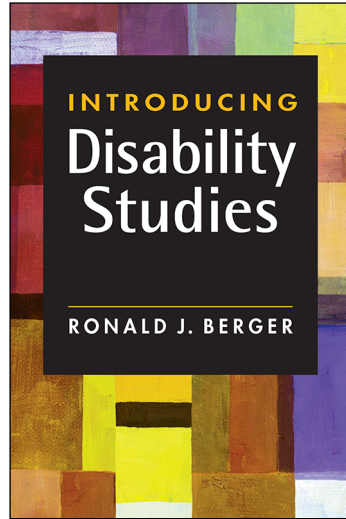


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Introducing Disability Studies

Ronald J. Berger



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Contents

<i>Preface</i>	ix
1 Disability in Society	1
Speaking About Disability	5
Defining Disability and the Subject Matter of Disability Studies	6
The Disability Rights Movement	15
2 Explaining Disability	25
Beyond the Medical Model	26
Disability Culture and Identity	30
The Political Economy of Disability	34
Insights from Feminist and Queer Theory	37
Disability and Symbolic Interaction	43
3 History and Law	51
Preiterate, Ancient, and Medieval Societies	51
The Uneven March of Progress	55
Rehabilitation and Reform	62
The Contribution of Franklin Delano Roosevelt	65
The Politics of the ADA	69
The Legal Aftermath of the ADA	72
4 The Family and Childhood	79
Parental First Encounters with Childhood Disability	81
Measuring Up to the Norm	89
The Child's Perspective	93

viii *Contents*

Impact on Family Life	99	
The Dilemmas of Special Education	104	
5 Adolescence and Adulthood		113
The Trials and Tribulations of Adolescence	113	
The Transition to Adulthood	123	
The World of Work	128	
Sexual and Emotional Intimacy	132	
Health Care and Personal Assistance	137	
6 The Bodily Experience of Disability		145
Perceiving the World Without Sight or Sound	146	
The Phenomenology of Sign Language	154	
Navigating the Physical Environment with a Mobility Impairment	156	
Recovery from Spinal Cord Injury	159	
Disability Sport and Athleticism	166	
7 Representing Disability in Literature and Film		181
Lessons from <i>Grimms' Fairy Tales</i>	182	
Classic Literary Characters	183	
The Emergence of the Horror Film Genre	188	
Postwar Recovery Films	191	
The Uneven Progress of Disability Filmmaking	193	
Disability and Humor	198	
8 The Future of Disability		209
The Paradox of Computer Technology	209	
The Problem of Genetic Selection	213	
The Problem of Physician-Assisted Suicide	217	
Revisiting the Medical Model and Its Place in Disability Studies	221	
Disability and Human Rights	226	
<i>References</i>		231
<i>Index</i>		259
<i>About the Book</i>		271

1

Disability in Society

DISABILITY IS A SOCIAL ENIGMA. THROUGHOUT HISTORY people have felt compelled both to stare at the disabled people in their midst and then to turn their heads in discomfort. Franklin Delano Roosevelt is considered by many to be one of the greatest presidents in the history of the United States, but he had to hide his polio-induced paralysis and use of a wheelchair lest the public think him too weak to lead the free world (Fleischer and Zames 2001; Holland 2006). The Hebrew Bible teaches that “thou shalt not curse the deaf nor put a stumbling block before the blind” (*Leviticus*) but also that “if you do not carefully follow His commands and decrees . . . the Lord will afflict you with madness, blindness and confusion of mind” (*Deuteronomy*) (cited in Braddock and Parish 2001:14).

The institution of the “freak show,” which reached its heyday in the nineteenth century but lasted in the United States until the 1940s, featured people with disabilities as public spectacle. People with physical disabilities and bodily deformities, as well as tribal non-white “cannibals” and “savages,” were displayed for public amusement and entertainment along with sword swallows, snake charmers, bearded women, and the full-bodied tattooed (Bogdan 1988; see Chapter 3).

The rise of a medical approach to disability, what disability studies calls the “medical model” (see Chapter 2), helped change this state of affairs. People with disabilities were now deemed worthy of medical diagnosis and treatment and viewed more benevolently

2 Introducing Disability Studies

(Williams 2001). But benevolence may breed pity, and the pitied are still stigmatized as less than full human beings. Thus the Muscular Dystrophy Association's annual telethon, which was hosted by Jerry Lewis for more than five decades, features pitiable "poster children" who help raise money for a preventative cure but does little to improve the lives of those who are already disabled (Haller 2010; Shapiro 1993).¹ Some may wonder why one would even want to live in such a state. In fact, the storyline of Clint Eastwood's 2004 Academy Award-winning *Million Dollar Baby* went so far as to suggest that euthanasia could be the most humane response to quadriplegia (Davis 2005; Haller 2010).

In *Million Dollar Baby*, Maggie Fitzgerald, played by Hilary Swank, is a feisty young woman who wants Frankie Dunn, played by Clint Eastwood, to train her to become a professional boxer. Frankie reluctantly agrees to do so, and as Maggie becomes virtually unbeatable in the ring, he becomes her mentor and friend. When Maggie breaks her neck in a boxing accident (the result of an unscrupulous opponent) and is severely disabled, she does not want to live with quadriplegia and asks Frankie to administer a lethal dose of adrenaline while she is still recovering in the hospital.

Disability scholars and activists were dismayed that so many viewers and reviewers of the film seemed to sympathize with the decision to kill the disabled character, as if her life no longer had meaning.² Maggie did not even have the opportunity to receive counseling or physical therapy to adapt to her new condition and consider her options for *living* in the world. "Disability Is Not a Death Sentence" and "Not Dead Yet" read protest signs in Chicago, Illinois, and Berkeley, California (Davis 2005; Haller 2010).

Some nondisabled film columnists, such as liberal writers Maureen Dowd and Frank Rich, were equally dismayed at the protesters' response: What's all the fuss? Isn't this just one artist's view of the situation? Doesn't Eastwood, as a filmmaker, have the right to make any film he wants? People wondered whether the negative reaction to the film might have been fueled by Eastwood's opposition to the **Americans with Disabilities Act*** (ADA), passed in 1990, which

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

granted civil rights to people with disabilities in the United States. Appearing before the House Subcommittee on the Constitution in 2000, which was considering a measure to amend the ADA, Eastwood's testimony was received in the context of a lawsuit that had been filed against him by a disabled patron who alleged that his Mission Reach Inn resort in Carmel, California, was inaccessible to disabled guests and was therefore not ADA compliant (Cleight 2005; Davis 2005; Switzer 2003).³

Lennard Davis (2005), among others, wants people to understand that disabled people's opposition to the film was not about Eastwood's anti-ADA politics, or about the storyline of *Million Dollar Baby* alone, but about the entire social and cultural apparatus that invalidates the experience of people with disabilities. According to Davis, the issue is not simply

that Eastwood is speaking his mind. It's that he's speaking the mind of a country that is largely ignorant of the issues and politics around disability. . . . The history of oppression of disabled people is unknown to most people, and so they see disability as an individual tragedy, worthy of being turned into a movie, and not as political oppression and the struggle to fight that oppression. . . . It's a lot easier to make a movie in which we weep for the personal defeat of a person who loses a leg or two, or cry with joy for the triumph of an individual with disabilities, than it is to change the whole way we as a society envision, think about, and deal with people who are disabled. (p. 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 vital to an understanding of humankind.⁴ It is a way for people with disabilities to stare back at those who have stared at them (Fries 1997), to turn society's gaze back on itself and point out the things that nondisabled people don't seem to notice because, as Davis observes, they “see themselves as living in a mirage of being normal” (2005:3). As a contribution to the advancement of disability studies, this book represents a distillation of the literature, imbued with a sociological sensibility, which aims to illuminate disability as a social phenomenon and help us all to see “how interconnected human beings really are and how very much it diminishes us to assume that any life” is without value (Cleight 2005:1).

4 *Introducing Disability Studies*

While understanding that disability is a global issue, this book will focus on the United States. Chapter 1 begins our inquiry with a consideration of how disability is spoken about, defined, and understood sociologically; and it introduces the disability rights movement, the movement that is largely responsible for the very existence and disciplinary thrust of disability studies as a particular academic endeavor. Chapter 2 then delineates the diversity of theoretical approaches to the field, beginning with a critique of the medical model and the alternative perspectives, including the social model, that constitute the conceptual core of disability studies. This chapter also examines the question of disability culture and identity, the political economy of disability, the contributions of feminist and queer theory, and disability and symbolic interaction. Next, Chapter 3 offers historical background, tracing the evolving treatment of people with disabilities from preliterate, ancient, and medieval societies through the nineteenth-century and twentieth-century United States.

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, and the receipt of health care and personal assistance.

Chapter 6 takes a phenomenological approach to the subject matter, examining the disability experience 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, use sign language, navigate the physical environment with mobility impairments, experience rehabilitation after a spinal cord injury, and participate in disability sports and athletics. Chapter 7 draws on selective examples from classic literature and Hollywood films to examine ways in which disability has been portrayed in popular culture. Finally, Chapter 8 concludes the book by considering a range of issues that inform prospects for the future of disability, including the role of computer 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.

Speaking About Disability

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 one to be ashamed of, that identifies the common cause of a particular political constituency (Gordon and Rosenblum 2001; Kleege 1999; Linton 1998).

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, and transgendered people appropriate the term “queer” as an affirmative identity.⁵ 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 (1998:15; see also Connor and Ferri 2007; Wendell 1996).

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 ways 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.

Defining Disability and the Subject Matter of Disability Studies

To begin with, 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 (1996:24).⁶ 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” (1996:24; see also Altman 2001; Grönvik 2009).

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 has been 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 and Sammons 1999; Wendell 1996; Whyte and Ingstad 1995).⁷

For our purposes, therefore, the distinction between impairment and disability is what is most germane. Thus, 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 and Rosenblum 2001; Hahn 1988; Siebers 2008). 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" (1996:44). 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” (1987:117). 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” beings. Goffman defined **stigma** as a characteristic of a person who is “reduced in our minds from a whole and usual person to a tainted, discounted one” (1963:3). 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 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.⁸

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 hardwired 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 persons 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” (1995:693). Cahill and Eggleston also learned about occasions in which a wheelchair user was treated as a “non-person,” for instance, when they were with a group at a restaurant and the waiter or waitress 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 ran counter to the view that people with disabilities are uniformly stigmatized and treated badly (see also Bogdan and Taylor 1989; 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 **constructionist**, or **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; Omansky 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 (Brown 1995). Take the case of

autism, for example, which is now understood as consisting of a 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, a US 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, lacking the ability to empathize with others and appearing emotionally detached. They 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 programming, music, and art (Cowley 2003; Grandin 2006; Kalb 2005; O’Neil 2008).⁹

Whereas Kanner went on to become a leading figure in child psychiatry, Asperger’s clinic was destroyed during the war, 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; O’Neil 2008; Silberman 2001; Singer 1999).

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 each 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 Box 4.3).¹⁰

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.¹¹ 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; Zola 1991).¹² Indeed, most anyone who lives long enough can expect to have an experience with disability before they die. Joseph Shapiro adds that fewer than 15 percent of those who are disabled are actually born with their impairment, and therefore anyone at any time, "as a result of a sudden automobile accident, a fall down a flight of stairs," or the acquisition of a serious illness, can join the ranks of people with disabilities (1993:7). One national poll taken in 2004 found that the median age for the onset of disability in the United States was 35.7 years, with 47 percent acquiring their disability after the age of forty (National Organization on Disability/Harris Poll 2004).

FURTHER EXPLORATION

Box 1.1 Counting Disability

Studies that try to count the number of people who have a disability are complicated by the question of how disability is defined, but with this caveat in mind, we can still get an idea of what this number may be. The US Census Bureau, for example, reported that in 2005 about 19 percent of the US population indicated that they had at least some level of disability, with about 12 percent having a severe disability. The census found that nearly 4 percent of people six years of age and older needed assistance with everyday activities such as showering or bathing and getting around inside their homes. While the majority of disabilities were physical in nature, about a third of all those reporting a disability were classified as having difficulty with cognitive, mental, or emotional functioning. Not surprisingly, older Americans reported a higher level of disability than younger Americans, with adults over sixty-four years of age comprising about a third of all those reporting disabilities (Moore 2009).

In addition to census data, a study by the Centers for Disease Control and Prevention (CDCP) reported that in 2005 about 22 percent of US adults had a disability, with about 10 percent indicating they had difficulty walking three city blocks or climbing a flight of stairs. The top ten causes of disability were listed as the following (in order of most common to least common): arthritis or rheumatism, back or spine problem, heart trouble, mental or emotional problem, lung or respiratory problem, diabetes, deafness or hearing problem, stiffness or deformity of limbs/extremities, blindness or vision problem, and stroke (CDCP 2011).

The US Department of Health and Human Services (USDHHS) also collected survey data on adults with disabilities in the United States between 2001 and 2005, operationalizing disability as having difficulty with *basic actions* and *complex activity*. Basic action difficulty was defined in terms of limitations in movement or sensory, emotional, or mental functioning, while complex activity difficulty was defined in terms of limitations in self-care tasks, ability to work, or ability to fully participate in social activities. About 30 percent of Americans reported some kind of basic action difficulty, with the most common related to movement, such as

continues

Box 1.1 continued

walking, bending, reaching overhead, or using their fingers to grasp something. About 13 percent reported noticeable vision or hearing difficulties, and 3 percent reported emotional or cognitive difficulties. Work limitation was the most commonly reported complex activity limitation (12 percent), followed by social limitation (7 percent) and self-care limitation (4 percent). Adults over sixty-five years of age made up about 33 percent of those with basic limitations and 36 percent of those with complex activity limitations (USDHHS 2008).

Internationally, the World Health Organization (2011) reported that in 2010 there were more than one billion disabled people around the globe, about 17 percent of the world's total population. Other international data indicate that disabled people are more likely than nondisabled people to live in poverty, as is true in the United States, although poverty in less developed, nonindustrialized countries is more severe. About 80 percent of the world's disabled population lives in such countries, where just 20 percent of the world's health-care dollars are spent. In many places around the globe, war and armed conflict are major causes of disability. Today, there are millions of disabled refugees and displaced persons in places such as the Middle East, the Balkans, Central Africa, and Southeast Asia; and at least 2,000 people are killed or injured every month by landmines that are buried in more than seventy countries (Albrecht, Seelman, and Bury 2001; Priestley 2001).

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 (2008b), among others, rejects a conception of disability as undesirable deviance, as 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 Richard Scotch and Kay Schriener’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 and 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; Wright 1960). 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 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).¹³ Siebers calls this the “ide-

ology 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, to bring it out in the open for all to see.

The Disability Rights Movement

One cannot begin to approach disability studies without crediting its very existence and conceptual thrust to the contemporary **disability rights movement**.¹⁴ The social movement for disability rights is an international phenomenon, but the movements in the United States and Great Britain are most notable for their contribution to disability studies (Bickenbach 2001; Fleischer and Zames 2001; Shakespeare and Watson 2001). In the United States this movement emerged 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 marginalized and underrepresented political constituencies (Mansbridge and Morris 2001).

We will explore this movement in more detail in Chapter 3, but it is worth noting here that unlike some of the other movements of this era, the disability rights movement does not have a widely known figure with name recognition such as a Martin Luther King Jr., Rosa Parks, Betty Friedan, Gloria Steinem, or Ralph Nader. But Ed Roberts is arguably someone deserving of comparable recognition. Roberts, who was severely disabled from polio—he was a quadriplegic who had some minimal use of his hands—had gained admission to the University of California, Berkeley (UCB), in 1962, the same year that James Meredith became the first African American to attend the University of Mississippi. As a youth, Roberts had had to fight to get his high school “diploma because he had not completed the driver’s education and gym requirements. . . . [Then] California’s Department of Rehabilitation [CDR] refused to pay for his college education, as it did for other, less disabled students, because

Roberts's [CDR] counselor . . . believed that spending taxpayer money on [him] would be wasted since it was 'infeasible' he could ever work" (Shapiro 1993:44). Roberts took his case to the media, eventually forcing the CDR to relent (Braddock and Parish 2001; Fleischer and Zames 2001; Scotch 2001b).

Roberts's success ushered in opportunities for other students with disabilities at UCB. Influenced by the political radicalism of the day, Roberts and this 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. Known as the **independent living movement**, activists 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 but wanted "to be fully integrated [into] their communities" (Shapiro 1993:52). 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 and Zames 2001; 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). Most politicians who had voted for the act, however, had not seriously considered its broader implications and potential costs

FURTHER EXPLORATION

Box 1.2 Judy Heumann: Disability Rights Activist

In addition to Ed Roberts, one of the notable figures in the early disability rights movement is Judy Heumann. Heumann was born in Brooklyn, New York, in 1947, contracting polio when she was eighteen months old. Like Roberts, she became a quadriplegic. One physician advised her parents to put her in an institution, which they did not, and relatives told them that “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.” But her parents 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 and Zames 2001; Scotch 2001b; Shapiro 1993).

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 and Parish 2001; Fleischer and 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 officers 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 ADA, 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 (Braddock and Parish 2001; Fleischer and Zames 2001; Scotch 2001b; Switzer 2003).

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" (1997:105). All too many times she experienced complete strangers coming up to her on the street to inquire about her physical appearance and children gasping 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, “ssshhhhhh!” (1997:105–106).

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 they 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 and Munger 2003:14). Moreover, Nick Watson (2002) found that most 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 dis-

FURTHER EXPLORATION

Box 1.3 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 (Baker 2011; Singer 1999). Nowadays neurodiversity is used to refer to a variety of atypical cognitive styles due to neurological differences, including autism, intellectual disabilities, learning disabilities, attention deficit hyperactivity, epilepsy, post-traumatic stress disorder, bipolar disorder, Tourette's syndrome, and schizophrenia (Antonetta 2005; Baker 2011; Fenton and Krahn 2007). But the impetus for neurodiversity as a *social movement* arguably comes from the community of relatively high-functioning people on the autism/Asperger's 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 (Baker 2011; Singer 1999).

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; Fenton and Krahn 2007). Although functioning at the lower end of the autistic spectrum may entail deficits that can include intellectual disabilities and difficulty with speech, functioning at the high end is not viewed as a "disorder" or as 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 biographical accounts of notable figures in human history, innovators in their respective fields—such as Albert Einstein, Charles Darwin, Wolfgang Amadeus Mozart, Vincent van Gogh, Ludwig Wittgenstein, and Thomas Jefferson—strongly suggests that they meet the criteria now classified under the rubric of autism or Asperger's syndrome (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 those who at one time were denigrated in popu-

continues

Box 1.3 continued

lar culture as “nerds” or “geeks,” such as Bill Gates himself, may have been (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 wrongly tracked into special education curriculums in school rather than into programs for the gifted and talented (see Box 6.1). In doing so, both these children and our society are being done a disservice.

ability identity, the people in Watson’s study preferred to “negate impairment as an identifier” altogether (2002:524). 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 and 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 sociolog-

ical 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. Muscular dystrophy is a group of genetic muscle disorders that weaken the musculoskeletal system and impede movement. The condition is progressive, worsening over time. See Box 8.2 for further discussion of Lewis and the telethon issue.

2. We will discuss the question of physician-assisted suicide in Chapter 8.

3. Eastwood's resort had just undergone a \$6.5 million renovation that still left hotel washrooms inaccessible to wheelchair users. The proposed amendment would have required defendants in lawsuits to take corrective actions within 90 days. Eastwood lost the lawsuit and was required to pay the plaintiff's attorney's fees and make his resort accessible.

4. 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).

5. Robert McRuer (2006, 2010) advances a theoretical perspective he calls "crip theory," which applies insights from feminist and queer theory to disability studies (see Chapter 2).

6. The ADA defines disability as a physical or mental impairment that substantially limits one or more of an individual's major life activities.

7. Two international organizations, the UN and the World Health Organization, were influential in propagating the distinction between impairment, disability, and handicap (Altman 2001; Wendell 1996; Whyte and Ingstad 1995).

8. 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 of college education, fully employed, of good complexion, weight, and height, and a recent record of sports" (1963:128).

9. Autism is marked by rapid brain growth between the first 6 to 14 months of life. Researchers now think that this growth process may generate more sensory neurons than the brain can integrate into a coherent network, accounting for why people with autism feel anxious around too much stimuli and new situations. Autism appears to have a genetic component, but environmental toxins have been implicated as well (Cowley 2003; Grandin 2006; Kalb 2005; King and Bearman 2011). For further discussion of autism, see Box 2.1 and Box 4.2.

10. 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 also identify a category of "emotional disabilities," which is used interchangeably with emotional disturbances or behavioral disorders (Virginia Department of Education 2012).

11. Robert Murphy and colleagues (1988) characterize disability as a condition of social liminality that resides "betwixt and between" the social states of sickness and health (see also Cahill and Eggleston 1995). The illness versus disability question also involves mental illnesses and includes conditions such as schizophrenia (Baker 2011).

12. 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), Omansky (2011), and Shakespeare (2006).

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

14. Snyder describes disability studies as the "theoretical arm" of the disability rights movement (2006:478).