EXCERPTED FROM

Introducing Disability Studies

SECOND EDITION

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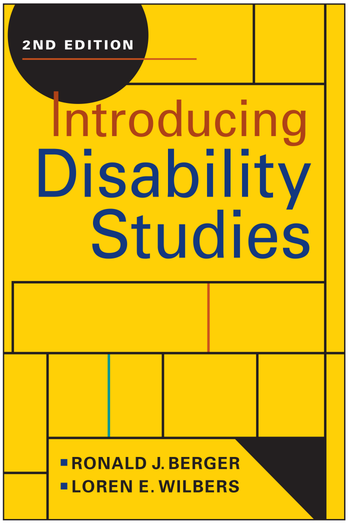
ISBN: 978-1-62637-925-1 pb



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Disability and Society

Ed Roberts, born in San Mateo, California, in 1939, contracted the poliomyelitis virus when he was fourteen years old, just two years before Jonas Salk invented the polio vaccine. While most people who contract the virus do not experience serious debilitating symptoms, in a small percentage, it attacks the motor neurons of the spine, causing paralysis. In Roberts's case he became quadriplegic with only minimal use of his hands. He also had difficulty breathing due to loss of muscle control, and when he was sleeping he used an iron lung, a device that is fitted over the body to create a sealed environment of oscillating air pressure that enables the lungs to expand and contract.[1] When not using his iron lung, Roberts relied on a technique called "frog breathing," which uses facial and neck muscles to force air into the lungs (Anderson 2013).

In spite of the hardships he faced, Roberts received his high school diploma, although he had to overcome the resistance of a school administrator who complained that he had not completed the physical education and driver's education requirements. Subsequently he received his associate degree from the College of San Mateo and gained admission to the University of California, Berkeley (UCB) in 1962, the same year James Meredith became the first African American to attend the University of Mississippi. But when he applied for financial aid from the California Department of Rehabilitation (CDR), he was denied the public benefit that was available to less disabled students. According to his CDR counselor, spending taxpayer money on Roberts would be a waste of resources because it was "infeasible" he could ever work (Shapiro 1993).

Roberts took his case to the media, eventually forcing the CDR to relent, and his success ushered in opportunities for other students with disabilities at UCB. Influenced by the political radicalism of that era, Roberts and his cohort of activists lobbied for accessibility reforms both on campus and in the larger Berkeley community. They questioned the conventional definition of "independence," which defined it in terms of the tasks a disabled person could perform *without* assistance. These activists, who were part of the **independent living movement**,* wanted to define independent living in terms of the quality of life that people with disabilities could achieve *with or without* assistance. They argued that people with disabilities did not simply need **custodial care**, that is, assistance with their daily basic needs such as eating and bathing, but they wanted to be fully integrated into their communities. They also aimed to reverse the power relationship between themselves and the medical, educational, and social service professionals whose services they required. People with disabilities no longer wanted to be treated as clients who were *told* by professionals what to do. Instead, they wanted to be treated as self-advocates and consumers of services who could *decide* what was best for themselves. To achieve these ends, Roberts and his allies established the first Center for Independent Living in the United States, which eventually evolved into a nationwide network of consumer-controlled, community-based centers that provide independent living skills training, peer counseling, information and referral, and advocacy for people with disabilities (Fleischer & Zames 2001; Scotch 2001b; Shapiro 1993).

More generally, what Roberts's activism represents is the birth of the contemporary **disability rights movement**, a movement of equality and social justice that should be placed in the context of other oppositional movements of the 1960s, such as the civil rights movement, women's movement, consumer movement, and gay and lesbian movement, which advocated on behalf of previously underrepresented political constituencies (Mansbridge & Morris 2001). Although the disability rights movement is an international phenomenon, the movements in the United States and Great Britain are

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*Key terms, laws, and court cases are indicated in **boldface** the first time they appear in the book.

most notable for their contribution to disability studies. In many respects, disability studies may be understood as the theoretical and research arm of the disability rights movement (Meekosha 2004; Shakespeare 2006; Snyder 2006).[2]

Lennard Davis notes that the history of disabled people is unknown to most individuals, "and so they see disability as an individual tragedy" and not as a form of "political oppression and the struggle to fight that oppression" (2005:2). And this is why **disability studies**—an interdisciplinary field of inquiry that includes representation from the social sciences, the humanities, and the medical, rehabilitation, and education professions—is so important. It is a way "to change the whole way we as a society envision, think about, and deal with people who are disabled."

As a contribution to the advancement of disability studies, this book represents a distillation of the literature, imbued with a sociological sensibility, aimed at illuminating disability as a social phenomenon, and committed to the broader goal of helping us see how we are all interconnected as human beings and how we are diminished when we assume that any life is without value. Although disability is a global issue, we focus on the United States. Chapter 1 begins our inquiry with a consideration of how disability is spoken about, defined, and understood sociologically, as well as an introduction to the disability rights movement. Chapter 2 then delineates the diversity of theoretical perspectives and conceptual models that constitute the core of disability studies. It also examines issues pertaining to disability culture and identity; disability in social interaction; the political economy of disability; feminist, queer, and crip theory; and critical disability studies. Next, Chapter 3 offers historical background, tracing the evolution of societal attitudes toward, and treatment of, people with disabilities (including legal practices) from early to contemporary societies.

Chapters 4 and 5 examine disability across the life course, with Chapter 4 focusing on the family and childhood and Chapter 5 on adolescence and adulthood. Chapter 4 considers parental first encounters with childhood disability, the child's perspective on disability, the impact of childhood disability on family life, and the challenges of assessing and receiving special education services for children with disabilities. Chapter 5 looks at relationships with peers, the education system, the world of work, sexual and emotional intimacy, the receipt of health care and personal assistance, and aging.

Chapter 6 examines the bodily experience of disability from the vantage point of those who live with a physiological-based impairment.

Here we consider the ways in which people perceive the world without sight and sound, think autistically, suffer from schizophrenia, live with traumatic brain injury, rehabilitate after a spinal cord injury, navigate the physical environment with mobility impairments, and participate in disability sports and athletics. Chapter 7 considers the place of disability in popular culture, with a focus on fictional literature, film, and television. Finally, Chapter 8 concludes the book by considering a range of issues that inform prospects for the future of disability, including the role of technology, the problems of selective abortion and physician-assisted suicide, the place of the medical model in disability studies, and the question of disability and human rights.

Disability in Everyday Language

Before embarking on such a complex subject as disability, we first need to consider the language we use to talk about it. To begin with, disability studies asks us to become more aware of the words and phrases we may use, sometimes intentionally and sometimes unintentionally, that demean people with disabilities (such as "gimp," "spastic," or "retard"), including metaphors that conflate physical impairment with mental impairment (such as "lame" or "the blind leading the blind") or indifference (such as "turning a blind eye" or "turning a deaf ear"). Or take a word such as "invalid," which is used both to refer to someone with a physical disability and to something that is illegitimate. Nowadays, even the term "handicap" has fallen into disrepute in disability studies. In contrast, disability studies often uses "people first" language, referring to "people with disabilities" to emphasize the person rather than the disability. However, it is also common, particularly in Great Britain, to use the term "disabled people" to highlight disability as an affirmative identity, not something to be ashamed of, that identifies the common cause of a particular political constituency.

To be sure, nondisabled people sometimes find these language issues tiresome and confusing, especially when disabled people appropriate such terms as "gimp" or "crip" in an affirmative way, similar to the way in which gay, lesbian, bisexual, and transgender people appropriate the term "queer" as an affirmative identity.[3] Moreover, we now hear people using terms such as "differently abled," "physically challenged," "developmentally challenged," or "children with special needs." Simi Linton, for one, does not find these euphemisms or "nice" terms useful, characterizing them as "well-meaning attempts to inflate the value of people with disabilities [that] convey the boosterism and do-gooder mentality endemic to the paternalistic agencies that control many disabled people's lives" (1998:14). She notes as well that an entire profession called "special education" has been built around the appropriation of a term, "special," which may have been "a deliberate attempt to confer legitimacy on the educational practice and to prop up a discarded group," but nonetheless obscures the reality that society considers "neither the children nor the education" truly desirable (p. 15).

More generally, the point to be made here is that disability studies is an attempt to reassign meaning(s) to our use of the term "disability" and the way we speak about it, and in doing so reveal "the complex web of social ideals, institutional structures, and government policies" that impact the lives of people with disabilities (Linton 1998:10). One of our first challenges in this effort is to develop a more systematic working definition, or definitions, of disability. It is to this matter that we now turn.

Delineating the Subject Matter of Disability Studies

In order to delineate the subject matter of disability studies, we need to ask, as does Susan Wendell, "Who defines disability and for what purposes?" (1996:23). Insurance companies or government agencies, for example, may have particular administrative criteria they use to define who is eligible for payments or benefits, and it may be in the interest of these providers "to define disability narrowly" in order to save money (p. 24). Similarly, laws that entitle people with disabilities to services, such as children in schools who need special accommodations, may utilize different criteria. Indeed, anyone who tries to negotiate the administrative-legal system will often find themselves entangled in a maze of competing and contradictory definitions of what it means to be disabled, or disabled "enough," to qualify, whereby they fit "some bureaucracies' definitions of disability and not others" (p. 24).

The field of disability studies, however, is not governed by such administrative-legal criteria; and in this field, a discussion of definitional issues typically begins with a distinction between impairment and disability, whereby **impairment** refers to a biological or physiological condition that entails the loss of physical, sensory, or cognitive function, and **disability** refers to an inability to perform a personal or socially necessary task because of that impairment or the societal reaction to it. Although it was common in the past to also use the term **handicap** to refer to the social disadvantage that accrues to an individual due to an impairment or disability, *handicap* as a concept is rarely used in scholarly or activist circles these days, largely because it has negative connotations when used to refer to persons with disabilities as inferior or deficient in some way (Miller & Sammons 1999; Wendell 1996).

For our purposes, therefore, the distinction between impairment and disability is what is most germane. For instance, people who use a wheelchair for mobility due to a physical impairment may only be socially disabled if the buildings to which they require access are architecturally inaccessible. Otherwise, there may be nothing about the impairment that would prevent them from participating fully in the educational, occupational, and other institutional activities of society. Or take the case of visual impairment. Nowadays people who wear eyeglasses or contacts don't even think of themselves as having an impairment, because these corrective devices have become commonplace. But if it were not for these technological aids, which are now taken for granted, their visual impairments might also be disabilities.

Moreover, people with disabilities often experience prejudice and discrimination comparable to what is experienced by people of color and other minority groups, and they are therefore socially marginalized and disadvantaged in similar ways (Gordon & Rosenblum 2001). It remains sadly true that people whose bodies are different from "a society's conception of a 'normal' or acceptable body," even when it causes "little or no functional or physical difficulty for the person who has them, constitute major social disabilities" (Wendell 1996:44). Take the case of facial scarring or disfigurement, "which is a disability of appearance only, a disability constructed totally by stigma and cultural meanings" (p. 44). Lucy Grealy, for example, whose face was disfigured due to surgery for facial bone cancer, recalls with great pain the cruel stares and laughing at her appearance: "I *was* my face, I *was* ugliness," she writes (1997:17). In earlier times, it was even illegal to appear in public if one's physical appearance offended others' sensibilities, as in the case of the so-called **ugly laws**, ordinances that were prevalent in various cities across the United States. The oft-cited Chicago ordinance passed in 1881 (and not repealed until 1973) is a good illustration. It read: “Any person who is diseased, maimed, mutilated, or in any way deformed, so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares, or public places in this city, shall not therein or thereon expose himself to public view, under the penalty of a fine of $1 [about $20 today] for each offense” (cited in Schweik 2009:1–2).

More generally, nondisabled people are often uncomfortable, even fearful, around people with disabilities, as if the disabling condition might be contagious. Robert Murphy thinks that all too many nondisabled people view people with disabilities as a “fearsome possibility” (1987:117). They displace their fears that the “impairment could happen to them” onto the other person. In this way, “the disabled person becomes the Other—a living symbol of failure, frailty, and [for men] emasculation; a counterpoint to normality; a figure whose very humanity is questioned” (p. 117). Similarly, in his book *Stigma: Notes on the Management of Spoiled Identity* (1963), Erving Goffman argued that disparaging reactions from others serve to invalidate the disabled person as less than “normal” if not less than “human.” Goffman defined **stigma** as a process by which a person is “reduced in our minds from a whole and usual person to a tainted, discounted one” (p. 3). Published the same year as Howard Becker’s *Outsiders: Studies in the Sociology of Deviance* (1963), Goffman essentially framed the question of disability within the **labeling theory** school of deviance, which posited that “**deviance** is not a quality of the act a person commits, but rather a consequence” of others’ reactions (Becker 1963:9). Goffman thus proffered a general theory of stigma, attributing common devalued statuses to deviants of all types: people with disabilities, gays and lesbians, ex-convicts, mental patients, drug addicts, and alcoholics.[4]

Nancy Miller and Catherine Sammons (1999) observe that it is natural for people to notice others who look different. Indeed, they argue, the human brain is hard-wired to scan the environment and notice differences from the routine or “expected average” (p. 7).

> Everybody reacts to differences. In the whole universe of differences, some attract us, some surprise or frighten us, and some aren’t important to us at all. Our reactions to differences are sometimes complex and confusing. We often want to be open-minded and feel comfortable about other people’s differences

> but find that some unfamiliar differences make us feel tense and judgmental instead. We are caught off guard when someone with an unexpected difference enters the room, and we may feel awkward as we try to appear unsurprised. When we see an unsettling difference, it can cause anxiety, uncertainty, and even a wish to avoid the other person. (pp. 1–2)

Miller and Sammons believe we can all learn to override these reactions through habituation to new experiences and exposure to alternative cultural norms, and in this way expand our "personal comfort zones" about disability and other social differences. Similarly, Spencer Cahill and Robin Eggleston (1995) note that awkward encounters between able-bodied and disabled-bodied people often stem not from malicious intent but from the uncertainty of what is expected. Should an able-bodied person, for example, offer assistance to someone who uses a wheelchair by opening a door for them or asking them if they need help retrieving something from a shelf in a grocery store? In their study of wheelchair users' public experiences, Cahill and Eggleston found that able-bodied people sometimes feared being rebuked for thinking that the wheelchair user might need help, finding "that they have judged [them] less competent than [they] want to be considered or consider themselves" (p. 693). Cahill and Eggleston also learned about occasions in which a wheelchair user was treated as a "nonperson," for instance, when they were with a group at a restaurant and the server asked others what the wheelchair user was ordering, as if they were incapable of speaking for themselves. At the same time, the researchers also learned of many acts of public kindness, where the nondisabled offered wheelchair users much appreciated assistance, which runs counter to the view that people with disabilities are uniformly stigmatized and treated badly (see also Makas 1988).

All this is to say that it is important to understand "disability" as a social phenomenon, an experience that cannot be reduced to the nature of the physiological impairment. Rather, it is a product of societal attitudes and the social organization of society. This view is sometimes referred to as a **social constructionist** approach to disability, which understands disability as constructed by or residing in the social environment, in contrast to an **essentialist** view, which understands disability as a condition that resides or is inherent in an individual's particular impairment (Baker 2011; Wendell 1996).

To complicate matters further, disability scholars note that impairment itself is a product of social definition, as in the case of medical diagnosis and classification systems that are themselves subject to dispute and change over time (Blum 2015; Brown 1995). Take the case of **autism**, for example, which is now understood as consisting of a continuum or spectrum of conditions that includes people who are considered very “low functioning” and very “high functioning.” Autism was discovered separately but nearly simultaneously by Leo Kanner, an American child psychiatrist, and Hans Asperger, an Austrian pediatrician, in 1943 and 1944, respectively. Both Kanner and Asperger chose the term “autism” from the Greek word *autos* (self) to refer to the children’s “powerful desire for aloneness” and “anxiously excessive desire for the maintenance of sameness” (Kanner 1943:242, 249). People with autism have difficulty with face-to-face interaction and may appear emotionally detached and lacking in the ability to empathize with others. They tend to become attached to routines and can become anxious when these routines are disrupted. They often become focused on specialized, complex topics, which can be associated with a number of strengths, as people with autism can be exceptionally skilled at systematizing information, mathematics, computer science, music, and art (Grandin 2006; O’Neil 2008; see also Box 1.2).[5]

Whereas Kanner went on to become a leading figure in child psychiatry, Asperger’s clinic was destroyed during World War II, and he was virtually ignored outside of Europe until his work was discovered by British psychologist Lorna Wing and translated into English in 1991. It was Wing who popularized Asperger’s observation that the condition, now called **Asperger’s syndrome** or **autism spectrum disorder**, consisted of a range of conditions that are markedly different from one another (Grandin 2006; Wing 1996).

Up until 1980, the term *autism* did not appear as a distinct condition in the *Diagnostic and Statistical Manual* (DSM), the official diagnostic guidelines of the American Psychiatric Association. Previously the only mention of it had been as a symptom of childhood schizophrenia, and Asperger’s syndrome was not included until 1994 (Straus 2010). Thus, Donna Williams (1992), born in 1963, did not understand her condition as “autism” until she was twenty-five years old. She knew she was not like other children but did not know why. As a child, she was even thought to be deaf because she avoided eye contact and was emotionally unresponsive to others. Even today, there is some controversy about whether autism, Asperger's syndrome, and a few other disorders should be characterized as distinct diagnostic conditions or, rather, as constituting a unitary set of conditions that exist along a continuum. Thus, in the 2013 revision of the DSM, Asperger's syndrome was placed under the rubric of autism, essentially removing the distinction between them (Baker 2011; Grandin 2006).

Another definitional issue that complicates our subject matter is the distinction between **physical, sensory, and cognitive impairments**. In some instances one may find the term *physical impairment* being used to refer to both mobility impairments and sensory impairments, such as vision and hearing loss, and in other instances only for mobility and not sensory impairments. As for *cognitive impairment,* this term is generally used to refer to a wide range of conditions such as autism, traumatic brain injury, and mental illness. Within this broad category, a distinction is also made between **intellectual disabilities**, the term that is now used to refer to mental retardation and that involves limitations "rooted in sub-average intellectual and adaptive functioning occurring early in life," and **learning disabilities**, a term that refers to limitations involving "the brain's ability to receive, process, analyze, or store information" (Carey 2009:190; see also Box 4.3).[6]

Still another issue that complicates our subject matter is the distinction between illness and disability, a distinction some disability scholars and activists insist on making, in part because they want people to know that people with disabilities are often perfectly healthy, requiring no particular medical care.[7] Wendell (1996) thinks that the adamancy by which some have opposed including people with illnesses among the constituency of disabled people may stem from the desire to avoid the additional stigma that is associated with illnesses such as AIDS and cancer. Nevertheless, it remains true that many people with disabilities are also ill, and chronic or life-threatening illnesses, as well as the normal process of aging, can have disabling consequences for individuals (Bury 2000).[8] Relatively few people are born with a disability—less than 1 percent of all people with disabilities are younger than five years of age—but most people who live long enough can expect to have an experience with disability before they die (US Census Bureau 2018). Moreover, anyone at any time—as a result of an automobile accident, a serious fall, or the acquisition of a serious illness—can join the ranks of the disabled.

FURTHER EXPLORATION

Box 1.1 Counting Disability

Studies that try to count the number of people with disabilities are complicated by the question of how broadly or narrowly disability is defined (Grönvik 2009). For example, the American Community Survey, an annual survey conducted by the US Census Bureau, is based on responses to questions about six general categories of disability. Overall, in 2018, these data indicate that the percentage of the (civilian noninstitutionalized) population in the United States that had a disability was 12.6 percent, with some individuals having multiple disabilities: 6.8 percent had an *ambulatory difficulty*, 5.1 percent had a *cognitive difficulty*, 3.6 percent had a *hearing difficulty*, 2.4 percent had a *vision difficulty*, 5.8 percent had an *independent living difficulty*, and 2.6 percent had a *self-care difficulty*. These data also indicate that the percentage of the population that had a disability increased with age: 0.7 percent for individuals under five years of age, 5.5 percent for individuals five to seventeen years, 6.4 percent for individuals eighteen to thirty-four years, 12.5 percent for individuals thirty-five to sixty-four years, 24.4 percent for individuals sixty-five to seventy-four years, and 47.5 percent for individuals seventy-five years and older (US Census Bureau 2018).

At the same time, another study using data from the Social Security Administration (SSA), which employs a broader definition of disability, asked respondents "more than 100 questions about specific functional and participatory activities, conditions, and symptoms to arrive at a measure of disability," including questions about both nonsevere and severe disabilities (Taylor 2018:2). A report based on 2014 SSA data, which was published in 2018, found that 9.6 percent of the (civilian noninstitutionalized) population had a *nonsevere disability* and 17.6 percent had a *severe disability*, for a total of 27.2 percent of the US population. Among those less than eighteen years of age, 7.2 percent had a nonsevere disability and 9.8 percent had a severe disability. Among those eighteen to sixty-four years of age, 8.8 percent had a nonsevere disability and 14.9 percent had a severe disability. And among those sixty-five years and older, 17 percent had a non-severe disability and 41.6 percent had a severe disability.

continues

Box 1.1 Continued

Additionally, the SSA study reported on specific measures of disability for adults eighteen years and older, finding that 7.1 percent had *serious difficulty hearing,* 5.1 percent had *serious difficulty seeing,* 12.4 percent had an *upper-body functional limitation* (such as lifting 10 pounds or grasping small objects), 17.6 percent had a *lower-body functional limitation* (such as walking a quarter mile or climbing a flight of stairs), 12.9 percent had difficulty with at least one *daily living or instrumental life activity*, 10.1 percent needed help performing at least one *daily living or instrumental life activity*, and 9.5 percent had a condition that limited *mental or cognitive functioning* (Taylor 2018; see also Centers for Disease Control and Prevention 2017).

Be that as it may, contemporary approaches to disability try to avoid the pejorative connotations of the term and reframe it as a matter of **social difference**. As Miller and Sammons argue:

> Everybody's different. Some of us have differences that no one notices, while others are different in very apparent ways. We all look different from others, sometimes by chance, sometimes by choice. Some people move on foot, while others use wheelchairs or other ways of getting around. We communicate in a variety of languages and dialects and also by using hand signs. Our behavior patterns have incredible variety, even within our own families. We all have unique physical strengths and limitations as well as different learning abilities, creative talents, and social skills. (1999:1)

In this way, Christina Papadimitriou (2001), among others, rejects a conception of disability as undesirable deviance, a "perversion of the human condition," or unrelenting tragedy that propels people into the depths of despair (Camilleri 1999:849). Rather, disability should be understood as a form of diversity that can be appreciated as a different way of being embodied in the world. Papadimitriou does not view disability and normality as polar opposites but as falling "along a continuum of . . . humanly possible ways" of being (2008b:219), or in Robert Scotch and Kay Schriner's (1997) terms, the natural variation that occurs among human beings. While impairments may never be wished for and are often the source of great suffering (for physical and social reasons), people with disabilities differ quite dramatically in the nature of their conditions, which are not as "wholly disastrous" as people often imagine (Fine & Asch 1988:11). They commonly learn to appreciate and enhance their remaining abilities and to strive for goals and qualities of human worth that are within their grasp (Gill 2001; Potok 2002). According to Tobin Siebers, "People with disabilities want to be able to . . . live with their disability, to come to know their body, to accept what it can do, and to keep doing what they can for as long as they can. They do not want to feel dominated by people on whom they depend for help, and they want to be able to imagine themselves in a world without feeling ashamed" (2008:69). In almost every case, Siebers adds, people with disabilities have a better chance of enjoying a fulfilling life if they accept their disability as a positive aspect of their identity that provides them with a unique and at times contentious way of being in and viewing the world.

At its core as a scholarly discipline, disability studies rejects approaches to disability that seek to eradicate it. This does not necessarily mean that it opposes medical or rehabilitative interventions that might enhance a person's ability to live the life she or he most wants to live. What it does aim to do is critique "the widespread belief that having an able body and mind determines whether one is a quality human being" (Siebers 2008:4). In doing so, it identifies a source of oppression, **ableism**, which is comparable to racism, sexism, and heterosexism in constituting a system that subjects people to "political, economic, cultural, or social degradation" (Nowell 2006:1179). Ableism assumes that some people (and bodies) are "normal" and superior, while other people (and bodies) are "abnormal" and inferior, and it entails institutional discrimination on the basis of this distinction (Linton 1998; Papadimitriou 2001).[9] Siebers calls this the "ideology of ability," which in its simplest form constitutes a preference for able-bodiedness, but in its most radical form "defines the baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons" (2008:8). As a dominant or hegemonic ideology, ableism is so taken-for-granted that it remains unconscious and invisible to most people, even though it constitutes an overarching regime that structures the lives of people with disabilities. Disability studies aims to unmask the ideology of ableism, to deconstruct it, and to bring it out in the open for all to see.

The Disability Rights Movement

In addition to Ed Roberts, one of the notable figures of the early disability rights movement in the United States is Judy Heumann. Born in Brooklyn, New York, in 1947, Heumann contracted polio when she was eighteen months old; and like Roberts, she became quadriplegic. One physician advised her parents to put her in an institution, which they did not do, and relatives told them "their misfortune must have been the result of some sin on their part" (Shapiro 1993:56). For three years during elementary school, Heumann was required to receive home instruction because the principal said her presence in a wheelchair was a "fire hazard." Her parents, however, were determined to give their daughter a sound education. They placed her in a school for disabled children, where Heumann soon "realized that the parents of her classmates had low expectations for their children, and that the teachers, when not prodded by pushy parents, respond accordingly" (Shapiro 1993:56). Nevertheless, Heumann graduated high school and was accepted to Long Island University, where she had to fight for "everything from the right to live in a dormitory to getting someone to lift her wheelchair up the steps to the classroom buildings. She organized other disabled students to fight for ramped buildings . . . [and] took part in protests against the Vietnam War" (p. 57).

In 1970, one year after graduating from college with a teaching degree, Heumann was denied a license to teach in New York City's public schools because she could not pass the medical exam. The testing physician questioned whether Heumann could get to the bathroom by herself or help children out of the building in an emergency. A media campaign resulted in her receiving her teaching license. A newspaper headline read, "You Can Be President, Not Teacher, with Polio," and quoted Heumann as saying, "We're not going to let a hypocritical society give us a token education and then bury us" (Shapiro 1993:57). Still, no one would hire her until the principal of the elementary school she had attended offered her a job.

Heumann formed her own disability rights activist group, Disabled in Action. In 1972, she traveled to Washington, DC, to demonstrate at the Lincoln Memorial after President Richard Nixon vetoed a spending bill to fund federal disability programs. In the closing days of the presidential election, she joined with a group of disabled Vietnam veterans to take over Nixon's New York reelection headquarters to demand an on-camera debate with the president himself.

The following year, Roberts invited her to come to California to work for the Center for Independent Living that he had just opened (Fleischer & Zames 2001; Scotch 2001b; Shapiro 1993).

As this type of political activism spread throughout the country, the US Congress eventually responded by passing a landmark piece of federal disability legislation, the **Rehabilitation Act of 1973**, which, among other things, mandated reasonable accommodations in public education and employment, required public institutions to initiate architectural accessibility reforms, and "made it illegal for any federal agency, public university, defense or other federal contractor, or any other institution or activity that received federal funding, to discriminate against anyone solely" for reason of disability (Shapiro 1993:65). But most politicians who had voted for the act had not seriously considered its broader implications and potential costs of implementation. Thus the Department of Health, Education, and Welfare (HEW) under presidents Gerald Ford and Jimmy Carter tried to stall the development and implementation of enforcement provisions (Braddock & Parish 2001; Fleischer & Zames 2001; Scotch 2001b).

When Joseph Califano, Carter's secretary of HEW, tried to push through regulations that would have allowed "some disabled children to be educated in special schools rather than [in] regular schools adapted for them," disability activists derided the measure as "separate but equal" (Shapiro 1993:68). And when Califano also came out for exceptions to rules requiring wheelchair ramps in schools and hospitals, the activists organized demonstrations around the country, particularly in the ten cities where HEW regional offices were located—Atlanta, Boston, Chicago, Dallas, Denver, Kansas City, New York, Philadelphia, San Francisco, and Seattle, in addition to Washington, DC.

Until this time, the disability rights movement in the United States had been local and disparate; it now became a national and cross-disability movement of diverse groups working together for social change. It was this movement that later culminated in the passage of the **Americans with Disabilities Act** (ADA) in 1990, which further expanded the rights of disabled people in both the public and private sectors. Although the implementation of the ADA, like previous progressive legislation for disabled people, has been plagued by controversy over its interpretation and implementation, it marked a seminal point in the legal rights and expansion of opportunities for people with disabilities in the United States (see Chapter 3).

Joan Tollifson (1997), who is missing her right hand and half of her right arm, describes how exhilarating and empowering it was to be part of this movement. Tollifson writes that while growing up she "used to dream about being in a world where being disabled was no big deal, where no one considered it a tragedy, [where] no one thought you were inspiring or felt sorry for you, [where] no one stared at you" (p. 105). All too many times she experienced complete strangers coming up to her on the street and inquiring about her physical appearance, and children gasping at her in horror. People would tell her with tears in their eyes how amazingly well she did things, such as tying her shoes, or that they didn't think of her as disabled—she guesses because they thought that a "real cripple" would have been totally incompetent. Others would "try desperately to pretend that they [didn't] even notice." People would "swallow their curiosity and conceal their discomfort." Adults would tell children who asked her about her arm, "ssshhhhhhh!" (pp. 105–106).

Growing up, Tollifson recalls, she intentionally avoided other disabled people, "dis-identifying" with them and refusing to see herself as part of that group. Still, she was in a great deal of emotional pain. While in therapy, she reluctantly joined a group of "marvelous, dynamic" disabled women who shared many of the same experiences she had. She no longer felt isolated and alone and began to realize that her private pain was a social phenomenon, "part of a collective pattern that was much larger than any one of us" (1997:105–106). Indeed, what Tollifson now realized is the essence of what C. Wright Mills (1959) famously called the **sociological imagination**, that personal or private troubles are actually public issues.

In the late 1970s, Tollifson got involved in the disability rights protest movement, participating in a month-long occupation of the San Francisco Federal Building, demanding that the Carter administration sign into law the regulations it had been opposing:

> We created a whole society in microcosm inside that building, with work committees, church services, study groups, wheelchair races, long strategy meetings. People laughed, argued, shared their lives; some even fell in love and later married. In this society, you never had to worry about being discriminated against because of your disability. No one was going to tell you that you couldn't do a particular task because you only had one hand or were in a wheelchair. At last, here was a society where being disabled was no big deal. . . . After a lifetime of isolating myself from other disabled people, it was an awakening to be

> surrounded by them. . . . Finally identifying myself as a disabled person was an enormous healing. (1997:107)

To be sure, the social category of “people with disabilities” is constituted by a diverse set of conditions and people who “may have little in common except the stigma society imposes on them” (Engel & Munger 2003:14). Moreover, Nick Watson (2002) found that most

FURTHER EXPLORATION

Box 1.2 Autism and the Neurodiversity Movement

The concept of **neurodiversity**, which first appeared in print in an article by Harvey Blume that was published in *The Atlantic* magazine in 1998, originated among self-aware members of autistic communities. Nowadays neurodiversity is used to refer to a variety of atypical cognitive styles that are due to neurological differences, including autism, intellectual disabilities, learning disabilities, attention-deficit/hyperactivity disorder, epilepsy, posttraumatic stress disorder, bipolar disorder, Tourette’s syndrome, and schizophrenia. But the impetus for neurodiversity as a *social movement* arguably comes from the community of relatively high functioning people on the autism spectrum. Within this community, people with conventional styles are referred to as “neurotypicals” or “normies,” while people with atypical styles are viewed as part of the normal variation of human beings (Antonetta 2005; Baker 2011; Fenton & Krahn 2007).

Dana Lee Baker notes that autism groups dedicated to neurodiversity evolved to help promote the view of neurological difference as a difference that “can be understood and experienced as much as a source of community and communal identity as can differences more routinely associated” with other forms of diversity such as those based on race, ethnicity, gender, and sexual orientation (2011:20). Although functioning at the lower end of the autistic spectrum may entail deficits that can include intellectual disabilities, difficulty with speech, and self-injurious behaviors (such as hitting their heads), functioning at the high end is not viewed as a “disorder” or as

continues

Box 1.2 Continued

a "fundamentally undesirable" element of the human condition and is, in fact, credited with contributing positively to human innovation (Baker 2011:20; Baron-Cohen 2000). Thus, evidence from biological accounts of notable figures in human history, innovators in their respective fields—such as Albert Einstein, Charles Darwin, Amadeus Mozart, Vincent van Gogh, Ludwig Wittgenstein, and Thomas Jefferson—strongly suggests that they meet the criteria classified under the rubric of autism spectrum disorder (Grandin 2006; O'Neil 2008). Judy Singer (1999) thinks that the development of computer technology and the internet itself may very well have been, in large part, the product of neurodiversity; and many of those who at one time were denigrated in popular culture as "nerds" or "geeks" may have been (or are) high-functioning cognitive atypicals. Temple Grandin (2006), who is known for her contributions to animal psychology and the development of humane methods of handling livestock, thinks that many atypical children are being done a disservice by being tracked into special education curriculums in school rather than into programs for the gifted and talented. In doing so, both these children and our society are being done a disservice (see Chapter 6).

of the disabled people he interviewed did not consider "disability" a salient part of their identity. They did not dismiss their impairment as irrelevant—it was an undeniable fact of their lives—but neither did they internalize its significance. Although the disability rights movement has aimed to advance an affirmative view of disability identity, the people in Watson's study preferred to "negate impairment as an identifier" altogether (p. 524). Siebers, on the other hand, thinks that the notion of disability identity will continue to be useful for advancing the collective interests of disabled people and helping all of us think about "fundamental democratic principles such as inclusiveness and participation" (2006:25). Carol Gill hopes for the day, not when her impairment will be deemed irrelevant, but when disability will provoke "a respectful curiosity about what I have learned from my difference that I could teach society. In such a world, no one would mind being called Disabled. Being unable to do something the way most people do it would not be seen as something bad that needs curing. It would be seen as just a difference" (1994:45). And John Hockenberry wonders, “Why aren’t people with disabilities a source of reassurance to the general public that although life is unpredictable and circumstances may be unfavorable, versatility and adaptation are possible; they’re built into the coding of human beings” (quoted in Fleischer & Zames 2001:205).

Summary

In this opening chapter of the book, we raised the question of why disability is vital to an understanding of humankind—as a life experience, as a scholarly endeavor, and as a subject for students taking courses in disability studies. We began by considering the language we use to talk about disability, both appropriately and inappropriately. We then raised the thorny issue of defining disability, noting the distinction between administrative-legal definitions and sociological approaches, the latter including a social constructionist view that locates the defining feature of disability as residing in the social environment and that reframes disability as a matter of social difference existing along a continuum of humanly possible ways of being embodied in the world. We also introduced the concept of ableism, the ideology and institutional practice that devalues people with disabilities as inferior and subjects them to discriminatory treatment. Finally, we considered the emergence of the disability rights movement in the United States, which is arguably responsible for the very existence and thrust of disability studies as a distinct academic endeavor. In doing so, we also discussed the independent living movement and the activism that revolved around the federal Rehabilitation Act of 1973, which culminated in the Americans with Disabilities Act of 1990, the landmark civil rights legislation for people with disabilities that we will examine more fully later in the book.

Notes

1. Nowadays the iron lung is a nearly obsolete device that has been replaced by more modern equipment that pumps air directly into the lungs.

2. Sharon Snyder (2006) associates the origins of disability studies in the United States with sociologist Irving Zola and the formation of the Society for the Study of Chronic Illness and Disability, later the Society for Disability Studies, in the early 1980s (see also Zola 1982).

3. Robert McRuer (2006) advances a theoretical perspective that he calls “crip theory,” which applies insights from feminist and queer theory to disability studies (see Chapter 2).

4. In this list, Goffman also included women and people of color—indeed, anyone who was not an "unblushing" American male, that is, "a young, married, white, urban, northern, heterosexual Protestant father [with a] college education, fully employed, of good complexion, weight, and height, and a recent record of sports" (1963:128).

5. On the causes of autism, see Chapter 6.

6. In her history of intellectual disabilities, Allison Carey (2009) traces the evolution of such terms as "idiot," "moron," and "feeble-minded," and by the twentieth century, their replacement with "mental retardation," which at the time was considered less of a pejorative. By the 1970s, the term "developmental disabilities" came to be seen as less pejorative than mental retardation and used as an umbrella term for multiple types of disabilities. Nowadays some school systems may also identify a category of "emotional disabilities," which is used interchangeably with emotional disturbances or behavioral disorders.

7. Robert Murphy and colleagues (1988) characterize disability as a condition of social liminality that resides "betwixt and between" sickness and health. The illness versus disability question also involves mental illnesses and includes conditions such as schizophrenia (Baker 2011).

8. Gary Albrecht (2010) characterizes the "sociology of disability" in the United States as a subspecialty of medical sociology. He also notes that US scholars have drawn less from the social constructionist tradition than their British counterparts. For further discussion of the US and British traditions in disability studies, see Meekosha (2004) and Shakespeare (2006).

9. Davis (1995) argues that the study of disability necessarily entails the study of normalcy.