy that she was born retarded”).

Let’s analyze the meaning of the term *disability*. The prefix *dis-* has meanings such as “no,” “not any,” and “apart from.” *Able* means competent or capable. Thus, to have a disability literally means to not be able, or to be without ability. Being disabled literally means to be without capability or competence. The dominant group defines disability as pathological. In discussing language, power, and disability, A. G. Johnson (2006) observes:

Disability and nondisability are also constructed through the language used to describe people. . . . Reducing people to a single dimension of who they are separates and excludes them, marks them as “other,” as different from “normal” [white, heterosexual, male, nondisabled] people and therefore as inferior. . . . There is a world of difference between using a wheelchair and being treated as a normal human being [who happens to use a wheelchair to get around] and using a wheelchair and being treated as invisible, unintelligent, frightening, passive, dependent, and nothing more than your disability. . . . And the difference is not a matter of the disability itself but how it is constructed in society. . . . What makes socially constructed reality so powerful is that we rarely if ever experience it as that. We think the way our culture defines something like race

or gender [or disability] is simply the way things are in some objective sense. (pp. 19–20)

The perception perpetuated by the nondisabled majority is that the pathology of disability is objective reality. Few people, including disabled persons who have internalized ableist views, have challenged this socially constructed belief that people with disabilities are uni-dimensionally defined by their deviance from normalcy. Out of this environment came the move to modify language to reflect the multidimensional lives of people with disabilities.

DISABILITY LANGUAGE IN CONTEMPORARY SOCIETY

The last three decades of the twentieth century witnessed the rise of *person-first* language to describe disability. Person-first language places the person first rather than defining people by their disabilities, their perceived pathological characteristics. Person-first language assumes that the characteristics that lead to the label of “disabled” are a part of the individual but do not define the person. This approach is summarized in “Together We Will Make It,” a song by Clyde Lambourn (1993) from People First of New Zealand.

Put the people first
That's how it's going to work
When thinking up your schemes
When dreaming up your dreams
When planning all your plans
When governing our lands
Listen to our verse
And put the people first

We want to live in the real world
We want a share of the pie
But we need you
And you need us too
And together we will make it
You and I.

Kathie Snow (2008), the mother of a child with a disability, echoes these sentiments with the statement:

Contrary to conventional wisdom, individuals with disabilities are not:

- People who *suffer* from the *tragedy* of *birth defects*.
- *Paraplegic heroes* who *struggle* to become *normal* again.
- *Victims* who *fight* to *overcome* their *challenges*.

Nor are they *retarded*, *autistic*, *blind*, *deaf*, *learning disabled*, etc.—*ad naseum!*

20 CONTEXT FOR PRACTICE

They are *people*: moms and dads; sons and daughters; employees and employers; friends and neighbors; students and teachers; scientists, doctors, actors, presidents, and more. People with disabilities are people, *first*.

Given the traditionally derogatory nature of terms such as *handicap* and *disability*, person-first language has become widely adopted. Person-first language views terms such as *person with a disability* as more acceptable than *disabled person* because of the belief that disabled persons are not defined by their disability; rather, disability is a characteristic they live with. Person-first language was an important sociolinguistic step in changing societal and personal perceptions about disability. Whereas disability language was once almost universally used to exclude people and characteristics, person-first language reflects an inclusive perspective. Person-first language acknowledges the basic humanity of individuals with disabilities irrespective of their individual traits and characteristics.

Increasingly, life with a disability is being perceived as different, not deficient (Gerber, Ginsberg, & Reiff, 1992). People are not “confined to wheelchairs.” Instead, they use wheelchairs for mobility. The *Disability Rag*, an early militant disability newspaper, portrayed persons with disabilities as having “disability cool.” Its successor, the online publication the *Ragged Edge*, advocates freeing disabled people from the tyranny of “nursing *facilities*,” not “nursing *homes*.” Ed Roberts defined himself on national television when he corrected Larry King’s reference to him as a “victim” of polio. He acknowledged his disability but refuted the “victim” label applied by King, a label readily accepted in an ableist society. *Disability Rag* editor Mary Johnson embraced the term *disability* and rejected terms such as *differently abled* and *physically, emotionally, or mentally challenged*, stating that such words are used by nondisabled “do-gooders” who “wouldn’t understand disability culture if we ran over their toes with a wheelchair.” She describes such words as having “no soul” and “no power. They’re like vanilla custard” (qtd. in Shapiro, 1993, p. 33).

The closing years of the twentieth century and first decade of the twenty-first century have seen further developments in the use of disability language. For one, disability advocates and activists are increasingly eschewing person-first language in favor of disability identity language. We refer you to the personal narrative of Judy Heumann at the end of this chapter as an example. Notice how Heumann uses terms like *disabled people* as opposed to *people with disabilities*. Heumann explains that person-first language is euphemistic and serves to hamper the political agenda of disability civil rights activists. DePoy and Gilson (2004) argue against person-first language based on their belief that person-first language is almost always used when descriptors (e.g., disability, cancer) are undesirable, and that person-first language implies that disability is located within individuals rather than a societal construction. In her book on increasing disability awareness, Mary

Johnson (2006) embraces disability-first versus person-first language, stating, "In this book, you'll find us more often using the term 'disabled person' or 'disabled people.' Many disability studies scholars prefer using 'disabled person.' . . . Instead of able-bodied, we use non-disabled" (p. 2).

In September 2006, an extensive discussion on disability language was initiated on the Listserv for the Society for Disability Studies, an international organization of disability academics.

Friday, September 01, 2006 12:05 PM
Subject: [SDS] people first language?

I feel this is an old issue but I've been getting a lot of flack lately for using the term "disabled people" in grant applications and manuscripts. One recent grant review launched into a long diatribe about "disabled people" conveying a lack of respect for the community and serving as a barrier to full social inclusion. I always try to frame and explain my use of language but invariably someone (usually a non-disabled health or rehab science researcher) will demand that the terms be changed to people first language. I'd like an insider perspective on this, including pros and cons of various language choices, tips on phrasing from people who have been successful in justifying the use of disabled people.

Thanks, Susan

The ensuing discussion revealed that disability scholars from all over the world are split on the use of person-first language. This discussion reflects current international realities.

In some countries such as New Zealand, disability rights advocates have adopted disability-first language, as evidenced by the New Zealand Disabled Persons Assembly, which avers that disabled people live in a "disabling society." However, People First of New Zealand, an organization for people with intellectual disabilities, still advocates the use of person-first language. The United Kingdom's Disabled People's Council, comprised of more than seventy groups run by disabled people, has adopted disability-first language in their name and communications, as have leading English disability scholars such as Tom Shakespeare and actress Liz Carr, a self-described crip activist. However, in much of the world, activists, scholars, and advocates are split.

People who are culturally Deaf have always rejected person-first language. In the United States, those who identify with Deaf culture use American Sign Language as their primary language and method of communication, identify Deafness as a cultural characteristic, and identify with other Deaf people as their primary sources of socialization. Culturally Deaf persons use language such as *Deaf person* with a capital *D* to connote a person who identifies with Deaf culture and *deaf person* with a little *d* to signify deafness as an auditory condition.

Similarly, many blind people also eschew the use of person-first language. For example, the National Federation of the Blind took serious

22 CONTEXT FOR PRACTICE

umbrage with a 1993 U.S. Department of Education Office of Civil Rights memorandum that directed employees to use person-first disability language only instead of terms such as *blind people*. In reference to the memorandum, the National Federation of the Blind's Resolution 93-01 states, "A differentiation must be made among these euphemisms: some (such as hard of seeing, visually challenged, and people with blindness) are totally unacceptable and deserving only ridicule because of their strained and ludicrous attempt to avoid such straightforward, respectable words such as blindness, blind, the blind, blind person, or blind persons" (qtd. in Jernigan, 1999), and calls for straightforward language reflecting respect for the blind.

Interestingly, we ourselves are conflicted on the use of language as well. On one hand, we acknowledge that person-first language is respectful and that the pervasive and almost universal negative perceptions of disability throughout history have produced a contemporary environment that is so imbued with ableism that person-first language promotes the basic humanity of persons with disabilities. Conversely, however, we acknowledge that person-first language may foster a belief that disability is inherently pathological rather than a characteristic of diversity, as illustrated by the application of person-first language to other characteristics. Blacks and whites do not want to be called "persons with blackness," or "persons with whiteness." Women and men do not want to be called "persons with femaleness" or "persons with maleness." Similarly, disability-first language (e.g., *disabled man*, *disabled woman*, and *disabled persons*) embraces disability as a characteristic and identity. On one point the authors agree: people, disabled or not, have the right to be called by whatever names they choose. Currently, both person-first and disability-first language are acceptable.

A challenge for listeners and readers is to be aware of the way people use language beyond the words spoken, written, or signed—to be cognizant of embedded meanings and underlying intent. A second challenge is to be aware of the evolution of language over time. Concomitantly, we should avoid the pitfall of "presentism," that is, applying today's sensibilities to the past. For example, the term *handicapped*, eschewed today by disability activists, was common lexicon in past generations. Similarly, the person-first versus disability-first debate will continue to evolve over time. To accurately comprehend historical events, including the use of language, one must try to understand the sensibilities and contexts at the time of those events.

As for language in the current edition of this text, we acknowledge that our thinking has evolved in the years since the first edition. You will find us using multiple forms of disability language. When referring to disability from pathology-driven perspectives such as the moral and medical models, we primarily use person-first (e.g., "person with . . .") language. Similarly, we primarily use person-first language when discussing impairments concomitant with disability. For example, a "person with paraplegia" may need a new wheelchair for mobility every few years or may require medications

to control spasticity. At times, such as when referring to disability as a social construct, we use person-first and disability-first language interchangeably. When referring to disability as an element of diversity (e.g., when discussing disability rights or a disabled athlete), we will primarily use disability-first language. As an example of interchangeable language, let's consider the celebrity Josh Blue, winner of NBC's 2006 *Last Comic Standing*. Josh has cerebral palsy (person-first language), is a disabled comic (disability-first language), and is also a disabled soccer player (disability-first language) who competed in the 2004 Paralympics in Greece.

One form of language we avoid is the use of terms such as “*the disabled*,” “*the physically disabled*,” and “*the sensory disabled*.” While we acknowledge commonalities, we reject this language as lumping people into a one-dimensional group. Just as there is no such thing as *the black man* or *the white woman*, we believe there is no *the disabled*. We also avoid using terms such as *able-bodied*. Since this book is about disability, we use terms such as *nondisabled* to describe departures from disability. Further, many disabled persons are also able-bodied; thus using the term as the opposite of disability is a non sequitur.

Finally, when we write about Disability culture and disability identity, we use disability-first language. Furthermore, we borrow from Deaf culture by using “big *D*” *Disability* when writing about the culture of Disability. This text is our first foray into big *D* Disability language, and we will be interested in the reactions of disability scholars and other readers to this use. We are aware that there are people who question the presence of a “disability culture” or “culture of disability.” We suggest that Disability culture is a burgeoning phenomenon and further assert that those in the disability community, including scholars, activists, humorists, sons, daughters, fathers, mothers, athletes, nerds, geeks, couch potatoes, and other disabled people, can all actively contribute to the development of an evolving Disability culture in which we view ourselves and our life experiences as inherently valuable to ourselves, our loved ones, our communities, and society. Thus, we are unabashed advocates for the strengthening of a culture of Disability. More important than the specific wording we use, our embedded intent is to imbue value and a sense of respect for disability, those who live with disabilities, and disabled people.

SUMMARY

Disabilities have been present in all societies and cultures from the beginning of recorded history. In most societies throughout history, disabilities have been viewed as abnormal, and people with disabilities have been marginalized. From ancient Greece to twentieth-century Western societies, disabled people have even been considered so objectionable that they have been deemed unworthy of life. However, there have also been times at

which disabled people have been incorporated into the fabric of society. This has been particularly true for those with acquired disabilities, especially when acquired during times of armed conflict.

During most of recorded history, disability has been primarily perceived as morally objectionable or contrary to the natural nature of existence. Explanations for disability often involved the displeasure of God. With industrialization and the modernization of society, disability became increasingly explained in scientific terms, but still with a pathological and deficiency orientation. Important to this characterization was the belief that people with disabilities were a burden to society's economic productivity. The Enlightenment era produced a belief that physical abnormalities could be treated, ameliorated, or cured through scientifically applied strategies. However, by the end of the nineteenth century, a new and pernicious philosophy of social Darwinism and eugenics sought to eradicate disabled people from the face of the earth. Most eugenicists limited their actions to stopping the reproduction of people they considered defective; however, others advocated—and the Nazis ultimately carried out—the murder of thousands of disabled people under the guise of merciful euthanasia. Even today, we find common portrayals of disability as a condition worse than death, as evidenced by the 2004 Academy Award–winning film, *Million Dollar Baby*, among others.

In the twentieth century, disability stereotypes continued to pervade societies throughout the world. However, in the second half of the century, sporadic attempts to redefine disability gained steam, and the disability rights movement was born. Disabled people have gained rights and access to society. An alternative to pathology-driven explanations for disability has been developed. A new philosophy locates the problems disabled people face externally—as resulting from discrimination, devaluation, and lack of opportunity. A new Disability identity and culture are gradually gaining recognition.

Language is a powerful tool that frames our worldviews and perceptions, often without our realizing it. Language is also constantly evolving. Person-first disability language arose to counter the perception that people with disabilities are defined by their disabilities. As the meaning of disability evolves, so does disability language. Contemporarily, in some circles we are witnessing the embracing of disability-first language as a way to demonstrate disability identity, pride, and Disability culture. We fully expect that disability language will continue to evolve, possibly rendering obsolete the language we use today.

DISCUSSION QUESTIONS

1. How have disability and people with disabilities been perceived throughout history?

2. How have perceptions of disability influenced the treatment of disabled persons in society?
3. What are the similarities between ableism and other isms such as racism and sexism?
4. How did historical views and perspectives of disability, sexual orientation, and race contribute to the Holocaust?
5. The unemployment rates of disabled persons exceed 50 percent in many countries. How do traditional moral and medical models explain the causes of high unemployment rates? How does the social/minority model explain this?
6. What has been the historical reciprocal relationship between the isolation of people with disabilities and ableism?
7. What stereotypes of disability have you witnessed in your life? How have the mass media reinforced this?
8. What are the advantages and disadvantages of the use of person-first language to describe disability? Disability-first language? What are your opinions on person-first versus disability-first language?

PERSONAL NARRATIVE: JUDY HEUMANN

Judy Heumann was assistant secretary for the Office of Special Education and Rehabilitation Services under President Clinton. She has also worked as the World Bank Group's adviser on disability and development. She acquired a disability from polio in 1949 when she was a young girl. She has been a leader in the disability civil rights movement since its early years in the sixties.

As far as disabled people are concerned, I didn't have a lot of role models as I was growing up. That was part of the problem. There weren't a lot of disabled role models out there; we didn't know them. The truth of the matter is from elementary to high school and even through college, I had one teacher with a disability. She was an elementary school teacher, and she had one leg that was four or five inches different in length from the other. Outside of that, I don't remember any disabled people in special positions.

I had one teacher, Mrs. Malikoff; she was a speech pathologist in my elementary school. She didn't have a disability, but she was the only professional who ever really talked to me about a career. I remember her very vividly, saying, "You can be a speech therapist."

President Roosevelt was an important person in my life because I knew that he was disabled and my parents always made sure that I knew that he was. You couldn't get a higher role model than at that level.

As I was growing up, I realized a lot of people influenced my life in different ways. Many were nondisabled civil rights leaders and women's leaders. They were challenging themselves and challenging the system. They had beliefs that they fought for. These role models have ranged from local people in the community to more famous people known at the national and international levels.

As far as disabled people are concerned, I have learned a lot over the years from people like Mary Lou Breslin and Ed Roberts and Kitty Cone and Denise McQuade and Justin Dart. In my lifetime, there has been a very strong emerging movement of disabled individuals who feel common problems and common solutions and feel an identity among each other as a group of disabled people. We have a common agenda, a common vision for what we hope to accomplish, and I think that's been critically important.

When you consider the 49 million disabled people in the United States, I do not know how many of them identify with Disability culture. For those of us who have felt the need to come together and work together, we definitely feel this is a very important part of our lives that has really helped us to improve our individual lives as well as the collective lives of disabled people.

Problems still exist in the United States, and they are many and varied. We don't have a national health care policy, which would guarantee that all individuals, disabled or not, can get health care. Work disincentives exist in policy that result in disabled individuals who are capable and who wish to work being unable to do so. Various policies also make it more difficult for children to be integrated into schools. For example, I personally wish personal attendant services were much easier for people to obtain and that people could get money directly to hire their own personal attendants. I wish personal attendant services were available on a twenty-four-hour-a-day basis. I wish the government would provide easy and direct assistance for things like technology at school and in the workplace. Those types of barriers still limit opportunities for too many people.

I think we're certainly moving ahead on implementing laws like the Individuals with Disabilities Education Act, section 504 of the Rehabilitation Act, and the Americans with Disabilities Act. We're seeing some major structural changes in this country as far as physical barriers are concerned, and I think those changes are quite remarkable and are having a profound effect on both disabled and nondisabled people.

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